

## **Reference Committee on Amendments to Constitution and Bylaws**

### **BOT Report(s)**

- 02 New Specialty Organizations Representation in the House of Delegates
- 13 Mergers of Secular and Religiously Affiliated Health Care Institutions and Their Impact on Patient Care and Access to Services
- 23 Healthcare as a Human Right
- 24 Appropriate Placement of Transgender Prisoners
- 25 Recognition of Physician Orders for Life Sustaining Treatment Forms
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### **CC&B Report(s)**

- 01 CCB Sunset Review of 2008 House Policies

### **CEJA Report(s)**

- 01 Competence, Self-Assessment and Self-Awareness
- 02 Mergers of Secular and Religiously Affiliated Health Care Institutions
- 03 Medical Tourism
- 04 Expanded Access to Investigational Therapies
- 05 Study Aid-in-Dying as End-of-Life Option / The Need to Distinguish "Physician Assisted Suicide" and "Aid in Dying"
- 06 CEJA's Sunset Review of 2008 House Policies

### **Resolution(s)**

- 001 Discriminatory Policies that Create Inequities in Health Care
- 002 FMLA-Equivalent for LGBT Workers
- 003 Proposing Consent for De-Identified Patient Information
- 004 Patient-Reported Outcomes in Gender Confirmation Surgery
- 005 Decreasing Sex and Gender Disparities in Health Outcomes
- 006 Living Donor Protection Act of 2017 (HR 1270)
- 007 Oppose the Criminalization of Self-Induced Abortion
- 008 Health Care Rights of Pregnant Minors
- 009 Improving and Increasing Clarity and Consistency Among AMA Induced Abortion Policies
- 010 Gender Equity in Compensation and Professional Advancement
- 011 Women Physician Workforce and Gender Gap in Earnings - Measures to Improve Equality
- 012 Costs to Kidney Donors
- 013 Opposing Surgical Sex Assignment of Infants with Differences of Sex Development
- 014 Promotion of LGBTQ-Friendly and Gender-Neutral Intake Forms
- 015 Human Trafficking / Slavery Awareness
- 016# Utilization of "LGBTQ" in Relevant Past and Future AMA Policies
- 017# Revised Mission Statement of the AMA

## REPORT OF THE BOARD OF TRUSTEES

B of T Report 2-A-18

Subject: New Specialty Organizations Representation in the House of Delegates

Presented by: Gerald E. Harmon, MD, Chair

Referred to: Reference Committee on Amendments to Constitution and Bylaws  
(Peter H. Rheinstein, MD, JD, MS, Chair)

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1 The Board of Trustees (BOT) and the Specialty and Service Society (SSS) considered the  
2 applications of the American Rhinologic Society, American Society for Reconstructive  
3 Microsurgery, American Society of Neuroimaging, North American Neuromodulation  
4 Society, and the North American Neuro-Ophthalmology Society for national medical  
5 specialty organization representation in the American Medical Association (AMA) House  
6 of Delegates (HOD). The applications were first reviewed by the AMA SSS Rules  
7 Committee and presented to the SSS Assembly for consideration.

8  
9 The applications were considered using criteria developed by the Council on Long Range  
10 Planning and Development and adopted by the HOD (Policy G-600.020). (Exhibit A)

11  
12 Organizations seeking admission were asked to provide appropriate membership  
13 information to the AMA. That information was analyzed to determine AMA membership,  
14 as required under criterion 3. A summary of this information is attached to this report as  
15 Exhibit B.

16  
17 In addition, organizations must submit a letter of application in a designated format. This  
18 format lists the above-mentioned guidelines followed by each organization's explanation  
19 of how it meets each of the criteria.

20  
21 Before a society is eligible for admission to the HOD, it must participate in the SSS for  
22 three years. All five organizations have actively participated in the SSS for more than three  
23 years.

24  
25 Review of the materials and discussion during the SSS meeting at the 2017 Interim  
26 Meeting indicated that: American Rhinologic Society, American Society for  
27 Reconstructive Microsurgery, American Society of Neuroimaging, North American  
28 Neuromodulation Society, and the North American Neuro-Ophthalmology Society meet  
29 the criteria for representation in the HOD.

### 30 31 RECOMMENDATION

32  
33 Therefore, the Board of Trustees recommends that the American Rhinologic Society,  
34 American Society for Reconstructive Microsurgery, American Society of Neuroimaging,  
35 North American Neuromodulation Society, and the North American Neuro-Ophthalmology  
36 Society be granted representation in the AMA House of Delegates and that the remainder  
37 of the report be filed. (Directive to Take Action)

Fiscal Note: Less than \$500

APPENDIX  
Exhibit A

**GUIDELINES FOR REPRESENTATION IN & ADMISSION TO  
THE HOUSE OF DELEGATES:**

**National Specialty Societies**

- 1) The organization must not be in conflict with the constitution and bylaws of the American Medical Association by discriminating in membership on the basis of race, religion, national origin, sex, or handicap.
- 2) The organization must (a) represent a field of medicine that has recognized scientific validity; and (b) not have board certification as its primary focus, and (c) not require membership in the specialty organization as a requisite for board certification.
- 3) The organization must meet one of the following criteria:
  - 1,000 or more AMA members;
  - At least 100 AMA members and that twenty percent (20%) of its physician members who are eligible for AMA membership are members of the AMA; or
  - Have been represented in the House of Delegates at the 1990 Annual Meeting and that twenty percent (20%) of its physician members who are eligible for AMA membership are members of the AMA.
- 4) The organization must be established and stable; therefore it must have been in existence for at least 5 years prior to submitting its application.
- 5) Physicians should comprise the majority of the voting membership of the organization.
- 6) The organization must have a voluntary membership and must report as members only those who are current in payment of dues, have full voting privileges and are eligible to hold office.
- 7) The organization must be active within its field of medicine and hold at least one meeting of its members per year.
- 8) The organization must be national in scope. It must not restrict its membership geographically and must have members from a majority of the states.
- 9) The organization must submit a resolution or other official statement to show that the request is approved by the governing body of the organization.
- 10) If international, the organization must have a US branch or chapter, and this chapter must be reviewed in terms of all of the above guidelines.

**RESPONSIBILITIES OF NATIONAL MEDICAL SPECIALTY ORGANIZATIONS**

1. To cooperate with the AMA in increasing its AMA membership.
2. To keep its delegate to the House of Delegates fully informed on the policy positions of the organizations so that the delegate can properly represent the organization in the House of Delegates.
3. To require its delegate to report to the organization on the actions taken by the House of Delegates at each meeting.
4. To disseminate to its membership information to the actions taken by the House of Delegates at each meeting.
5. To provide information and data to the AMA when requested.

***Exhibit B - Summary Membership Information***

<b>Organization</b>	<b>AMA Membership of Organization's Total Eligible Membership</b>
American Rhinologic Society	172 of 265 (65%)
American Society for Reconstructive Microsurgery	168 of 663 (25%)
American Society of Neuroimaging	105 of 280 (38%)
North American Neuromodulation Society	260 of 942 (28%)
North American Neuro-Ophthalmology Society	100 of 454 (22%)

## REPORT OF THE BOARD OF TRUSTEES

BOT Report 13-A-18

Subject: Mergers of Secular and Religiously Affiliated Health Care Institutions and Their Impact on Patient Care and Access to Services

Presented by: Gerald E. Harmon, MD, Chair

Referred to: Reference Committee on Amendments to Constitution and Bylaws  
(Peter H. Rheinstein, MD, JD, MS, Chair)

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1 Policy D-140.956, “Religiously Affiliated Medical Facilities and the Impact on a Physician’s  
2 Ability to Provide Patient Centered, Safe Care Services,” asks that the American Medical  
3 Association (AMA):

4  
5 conduct a study of access to care in secular hospitals and religiously affiliated hospitals to  
6 include any impact on access to services of consolidation in secular hospital systems and  
7 religiously affiliated hospital systems.  
8

9 AMA lacks the necessary research infrastructure to carry out an extensive empirical study  
10 regarding the impact of such mergers on patients’ access to care. This report reviews the best  
11 evidence currently available in this area from governmental agencies, academic institutions, and  
12 scholarly and popular publications. Council on Ethical and Judicial Affairs Report 2-A-18,  
13 “Mergers of Secular and Religiously Affiliated Health Care Institutions,” provides ethics guidance  
14 for physicians in this context.  
15

### 16 BACKGROUND

17  
18 The changing landscape of the American healthcare sector and evolving market forces have  
19 motivated health care institutions to consider mergers, acquisitions, partnerships, and other types of  
20 transactional relationships for the purpose of consolidation [1]. The economic recession from 2007  
21 to 2009 and the passage of the 2010 Affordable Care Act (ACA) may have played a substantial role  
22 in driving mergers in recent years; 112 mergers were reported in 2015, compared to 105 in 2012  
23 and 66 in 2010 [1,3]. With the ACA encouraging the creation of Accountable Care Organizations  
24 for coordinated care and new value-based payment models, health care institutions were  
25 encouraged to merge and create economies of scale to reduce expenses and share profits across  
26 larger patient volumes, standardize and streamline protocols to improve operational efficiency, and  
27 expand their scope of services and care networks to facilitate patient access [3–5].  
28

### 29 RELIGIOUSLY AFFILIATED HEALTHCARE IN THE UNITED STATES

30  
31 Secular and religiously affiliated institutions alike feel pressures to merge [6], in particular, small,  
32 independent, rural, and/or financially struggling hospitals [7]. Rural populations often face wide  
33 health disparities and lack of access to care, and over 2,000 rural hospitals struggle operationally  
34 and financially with low patient volume, provider shortages, and poor facilities and resources [8].  
35 Since 2010, more than 60 rural hospitals have closed in 20 states, and several hundred more may be

vulnerable to closure, especially in southern states [9]. Because of these issues, rural hospitals may be particularly susceptible to external and economic forces that lead them into merger transactions.

Religiously affiliated or faith-based health care institutions can include hospitals, clinics, and other centers of care partnered with, established by, owned by, and/or managed by a wide array of religious entities in the U.S., such as Catholic, Protestant (e.g., Methodist, Presbyterian, Baptist, Evangelical, Adventist), Mormon, and Jewish organizations. Catholic institutions are the most numerous, comprising over 600 hospitals and over 1,600 clinics and other care facilities [10]. Collectively, they serve as the nation's largest group of nonprofit health care providers [10,11]. Catholic hospitals constitute nearly 15 percent of all acute care hospitals, treating about one-sixth of all acute care hospital patients, with 5 million admissions and 20 million emergency room visits a year [10]. Since 1997, over 140 mergers have occurred between non-Catholic and Catholic institutions [12]. From 2000 to 2016, the number of acute care hospitals with Catholic affiliations grew 22 percent, even as the overall number of acute care hospitals declined [11]. Ten of the 25 largest health systems are Catholic-affiliated [11]. An estimated 25 percent of Catholic hospitals and 15 percent of Catholic continuing care facilities are located in rural areas [10]. Out of over 1,300 Critical Access Hospitals (specially designated hospitals located in high-need rural areas), 132 are Catholic-affiliated [10,13]; as of 2016, 46 Catholic hospitals were the sole health providers for their communities [11].

Protestant and Jewish institutions also form a prominent part of the religiously affiliated healthcare sector. In the U.S., around 50 hospitals and health systems are affiliated with the United Methodist Church; the Adventist Health System manages 46 facilities; and close to 20 Jewish hospitals are in operation; accurate figures are difficult to find for the numbers of Presbyterian, Baptist, Mormon, or other health care institutions [14,15,16].

## THE IMPACT OF MERGERS ON PATIENT CARE

Evidence about the impact of mergers between secular and religiously affiliated institutions is limited and largely anecdotal in nature. Much of our knowledge of these issues is derived from news articles and reports from advocacy organizations such as the American Civil Liberties Union (ACLU) and MergerWatch.

Based on what evidence we have the effects on clinical services and care of mergers that involve non-Catholic religiously affiliated institutions appear to be diverse. For example, some Baptist, Adventist, and Mormon institutions are opposed to abortions in accordance with their principles [1,2]; other merged entities, such as Missouri's Barnes-Jewish Hospital, and the Protestant-affiliated Advocate Health Care in Illinois do provide abortions [17,18,19]. (An institution's faith tradition may shape nonclinical aspects of patient experience, as when Jewish hospitals observe Shabbat and Jewish holidays, display ritual objects, provide kosher meals, or designate kitchens for Orthodox patients [20]. Similarly, at least one Adventist institution declines to serve nonvegetarian food or any stimulants [21,22].)

Not surprisingly given the prominence of Catholic institutions in U.S. health care, the published material focuses heavily on mergers that involve Catholic organizations, which are governed by the *Ethical and Religious Directives for Catholic Health Services* (ERDs) issued by the U.S. Conference of Catholic Bishops [23]. The ERDs address many aspects of institutional life in Catholic and Catholic-affiliated facilities, providing directives not only regarding the services available to patients, but also directives to guide partnerships between Catholic and non-Catholic health care institutions [23]. Other faith-based health care organizations do not have a comparable

body of detailed formal directives, though the websites of faith-based health systems or individual facilities generally state the institution's core values.

#### *Religious Directives for Catholic Health Services*

The Catholic Health Association of the United States (CHA) identifies its member institutions as ministries of the Catholic Church [24]. In line with the religious values of the Church and the guidance of the ERDs, Catholic institutions often restrict the provision of certain health services, particularly in reproductive care [11,23]. The ERDs state that "abortion...is never permitted," although "operations, treatments, and medications that have as their direct purpose the cure of a proportionately serious pathological condition of a pregnant woman are permitted when they cannot be safely postponed until the unborn child is viable" [23]. Additionally, Catholic institutions "may not promote or condone contraceptive practices," and "direct sterilization of either men or women, whether permanent or temporary, is not permitted" [23].

Reproductive Health Services. Women have been denied a wide range of reproductive services at Catholic hospitals, even when there may be substantial risk to the woman's health or life of the patient [25–28]. Women with nonviable pregnancies have reportedly been turned away from Catholic hospitals until severe hemorrhaging or infection occurs [29]. In other cases, patients who request tubal ligations to be performed at the same time as a C-section are refused this service, even if future pregnancies are risky [29]. Obstetrician-gynecologists have also reported feeling unduly constrained by Catholic hospital administrators when exercising their clinical judgment in managing miscarriage, nonviable pregnancies, and serious maternal complications [30–32]; in one sample, 52 percent of obstetricians-gynecologists in Catholic institutions reported experiencing conflict with their hospital's religious policies [32].

In 2010 in rural Arizona, the secular Sierra Vista Regional Health Center became affiliated with the Catholic-based Carondelet Health Network and adopted the ERDs to guide its clinical services [25]. In one incident at Sierra Vista, a physician is reported to have recommended termination of pregnancy to a woman who had miscarried one of her twins and faced a low chance of the other twin's survival and high risk of hemorrhage and infection. A hospital administrator denied the procedure; however, and the patient was instead driven by ambulance to a hospital 80 miles away for treatment. After the incident, Sierra Vista broke their relationship with Carondelet after one year of a two-year trial period and chose to affiliate with a secular network instead.

Patients have also reported being unaware that the services they want will not be provided until they have already arrived at a Catholic hospital or begun treatment, and religious facilities can be unwilling to refer patients elsewhere [26,29].

This is not to say that Catholic facilities always adhere strictly or uniformly to the ERDs. For example, under the ERDs, men could also be refused many reproductive services, including contraception, sterilization, and participation in decisions on prenatal diagnosis and artificial insemination [23]; however, at least one Catholic health system, Ascension Health, performs vasectomies for men but not tubal ligations for women [33]. In 2010, Sister Margaret McBride, an administrator at a Catholic Healthcare West hospital in Arizona, authorized the termination of a pregnancy due to the high risk of mortality for both mother and child [33]. Although both the CHA and the hospital supported McBride's decision, the local diocesan bishop later excommunicated McBride and stripped the hospital of its Catholic affiliation, causing controversy in the Catholic health community [34].



Services for Transgender Patients. The CHA does not specifically deny services on the basis of sexual orientation. In January 2018, Sister Carol Keehan, president and CEO of the CHA, stated that “any services [that Catholic institutions] offer are available to everybody,” elaborating that “transgender patients have heart attacks ... and gallbladder surgery” and that “[Catholic hospitals] have delivered many a lesbian couple’s baby and many a gay couple’s baby” [35]. The Human Rights Campaign’s Healthcare Equality Index evaluates nearly 600 American hospitals on the basis of their care, services, and policies relating to LGBTQ individuals and has previously rated several Bon Secours hospitals, which are members of the CHA, with moderate to high scores [36].

However, Catholic institutions have refused to perform gender-affirming surgery in the past; in one example, Franciscan Health in Indiana sued the Obama administration over a gender identity nondiscrimination rule mandated by the ACA [37]. The National Catholic Bioethics Center believes that “no Catholic health care organization should require its personnel to carry out, promote, refer for, or otherwise cooperate formally in procedures involved in gender transitioning, especially surgical or hormonal intervention” [38]. In 2017, the CHA’s senior director of ethics and theology stated, “For most medical providers the issue is settled in terms of seeing gender dysphoria as something that can be treated legitimately...[but] Catholic ethicists still have many questions about its moral permissibility” [39]. There have been media reports of instances in which transgender patients have been denied hysterectomies under the ERD restriction on sterilization [40,41] and mastectomies [42–44].

Physician-Assisted Suicide. In U.S. jurisdictions that have legalized physician-assisted suicide—as of March 2018, California, Colorado, the District of Columbia, Hawaii, Montana, Oregon, Vermont, and Washington—access to legally permitted “aid in dying” is unlikely to be available from religiously affiliated institutions and clearly will not be from Catholic-affiliated institutions. In guidance on care for patients who are seriously ill or dying, the ERDs unequivocally prohibit intentionally hastening death, stating “Suicide and euthanasia are never morally acceptable options” [23]. The ERDs provide that “Catholic health care institutions may never condone or participate in euthanasia or assisted suicide in any way” [23].

The possible impact of these or similar restrictions is difficult to estimate, but reports indicate that the ERDs have had an effect in jurisdictions where physician-assisted suicide is legal. For example, in Washington state in 2010, the Catholic-affiliated PeaceHealth merged with the Clark County public hospital, which then stopped referring patients for PAS-related counseling [45]. In 2013, physicians at Harrison Medical Center in Bremerton, Washington, were restricted from prescribing medications for assisted suicide after Harrison affiliated with the Catholic-based Franciscan Health System [46]. As of 2012, some 30 percent of hospital beds in Washington were owned by Catholic institutions [47].

#### *Effects on Health Plans*

There is also evidence to suggest that mergers among secular and religiously affiliated health care institutions can affect the terms of health insurance plans. In 2017 in northwestern Indiana, for example, a proposed merger between a Catholic-affiliated Franciscan system and Methodist Hospitals would have left only one non-Catholic hospital in the county [37]. This hospital would not be included in the network of the only insurer offering plans for the region on the ACA exchange, in effect making Franciscan Health and Catholic hospitals exclusive providers for this plan. This may have forced patients on this plan to travel out of their network to receive services not provided by in-network facilities [37]. Some large Catholic health systems, such as Catholic Health Initiatives and Ascension Health, have also expressed interest in offering their own health insurance plans as they have expanded their merged systems [37]. Catholic institutions attaining

1 exclusive provider status with insurance plans, especially those offered by employers or on  
2 subsidized ACA exchanges, could create serious concerns for patient access to care.

3  
4 **CONCLUSION**

5  
6 Although there has been limited scholarly research regarding the clinical impact specifically of  
7 mergers among secular and religiously affiliated health care institutions, this literature suggests that  
8 patients may have more difficulty gaining access to some services as a result of such mergers. A  
9 growing body of anecdotal evidence in the form of media reports describing cases in which these  
10 mergers appear to have affected care for individual patients argues to a similar conclusion, as do  
11 efforts to monitor the impact of mergers among advocacy organizations.

12  
13 **RECOMMENDATION**

14  
15 Your Board of Trustees concludes that the foregoing fulfills Directive D-140.956, "Religiously  
16 Affiliated Medical Facilities and the Impact on a Physician's Ability to Provide Patient Centered,  
17 Safe Care Services," and recommends that the directive be rescinded and the remainder of this  
18 report be filed. (Directive to take Action)

Fiscal Note: Less than \$500

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## REPORT OF THE BOARD OF TRUSTEES

B of T Report 23-A-18

Subject: Health Care as a Human Right (Resolution 7-A-17)

Presented by: Gerald E. Harmon, MD, Chair

Referred to: Reference Committee on Amendments to Constitution and Bylaws  
(Peter H. Rheinstein, MD, JD, MS, Chair)

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### 1 INTRODUCTION

2  
3 At the 2017 Annual Meeting, the House of Delegates referred Resolution 7-A-17, “Health Care as  
4 a Human Right.” This resolution was introduced by the Minority Affairs Section and asked that our  
5 AMA:

- 6  
7 1. recognize that a basic level of health care is a fundamental human right;  
8  
9 2. support the United Nations’ Universal Declaration of Human Rights and its encompassing  
10 International Bill of Rights as guiding principles fundamental to the betterment of public  
11 health; and  
12  
13 3. advocate for the United States to remain a member of the World Health Organization.  
14

### 15 HEALTH CARE AS A HUMAN RIGHT

16  
17 Human rights are ethical demands that create duty to safeguard underlying freedoms of significant  
18 social importance.<sup>1</sup> This duty may be legal, e.g., through statute or international treaty, or moral in  
19 its foundation. Depending on context, human rights can be thought of as legal, philosophical, or  
20 sometimes aspirational.<sup>2</sup> All these concepts of human rights are interrelated; indeed, human rights  
21 are conceived through ethical reasoning drawing on experience, beliefs, and theories of justice.  
22

23 The philosophical underpinning of creating an ethical human right is largely that of justice, which  
24 may be described as fairness in equitable distribution of primary social goods<sup>3</sup> such as liberty,  
25 opportunity, and income. From this concept of fairness comes the ethical demand to create a human  
26 right, which may then be extended to health care, because by keeping people healthy, people’s  
27 ability to participate in political, social, and economic life is promoted and preserved.<sup>4</sup> A right to  
28 health care does not give individuals a basic right either to be healthy or to have all their health care  
29 needs met.  
30

31 However, a right to health care will broadly encompass access to care.<sup>5</sup> Access means that health  
32 care facilities, goods, and services must be available to everyone in [a defined] jurisdiction without  
33 discrimination, [and must be] affordable, physically accessible, and within a reasonable distance  
34 for all people.<sup>6</sup> If people are denied access to a basic level of services adequate to protect normal  
35 functioning, an injustice is done to them. Indeed, the concept of accessibility as a core principle of  
36 human rights to health care is widely recognized and supported.



## AMA Policy

Although it does not directly support a “right to health care,” Principle IX of the AMA Principles of Medical Ethics states: “A physician shall support access to medical care for all people.” Equitable access to medical care is a core component of the right to health care, and Opinion 11.1.1, of the *Code of Medical Ethics*, “Defining Basic Health Care,” is derived from this principle. The Opinion maintains that health care is “a fundamental human good because it affects our opportunity to pursue life goals, reduces our pain and suffering, helps prevent premature loss of life, and provides information needed to plan for our lives. Society has an obligation to make access to an adequate level of care available to all its members, regardless of ability to pay.” Further, Opinion 11.1.4, “Financial Barriers to Health Care Access,” explains: “As professionals, physicians individually and collectively have an ethical responsibility to ensure that all persons have access to needed care regardless of their economic means.”

Other policies of the AMA House of Delegates also support access to healthcare. For example, it is AMA policy that “no one shall be denied necessary medical care because of inability to pay for that care” (Policy H-160.987, “Access to Medical Care”). Policy H-160.975, “Planning and Delivery of Health Care Services,” explains that “both the public and private sectors should be encouraged to donate resources to improve access to health care services. Where appropriate, incentives should be provided for those in the private sector who give care to those who otherwise would not have access to such care. In addition, existing shortcomings in the current public system for providing access need to be addressed.”

## SUPPORTING THE UNITED NATIONS’ DECLARATION OF HUMAN RIGHTS AND THE WORLD HEALTH ORGANIZATION

Resolution 7-A-17 also asks that our AMA support the [United Nations’ Universal Declaration of Human Rights](#) and the International Bill of Rights as guiding principles fundamental to the betterment of public health. The Declaration consists of 30 articles affirming an individual’s rights that, although not legally binding in themselves, have been elaborated in subsequent international treaties, economic transfers, regional human rights instruments, national constitutions, and other laws. The Declaration was the first step in the process of formulating the International Bill of Human Rights, which was completed in 1966, and came into force in 1976.

The United Nations (UN) is an intergovernmental organization made up of 193 member nations. The World Health Organization (WHO) is the directing and coordinating authority on international health within the UN system. The objective of WHO is the attainment by all peoples of the highest possible level of health. Governance takes place through the World Health Assembly (WHA), which is made up of representatives from the health ministries of these national governments, and is the supreme decision-making body. The Executive Board gives effect to the decisions and policies of the Health Assembly. The organization is headed by the Director-General, who is appointed by the WHA on the nomination of the Executive Board. The WHO collaborates with the UN system to position health in the debates and decisions of UN intergovernmental bodies; contributes to a coherent and effective UN system at global, regional, and country levels; provides leadership in health-related humanitarian efforts, and promotes alliances and interagency approaches to address health issues.

By contrast, the WMA is a non-governmental international organization representing physicians. The organization was created to ensure the independence of physicians and to work for the highest possible standards of ethical behavior and care by physicians at all times. The AMA is a founding member of the WMA, which has always been an independent confederation of free professional



1 associations and has grown to include 114 national medical association members. Our main role at  
2 the WMA is to develop policy and advocacy agendas in line with AMA policies.

3  
4 The WMA is in “Official Relations” with the WHO and seeks to advise and influence the work of  
5 this intergovernmental body. WMA’s cooperation with the WHO is very broad and covers nearly  
6 all areas of medicine and health. As a commitment to our international interests, AMA officers  
7 have regularly attended the WHA, either as non-governmental advisors to the United States  
8 Delegation or as Delegates to the Assembly from the WMA.

9  
10 AMA Policy H-250.986, “AMA and Public Health in Developing Countries,” outlines a  
11 circumscribed strategy for AMA participation in international policy and advocacy issues mainly  
12 by our involvement in the WMA and, to a lesser degree, in our advisory capacity at the WHA. For  
13 this and other reasons, our AMA does not take positions on treaties, such as the United Nations’  
14 Universal Declaration of Human Rights, but works through established channels to effect  
15 supportable outcomes.

16  
17 In addition, AMA Policy H-250.999, “World Health Organization,” expresses AMA’s direct  
18 support of the WHO as an institution and the United States’ involvement with it; this support is  
19 ongoing. AMA Policy H-250.992, “World Health Organization,” affirms support for the WHO and  
20 urges the United States to provide full funding for the organization. This policy also encourages the  
21 WMA to develop cooperative work plans with the WHO.

## 22 23 CONCLUSION

24  
25 The Board of Trustees appreciates that Resolution 7-A-17 expresses the desire to ensure that all  
26 people have access to a basic level of health care. Our AMA has long advocated for equitable  
27 access to health care through policy, advocacy, and a targeted strategy of active international  
28 policymaking through the WMA and the WHO. The Board of Trustees believes that existing policy  
29 adequately supports that intention.

## 30 31 RECOMMENDATION

32  
33 The Board of Trustees therefore recommends that AMA Policies H-160.987, “Access to Medical  
34 Care;” H-160.975, “Planning and Delivery of Health Care Services;” H-250.986, “AMA and  
35 Public Health in Developing Countries;” H-250.992, “World Health Organization;” and  
36 H-250.999, “World Health Organization,” be reaffirmed in lieu of Resolution 7-A-17 and that the  
37 remainder of the report be filed. (Reaffirm HOD Policy)

Fiscal Note: Less than \$500

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## REPORT OF THE BOARD OF TRUSTEES

B of T Report 24-A-18

Subject: Appropriate Placement of Transgender Prisoners (Resolution 15-A-17)

Presented by: Gerald E. Harmon, MD, Chair

Referred to: Reference Committee on Amendments to Constitution and Bylaws  
(Peter H. Rheinstein, MD, JD, MS, Chair)

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At the 2017 Annual Meeting the AMA House of Delegates referred Resolution 15-A-17, “Appropriate Placement of Transgender Prisoners,” from the New England delegation, which asked:

That our American Medical Association establish policy supporting the ability of transgender prisoners to be placed in facilities that are reflective of their affirmed gender status regardless of surgical status, if they so choose.

The Reference Committee on Amendments to Constitution and Bylaws noted that testimony was evenly divided in support of the resolution and ultimately recommended referral, recognizing the “complexities of this issue” and “that more information and research on the subject are necessary.” In response, this report identifies and addresses concerns relevant to the placement of transgender prisoners.

### BACKGROUND

The problem facing the safety and health of transgender prisoners is severe and well documented. Transgender prisoners are disproportionately the victims of sexual assault, suffering higher rates of sexual assault than general population inmates [1,2]. The increased rate of violence largely stems from transgender prisoners being housed based on their birth sex, and not according to their affirmed gender [1]. One study showed that birth sex-based housing policy has allowed transgender prisoners to suffer from rape, harassment, and physical violence at a rate of 34 percent compared to 10 percent for the overall population [3]. Another study, of only California prisons, has shown that 59 percent of transgender prisoners experience sexual assault, versus only 4.4 percent of the overall prison population [4], with another study showing that the proportion of transgender prisoners in California experiencing sexual assault to be as high as 75 percent [1].

The risks of violence typically are in the context of transfeminine inmates, because “of animosity toward the expression of their gender identity and because many have slight and effeminate builds” [5]. Genitalia-based prison housing policies place transgender inmates at special risk of sexual violence, because the “prison hierarchy subjugates the weak to the strong and equates femininity with weakness” [6].

### GENITALIA/BIRTH SEX-BASED HOUSING POLICY

The status quo of most prisons and jails in the United States is to house transgender prisoners according to their birth/biological sex and not according to their affirmed gender identity [7].

1 Genitalia based housing policy is “deeply ingrained” in the United States to the point where it is  
2 taken for granted without any official justification [8]. This status quo is founded on a limited  
3 definition of “transgender” constrained to the “gender binary,” a social construct where only two  
4 genders are recognized at birth: male or female [7,9]. A more useful definition of “transgender,”  
5 one that breaks free of the “gender binary,” is a person “whose inner gender identity and outward  
6 gender expression differ from the physical characteristics of the body at birth” [10].  
7

8 Under the status quo, many correctional institutions try to ameliorate the risks and hazards of sex-  
9 based housing by placing transgender prisoners in administrative segregation. Such segregation, in  
10 the interests of safety, isolates transgender prisoners from the general population [1]. However,  
11 administrative segregation is not a good solution as it creates its own sets of problems. It often  
12 differs little from punitive segregation or solitary confinement. Such confinement removes  
13 prisoners from the companionship of others, denies prisoners access to prison programs, and is  
14 psychologically damaging [7]. Administrative segregation acts as a further punishment of the  
15 transgender prisoner and has been significantly criticized by scholars and attorneys [2].  
16

#### 17 ALTERNATIVE HOUSING POLICIES

18

19 In an attempt to address health and safety problems of transgender prisoners several jurisdictions  
20 have created alternative jail housing policies based on “the sex the individual identifies with and  
21 where they will be the safest, as opposed to genitalia-based placement” [9].  
22

23 For example, in 2002 San Francisco County, California, instituted a protocol that requires jail  
24 officials to assess transgender prisoners for vulnerability and place vulnerable individuals in a unit  
25 with other vulnerable populations, away from “predators;” the policy has resulted in marked  
26 decreases in sexual assaults [2]. In 2009 the Washington, DC, Department of Corrections similarly  
27 enacted a housing policy that takes into account the opinions of transgender individuals and  
28 healthcare professionals and permits inmates to be housed according to their gender identity [9,11].  
29 In 2011 Cook County, Illinois, likewise changed its policy to allow transgender inmates to “be  
30 housed, dressed, and searched according to their gender identity rather than the sex/gender they  
31 were assigned at birth” [9].  
32

#### 33 AMA POLICY

34

35 Several AMA policies address a range of transgender issues [12,13,14]. House Policy H-65.964,  
36 “Access to Basic Human Services for Transgender Individuals,” opposes policies that prevent  
37 transgender individuals from accessing services and facilities (including restrooms) in line with  
38 one’s gender identity [12]. House Policy H-65.967, “Conforming Birth Certificate Policies to  
39 Current Medical Standards for Transgender Patients,” supports policies that allow for a change of  
40 sex designation on a birth certificate for transgender individuals, whether or not an individual has  
41 undergone surgery [13]. House Policy H-40.966, “Military Medical Policies Affecting Transgender  
42 Individuals,” affirms that there is no medical reason to prohibit transgender individuals from  
43 serving in the military [14].

1 RECOMMENDATION

2  
3 In consideration of evidence indicating the risk placement choices pose for transgender prisoners  
4 the Board of Trustees recommends that the following be adopted in lieu of Resolution 15-A-17 and  
5 the remainder of this report be filed:

- 6  
7 1. That our American Medical Association supports the ability of transgender prisoners to be  
8 placed in facilities, if they so choose, that are reflective of their affirmed gender status,  
9 regardless of the prisoner's genitalia, chromosomal make-up, hormonal treatment, or non-, pre-,  
10 or post-operative status; and (New HOD Policy)  
11  
12 2. That our American Medical Association supports that the facilities housing transgender  
13 prisoners shall not be a form of administrative segregation or solitary confinement. (New HOD  
14 Policy)

Fiscal note: Less than \$500

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## REPORT OF THE BOARD OF TRUSTEES

B of T Report 25-A-18

Subject: Recognition of Physician Orders for Life Sustaining Treatment (POLST) Forms  
(Resolution 20-A-17)

Presented by: Gerald E. Harmon, MD, Chair

Referred to: Reference Committee on Amendments to Constitution and Bylaws  
(Peter H. Rheinstein, MD, JD, MS, Chair)

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At the 2017 Annual Meeting, the House of Delegates referred Resolution 20-A-17, “Recognition of Physician Orders for Life Sustaining Treatment (POLST) Forms,” introduced by the Organized Medical Staff Section, which asked:

That our American Medical Association advocate with appropriate government, legislative and regulatory bodies to recognize Physician Orders for Life Sustaining Treatment forms completed in one state as valid and enforceable in other states; and

That our AMA create a universal Physician Orders for Life Sustaining Treatment form that would be valid and enforceable in all states.

The reference committee heard testimony unanimously in support of the intent of the resolution. Testimony highlighted the challenges of respecting the medical care orders of patients when they cross jurisdictional boundaries. However, testimony also emphasized that a universal POLST form may be impractical because POLST is one of many end-of-life care frameworks in use in the United States.

The reference committee agreed that reciprocity of physician orders between states is important, but noted myriad problems with a universal POLST form. The Reference Committee suggested that “model state legislation be crafted in order for [reciprocity] to be accomplished in a way that can realistically be implemented” and referred the resolution. This Board Report provides background and discussion of interstate recognition of POLST and provides a recommendation.

### BACKGROUND

Physician Orders for Life Sustaining Treatment were created in the 1990s in the state of Oregon in response to concerns that Do Not Resuscitate Orders (DNRO) had certain inadequacies; chief among them was their inability to transfer to other facilities (nursing homes, hospitals, hospice, ER’s, etc.) as the patient moved [1,2]. POLST was created to improve “end-of-life care by overcoming many of the advance directives’ limitations. It is designed to convert patient preferences for life-sustaining treatment into immediately actionable medical orders” that then “can be followed by medical personnel regardless of the patient’s location” [3,4]. POLST has largely been successful, with studies showing greater effectiveness in care “delivered in accordance with patient wishes” and recent years have seen increased adoption of the program in states around the country [5]. POLST is increasingly becoming established, alongside advance directives, as an important end-of-life decision making tool.

1 However, a problem has emerged with the recognition of POLST as patients cross state lines.  
2 There is a lack of uniformity in how states recognize a POLST from other states. This creates  
3 uncertainty if a POLST originating in one state will be followed in another state. This uncertainty  
4 risks the proper adherence of a patient's desires regarding life-sustaining treatment as they travel  
5 from one state to another.

## 6 7 STATE LAW

8  
9 To be effective, a POLST program must be universally recognized and honored. While POLST in  
10 each state aims to achieve the same goal of honoring patient wishes during a medical crisis, each  
11 state has its own requirements and procedures for a valid POLST.

12  
13 POLST currently exists at some level in all 50 states and Washington, DC. Sixteen states explicitly  
14 recognize out-of-state POLST: Colorado, Delaware, the District of Columbia, Georgia, Idaho,  
15 Illinois, Iowa, Maryland, Nevada, New Jersey, New York, Oregon, Rhode Island, Utah, Vermont  
16 and West Virginia. Only one state expressly limits reciprocity. In Oklahoma, an out-of-state form is  
17 only valid for 10 days after patient's admission into an Oklahoma medical facility [6]. In states  
18 with statutes that are silent on reciprocity, accepted medical practice or custom may allow  
19 recognition of an out-of-state POLST absent statutory guidance.

20  
21 There are four main statutory approaches taken to POLST reciprocity: states may honor a POLST  
22 if it complies with the originating state's requirements, if it complies with the receiving state's  
23 requirements, if it reasonably satisfies the receiving state's requirements or if it complies with  
24 either the originating or receiving state's requirements. State laws vary on approach [7].

## 25 26 ETHICAL ISSUES

27  
28 The scope of Resolution 20-A-17 is focused on the portability of POLST across state lines. In this  
29 context, significantly relevant is the ethical force of autonomy in end-of-life decision making and  
30 how it is central to continual support of POLST. "The POLST process increases the likelihood that  
31 each person will receive the desired care and not receive undesired care" [2]. Indeed, studies have  
32 also shown POLST to be successful in the "honoring of patient preferences" [8]. The fundamental  
33 ethical principle of patient autonomy (the driving force behind POLST) is the reason why, despite  
34 ethical shortcomings that exist with any end-of-life decision making model, POLST remains a  
35 durable clinical decision making tool. Therefore, there is ethical impetus to see greater portability  
36 of POLST across states lines, as the more likely a POLST from one state is enforced and  
37 recognized by another state, the greater likelihood that a patient's autonomy at the end-of-life will  
38 be respected.

## 39 40 RELEVANT AMA POLICIES

41  
42 End-of-life decision making is a significant issue in the medical profession and in the field of  
43 bioethics. As such, the AMA is strongly supportive of the concept and has published its support for  
44 such measures. For example, Chapter 5 of the *Code of Medical Ethics* focuses on caring for  
45 patients at the end of life. This chapter of the *Code* has several opinions supporting the concept of  
46 advance care planning and withholding life-sustaining treatment [9,10,11,12]. The *Code* explains  
47 that "advance care planning is widely recognized as a way to support patient self-determination"  
48 and that a patient "has the right to decline any medical intervention or ask that an intervention be  
49 stopped, even when that decision is expected to lead to his or her death" [9,11].

1 The AMA has additionally shown its support for end-of-life decision making through numerous  
2 House Policies and Directives [13,14,15,16,17,18]. Policies have called for the AMA to encourage  
3 people to establish advance directives and explain that advance directives “are the best insurance  
4 for individuals that their interests will be promoted in the event they become incompetent” [13,14].  
5 Also, the AMA has adopted a directive to endorse “The Uniform Health-Care Decisions Act,” a  
6 uniform law designed to help govern, simplify, and standardize advance directives [18]. AMA  
7 policy does not address issues of reciprocity across jurisdictions.

## 8 9 DISCUSSION

10  
11 Resolution 20-A-17 would instruct the AMA to create a universal POLST form. Drafting a  
12 universal POLST form is fraught with challenges as different jurisdictions have different  
13 hierarchies, rules and statutes with regards to end-of-life care. A universal form will not work  
14 across all states, as some states may not be able to adopt such a form.

15  
16 The reference committee’s recommendation to create model legislation that would enable POLST  
17 reciprocity between the states is a more workable solution. This approach was recognized by the  
18 National POLST Paradigm Task Force (NPPTF) legislative group. The group, an assembly of  
19 health law experts tasked with providing perspectives to POLST legal issues, offered solutions,  
20 among other things, to the problem of POLST portability across state lines. The group  
21 recommended the adoption of a “uniform law” that would offer reciprocity of POLST across state  
22 lines. The NPPTF legislative group notes:

23  
24 While it is still under revision and not directly applicable to POLST, one potential source of  
25 guidance is the draft Inter-jurisdictional Recognition of Substitute Decision-Making  
26 Documents Act from the National Conference of Commissioners on Uniform States Laws [19].  
27 If adapted to POLST, the reciprocity provisions in this Act would deem a POLST form valid if,  
28 when completed, it complied with the law of the jurisdiction where it was completed [7].  
29

30 However, a uniform law from the National Conference of Commissioners on Uniform State Laws  
31 specifically with regards to POLST is not yet in existence and remains a theoretical solution to the  
32 problem of POLST portability. Until such uniform law is available for consideration, states may  
33 elect to enact legislation establishing reciprocity to address current problems with POLST  
34 compliance across jurisdictions.

## 35 36 RECOMMENDATION

37  
38 The Board of Trustees recommends that the following be adopted in lieu of Resolution 20-A-17,  
39 and that the remainder of this report be filed:

- 40  
41 1. That our American Medical Association work with state medical associations to advocate with  
42 appropriate legislative and regulatory bodies to recognize Physician Orders for Life Sustaining  
43 Treatment forms completed in one state as valid and enforceable in other states; (Directive to  
44 Take Action) and  
45  
46 2. That our AMA draft model state legislation that will allow for reciprocity of POLST forms.  
47 (Directive to Take Action)

Fiscal Note: Modest—Between \$1,000 and \$5,000



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## REPORT OF THE BOARD OF TRUSTEES

BOT Report 26-A-18

Subject: Revision of Researcher Certification and Institutional Review Board (IRB) Protocols (Resolution 11-A-17)

Presented by: Gerald E. Harmon, MD, Chair

Referred to: Reference Committee on Amendments to Constitution and Bylaws  
(Peter H. Rheinstein, MD, JD, MS, Chair)

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Resolution 11-A-17, “Revision of Researcher Certification and Institutional Review Board (IRB) Protocols,” sponsored by the Florida Delegation, was referred by the House of Delegates in June 2017. This resolution asks our AMA to:

[S]tudy existing Collaborative Institutional Training Initiative standards, Institutional Review Board protocols and create recommendations that would simultaneously protect patients and permit physicians to easily participate in the dissemination of medical knowledge.

### HUMAN SUBJECTS PROTECTIONS

Concerns about the ethical conduct of research involving human participants date back to the 19<sup>th</sup> century, well before the evolution of the current regulatory framework in the U.S. [1]. The principles underlying the current system of oversight of human subjects protections were set out in the 1979 *Belmont Report* by the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research [2], and subsequently codified in regulations adopted by the Department of Health and Human Services (DHHS) and by 14 departments and agencies a decade later—the “Common Rule” [3]. The Common Rule sets basic standards for research oversight, including the establishment of institutional review boards (IRBs) and review procedures, and criteria for individual informed consent [4]. The goal of this—and similar regulatory efforts in other countries—is to protect the rights and well-being of individuals who participate as subjects in biomedical and behavioral research.

The Common Rule has been criticized as ineffective, cumbersome, and of questionable value in actually protecting research participants [5-7]. A 2011 review of empirical studies indicated, for example, that there is considerable variation in IRB structure, membership, processes, and in outcomes of IRB reviews [6]. A recent study of whether and how essential elements of human subjects protection are implemented during institutional review or research protocols found considerable variation among 20 participating IRBs [8]. The current system of oversight has also been critiqued as unable to address effectively the challenges of today’s research landscape, especially in light of the increasing prominence of multi-site research involving large numbers of participants and research involving large data sets or collections of biospecimens, and their implications for informed consent [9].

In 2011, the DHHS launched a review and reassessment of the Common Rule, issuing an Advanced Notice of Proposed Rule Making (ANPRM) seeking public comment to enhance protection of research subjects and improve the process of research review [10].

Four years later, DHHS issued a Notice of Proposed Rule Making (NPRM) soliciting comment on proposed updated policy. Stakeholders opposed the NPRM's proposal to require consent for secondary research use of unidentified biospecimens, but supported proposals for improving informed consent, especially for simplifying consent forms while suggesting some modifications, which are reflected in the Final Rule issued in January 2017 [11-12]. The Final Rule also retains provisions intended to reduce unnecessary regulation and streamline oversight processes, including creating new categories of exemption from IRB review for low-risk studies, eliminating the requirement of continuing review for some categories of research, and introducing new options for facilitating screening of prospective participants. (On January 19, 2018, DHHS issued notice that it would delay the compliance deadline for the updated Common Rule to July 19, 2018 [13].)

In 2008 and 2009, AMA shared its concern that over interpretation of Common Rule protections in the context of quality improvement activities imposed unnecessary regulatory burdens on important research [14-16]. AMA also provided input under the auspices of the Advanced Notice of Proposed Rule Making [17] and the Notice of Proposed Rule Making [18].

## EDUCATING THE RESEARCH COMMUNITY ABOUT HUMAN SUBJECTS PROTECTIONS

The National Institutes of Health requires that "key personnel" on NIH-funded research involving human subjects receive education on protecting human subjects [19]. These include principal investigators and all other individuals who are responsible for the design or conduct of the research, including foreign awardees or foreign subcontractors and third party personnel or consultants, even if they are not compensated through the NIH award, as well as investigators involved in research that is exempt from IRB review. Investigators in research with human specimens, tissues, or data that has been determined not to involve human subjects in keeping with guidance from the Office for Human Research Protections ([OHRP](#)) are not required to fulfill the educational requirement, nor are personnel who are not involved in the design and conduct of human subject research. NIH leaves the decision of what educational programs to use to meet this requirement to investigators' home institutions. The [NIH Clinical Center](#) offers free online education that institutions may elect to meet the education requirement.

In addition, the Collaborative Institutional Training Initiative ([CITI](#)) offers web-based education in human subjects protections developed by experts in research ethics, ethics committee process, and web-enabled learning [20-21]. Initially created in 2000 in response to the then newly announced NIH education requirement for agency grantees, CITI's offerings have expanded over time to encompass a robust catalogue of instruction in multiple aspects of the responsible conduct of research. Modules are available to learners through institutional subscriptions (at a current cost of \$3,400/year) or for purchase by individuals ("independent learners") (currently \$130/module).

Training is also available specifically for IRB members. OHRP, for example, offers periodic workshops on various topics in human subjects protections and has developed extensive policy guidance. It also offers practical tools to clarify interpretation of the Common Rule and help IRBs evaluate research protocols effectively; for example, decision charts to help IRBs answer such key questions as whether a proposed study involves human subjects, whether it is exempt from IRB review (or eligible for expedited review), or whether informed consent may be waived. Educational resources for IRBs are also available through organizations such as Public Responsibility in Medicine and Research ([PRiMR](#)), which offers certification for IRB professionals [5].

Although there are reservations about their effectiveness in meaningfully protecting human subjects, efforts have also been launched to accredit IRBs.<sup>5</sup> Thus the Association for the

1 Accreditation of Human Research Protection Programs ([AAHRPP](#)) promotes quality standards and  
2 performance improvement for IRBs and institutional human research protection programs [6].  
3

#### 4 INSTITUTIONAL AND JOURNAL POLICIES

5

6 Institutions that carry out federally funded research, as well as professional journals that publish the  
7 findings of research with human subjects have similarly established expectations that research  
8 personnel will adhere to human subjects protections in keeping with federal regulations. For  
9 example, the University of Illinois at Champaign Urbana requires that researchers complete CITI's  
10 "Core Basic Training for either social/behavioral research or biomedical research," and more  
11 specialized modules as may be needed for the purposes of specific studies, such as those involving  
12 children [22]. The University of California-Berkeley likewise requires that faculty, students, and  
13 staff engaged in human subjects research complete appropriate CITI [23], while San Francisco  
14 State University requires "all researchers using research volunteers to pass an online research  
15 training course," and provides links to both NIH and CITI courses [24]. Other institutions—e.g.,  
16 Vanderbilt University School of Medicine [25], Duke University School of Medicine [26] —  
17 require completion of in-person courses or other educational programs developed by the institution  
18 to address NIH educational requirements for research carried out with human subjects.  
19

20 Professional journals frequently require that authors reporting findings of social/behavioral or  
21 biomedical research with human subjects attest that the study presented adhered to human subjects  
22 protections and appropriate oversight. The International Committee of Medical Journal Editors  
23 (ICMJE) recommends that investigators ensure that "the planning, conduct, and reporting of human  
24 research" is in accord with the Declaration of Helsinki, the international statement of research  
25 ethics promulgated by the World Medical Association [27]. The *Journal of the American Medical*  
26 *Association* and JAMA Network journals, for example, require that authors of manuscripts  
27 reporting studies that involve human participants or animals submit documentation demonstrating  
28 formal review and approval (or waiver) of the research and describe the review and its  
29 determination [28]. *Annals of Internal Medicine* likewise requires authors to confirm appropriate  
30 review or affirm that the research reported is consistent with the principles of the Declaration of  
31 Helsinki [29], while *The Lancet* advises prospective contributors that it adheres to the ICMJE  
32 *Recommendations* [30].  
33

#### 34 AMA POLICY

35

36 Policy [H-460.980](#), "Ethical and Societal Considerations in Research," first adopted in 1987,  
37 provides that "All investigators involved in research projects should be responsible for the clear  
38 articulation and enforcement of standards that ensure the integrity of scientific data and  
39 conclusions." The *AMA Code of Medical Ethics* sets out expectations for ethical conduct for  
40 physician-investigators substantively in keeping with federal human subjects protections in  
41 opinions [E-7.1.1](#), "Physician Involvement in Research"; [E-7.1.2](#), "Informed Consent in Research";  
42 [E-7.1.3](#), "Study Design and Sampling"; [E-7.1.4](#), "Conflicts of Interest in Research"; [E-7.1.5](#),  
43 "Misconduct in Research"; and [E-7.2.1](#), "Disseminating Research Results."  
44

#### 45 CONCLUSION

46

47 Oversight of research that involves human participants must balance important interests of science,  
48 the community, and individuals. Commitment to protecting the well-being and rights of individuals  
49 who agree to participate in research is fundamental to the ethics of the medical profession and to  
50 public trust.

1 Significant attention has been given in recent years to enhancing the system of research oversight  
2 in ways that sustain robust protections for human participants while streamlining processes of  
3 review and oversight and minimizing the burden on investigators. As scholars recently noted in  
4 relation to the Common Rule, “In an age of big data and cybersecurity threats, and as new  
5 technologies reveal personal identities, ethics rules become even more important. Federal oversight  
6 will remain the bulwark against unethical practices. In the end, treating human research participants  
7 with respect and fairly is essential for continuing public support of vital scientific investigations”  
8 [31].  
9

#### 10 RECOMMENDATION

11  
12 In light of the importance of protecting the well-being and rights of research participants and the  
13 considerations reviewed above, your Board of Trustees recommends that the following be adopted  
14 in lieu of Resolution 11-A-17, “Revision of Researcher Certification and Institutional Review  
15 Board (IRB) Protocols,” and the remainder of the report be filed:  
16

17 That our AMA continue to support efforts to improve protections for human subjects of  
18 biomedical and behavioral research and advocate for change as opportunities arise. (New HOD  
19 Policy)

Fiscal Note: Less than \$250

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## REPORT OF THE COUNCIL ON CONSTITUTION AND BYLAWS

CCB Report 1-A-18

Subject: CCB Sunset Review of 2008 House Policies

Presented by: Colette Willins, MD, Chair

Referred to: Reference Committee on Amendments to Constitution and Bylaws  
(Peter H. Rheinstein, MD, Chair)

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At its 1984 Interim Meeting, the House of Delegates (HOD) established a sunset mechanism for House policies (Policy G-600.110, “Sunset Mechanism for AMA Policy”). Under this mechanism, a policy established by the House ceases to be viable after 10 years unless action is taken by the House to retain it.

The objective of the sunset mechanism is to help ensure that the American Medical Association (AMA) Policy Database is current, coherent, and relevant. By eliminating outmoded, duplicative, and inconsistent policies, the sunset mechanism contributes to the ability of the AMA to communicate and promote its policy positions. It also contributes to the efficiency and effectiveness of House of Delegates deliberations.

At its 2012 Annual Meeting, the House amended Policy G-600.110 to change the process through which the policy sunset review is conducted. The process now includes the following:

- As the House of Delegates adopts policies, a maximum ten-year time horizon shall exist. A policy will typically sunset after ten years unless action is taken by the House of Delegates to retain it. Any action of our AMA House that reaffirms or amends an existing policy position shall reset the sunset “clock,” making the reaffirmed or amended policy viable for another 10 years.
- In the implementation and ongoing operation of our AMA policy sunset mechanism, the following procedures shall be followed: (a) Each year, the Speakers shall provide a list of policies that are subject to review under the policy sunset mechanism; (b) Such policies shall be assigned to the appropriate AMA councils for review; (c) Each AMA council that has been asked to review policies shall develop and submit a report to the House of Delegates identifying policies that are scheduled to sunset. (d) For each policy under review, the reviewing council can recommend one of the following actions: (i) Retain the policy; (ii) Sunset the policy; (iii) Retain part of the policy; or (iv) Reconcile the policy with more recent and like policy; (e) For each recommendation that it makes to retain a policy in any fashion, the reviewing council shall provide a succinct, but cogent justification. (f) The Speakers shall determine the best way for the House of Delegates to handle the sunset reports.
- Nothing in this policy shall prohibit a report to the HOD or resolution to sunset a policy earlier than its 10-year horizon if it is no longer relevant, has been superseded by a more current policy, or has been accomplished.
- The AMA Councils and the House of Delegates should conform to the following guidelines for sunset: (a) when a policy is no longer relevant or necessary; (b) when a policy or directive has been accomplished; or (c) when the policy or directive is part of an established AMA practice

1 that is transparent to the House and codified elsewhere such as the AMA Bylaws or the AMA  
2 House of Delegates Reference Manual: Procedures, Policies and Practices.

- 3 • The most recent policy shall be deemed to supersede contradictory past AMA policies.
- 4 • Sunset policies will be retained in the AMA historical archives.

5  
6 In this report, the Council on Constitution and Bylaws presents its recommendations on the  
7 disposition of the House policies from 2008 that were assigned to it. The Council's  
8 recommendations on policies are presented in the Appendix to this report.

9  
10 RECOMMENDATION

11  
12 The Council on Constitution and Bylaws recommends that the House of Delegates policies that are  
13 listed in the Appendix to this report be acted upon in the manner indicated and the remainder of  
14 this report be filed.

Fiscal Note: Less than \$500 to update policy database.

## APPENDIX – Recommended Actions on 2008 House Policies

Policy Number/Title	Text	Recommended Action and Rationale
H-10.972, Blocked Fire Exits	AMA policy is that fire exits remain unlocked at all meetings of Federation members. The AMA will issue a statement that physicians should make certain that the observable fire exits are unlocked at any public gathering which they attend.	Sunset. Over the past 20 years fire safety regulations have been comprehensively promulgated by the International Code Council International Fire Code and the National Fire Protection Association Fire Protection Code, elements of which are included in all state and municipal fire codes. Codes distinguish between a fire exit and a fire door. A fire exit is an external door, which also functions as a security door. If locked to prevent unauthorized access from the outside, it must be fitted with a panic or push bar. Fire exit doors may also be fitted with a key lock override to allow outside access. A fire door is required to be kept closed at all times unless certified retainers are installed to hold it door open until a fire alarm is set off.
H-25.996, Retirement and Hiring Practices	It is urged that physicians, individually and through their constituent, <del>and component,</del> <u>and specialty</u> medical societies, continue to stress the need to reappraise policies calling for compulsory retirement and age discrimination in hiring from the standpoint of health among older people, and that they participate actively and lend medical weight in the efforts of other groups to create a new climate of opportunity for the older worker.	Retain as editorially amended.
H-405.991, Volunteerism and Community Service	The AMA supports continued promotion of community service and volunteerism by its membership.	Reconcile with H-405.996, Voluntary Service by Physicians, “Our AMA does not believe it would be appropriate to establish a separate committee to serve as a clearinghouse for service opportunities and to promote voluntary service, but encourages state association awards for exceptional voluntary community service and wider recognition of physicians who perform voluntary services.”

H-445.999, Chambers of Commerce	The AMA reaffirms its previously adopted recommendation to all state medical societies that they become active in the U.S. and state chambers of commerce and requests that a similar recommendation be made to all county medical societies so that they too might be encouraged to become active in local, state and U.S. chambers of commerce programs.	Sunset. Action requested has been accomplished.
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REPORT 1 OF THE COUNCIL ON ETHICAL AND JUDICIAL AFFAIRS (1-A-18)  
Competence, Self-Assessment and Self-Awareness  
(Reference Committee on Amendments to Constitution and Bylaws)

EXECUTIVE SUMMARY

The expectation that physicians will provide competent care is central to medicine. It undergirds professional autonomy and the privilege of self-regulation granted to medicine by society.

The ethical responsibility of competence encompasses more than knowledge and skill. It requires physicians to understand that as a practical matter in the care of actual patients, competence is fluid and dependent on context. Importantly, the ethical responsibility of competence requires that physicians at all stages of their professional lives be able to recognize when they are and when they are not able to provide appropriate care for the patient in front of them or the patients in their practice as a whole.

Self-aware physicians discern when they are no longer comfortable handling a particular type of case and know when they need to obtain more information or need additional resources to supplement their own skills. They recognize when they should ask themselves whether they should postpone care, arrange to have a colleague provide care, or otherwise find ways to protect the patient's well-being.

To fulfill their ethical responsibility of competence, physicians at all stages in their professional lives should cultivate and exercise skills of self-awareness and active self-observation; take advantage of tools for self-assessment that are appropriate to their practice settings and patient populations; and be attentive to environmental and other factors that may compromise their ability to bring their best skills to the care of individual patients. As a profession, medicine should provide meaningful opportunity for physicians to hone their ability to be self-reflective.

## REPORT OF THE COUNCIL ON ETHICAL AND JUDICIAL AFFAIRS\*

CEJA Report 1-A-18

Subject: Competence, Self-Assessment and Self-Awareness

Presented by: Dennis S. Agliano, MD, Chair

Referred to: Reference Committee on Amendments to Constitution and Bylaws  
(Peter H. Rheinstein, MD, JD, MS, Chair)

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1 The expectation that physicians will provide competent care is central to medicine. This  
2 expectation shaped the founding mission of the American Medical Association (AMA) and runs  
3 throughout the AMA *Code of Medical Ethics* [1-4]. It undergirds professional autonomy and the  
4 privilege of self-regulation granted to medicine by society [5]. The profession promises that  
5 practitioners will have the knowledge, skills, and characteristics to practice safely and that the  
6 profession as a whole and its individual members will hold themselves accountable to identify and  
7 address lapses [6-9].  
8

9 Yet despite the centrality of competence to professionalism, the *Code* has not hitherto examined  
10 what the commitment to competence means as an ethical responsibility for individual physicians in  
11 day-to-day practice. This report by the Council on Ethical and Judicial Affairs explores this topic to  
12 develop ethics guidance for physicians.  
13

### 14 DEFINING COMPETENCE

15  
16 A caveat is in order. Various bodies in medicine undertake point-in-time, cross-sectional  
17 assessments of physicians' technical knowledge and skills. However, this report is not concerned  
18 with matters of technical proficiency assessed by medical schools and residency programs,  
19 specialty boards (for purposes of certification), or hospital and other health care organizations (e.g.,  
20 for privileging and credentialing). Such matters lie outside the Council's purview.  
21

22 The ethical responsibility of competence encompasses more than knowledge and skill. It requires  
23 physicians to understand that as a practical matter in the care of actual patients, competence is fluid  
24 and dependent on context. Importantly, the ethical responsibility of competence requires that  
25 physicians at all stages of their professional lives be able to recognize when they are and when they  
26 are not able to provide appropriate care for the patient in front of them or the patients in their  
27 practice as a whole. For purposes of this analysis, competence is understood as "the habitual and  
28 judicious use of communication, knowledge, technical skills, clinical reasoning, emotions, values,  
29 and reflection in daily practice for the benefit of the individual and the community being served"  
30 and as "developmental, impermanent, and context dependent" [10].  
31

32 Moreover, the Council is keenly aware that technical proficiency evolves over time—what is  
33 expected of physicians just entering practice is not exactly the same as what is expected of mid-

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\* Reports of the Council on Ethical and Judicial Affairs are assigned to the Reference Committee on Amendments to Constitution and Bylaws. They may be adopted, not adopted, or referred. A report may not be amended, except to clarify the meaning of the report and only with the concurrence of the Council.

1 career physicians or physicians who are changing or re-entering practice or transitioning out of  
 2 active practice to other roles. Each phase of a medical career, from medical school through  
 3 retirement, carries its own implications for what a physician should know and be able to do to  
 4 practice safely and to maintain effective relationships with patients and with colleagues.

5  
 6 The concept that informs this report differs as well from the narrower definition of competence as  
 7 the knowledge and skills an individual has to do a job. Rather, this report explores a broader notion  
 8 of competence that encompasses deeper aspects of wisdom, judgment and practice that enable  
 9 physicians to assure patients, the public, and the profession that they provide safe, high quality care  
 10 moment to moment over the course of a professional lifetime.

## 11 12 FROM SELF-ASSESSMENT TO “INFORMED” SELF-ASSESSMENT

13  
 14 Health care institutions and the medical profession as a whole take responsibility to regulate  
 15 physicians through credentialing and privileging, routinely testing knowledge (maintenance of  
 16 certification, requirements for continuing education, etc.) and, when needed, taking disciplinary  
 17 action against physicians who fail to meet expectations for competent, professional practice.  
 18 However, the better part of the responsibility to maintain competence rests with physicians’  
 19 “individual capacity, as clinicians, to self-assess [their] strengths, deficiencies, and learning needs  
 20 to maintain a level of competence commensurate with [their] clinical roles” [11].

21  
 22 Self-assessment has thus become “integral to many appraisal systems and has been espoused as an  
 23 important aspect of personal professional behavior by several regulatory bodies and those  
 24 developing learning outcomes for students” [12]. Undergraduate and graduate medical education  
 25 programs regularly use self-assessment along with third-party evaluations to ensure that trainees  
 26 are acquiring the knowledge and skills necessary for competent practice [5,10,13-16].

27  
 28 Yet how accurately physicians assess their own performance is open to question. Research to date  
 29 suggests that there is poor correlation between how physicians rate themselves and how others rate  
 30 them [5,12,13]. Various studies among health professionals have concluded that clinicians and  
 31 trainees tend to assess their peers’ performance more accurately than they do their own; several  
 32 have found that poor performers (e.g., those in the bottom quartile) tend to over-estimate their  
 33 abilities while high performers (e.g., those in the top quartile), tend to under-estimate themselves  
 34 [5,12,17].

35  
 36 The available findings suggest that self-assessment involves an interplay of factors that can be  
 37 complicated by lack of insight or of metacognitive skill, that is, ability to be self-observant in the  
 38 moment. Similarly, personal characteristics (e.g., gender, ethnicity, or cultural background) and the  
 39 impact of external factors (e.g., the purpose of self-assessment or whether it is designed to assess  
 40 practical skills or theoretical knowledge) can all affect self-assessment [12,18]. The published  
 41 literature also indicates that interventions intended to enhance self-assessment may seek different  
 42 goals—improving the accuracy of self-assessors’ perceptions of their learning needs, promoting  
 43 appropriate change in learning activities, or improving clinical practice or patient outcomes [12].

44  
 45 Self-assessment tools alone are not sufficient measures of physicians’ ability to provide safe, high  
 46 quality care. Feedback from third parties is essential—or as one researcher has observed, “The road  
 47 to self-knowledge may run through other people” [19]. However, physicians are often wary of  
 48 assessment. They have indicated that while they want feedback, they are not sure how to use  
 49 information that is not congruent with their self-appraisals [20]. Physicians can be hesitant to seek  
 50 feedback for fear of looking incompetent or exposing possible deficiencies or out of concern that  
 51 soliciting feedback could adversely affect their relationships with those whom they approach [20].

1 They may also question the accuracy and credibility of the assessment process and the data it  
 2 generates [21].  
 3

4 To be effective, feedback must be valued both by those being assessed and by those offering  
 5 assessment [14]. When there is tension between the stated goals of assessment and the implicit  
 6 culture of the health care organization or institution, assessment programs can too readily devolve  
 7 into an activity undertaken primarily to satisfy administrators that rarely improves patient care [20].  
 8 Feedback mechanisms should be appropriate to the skills being assessed—multi-source reviews  
 9 (“360° reviews”), for example, are generally better suited to providing feedback on communication  
 10 and interpersonal skills than on technical knowledge or skills—and easy for evaluators to  
 11 understand and use [14]. High quality feedback will come from multiple sources; be specific and  
 12 focus on key elements of the ability being assessed; address behaviors rather than personality or  
 13 personal characteristics; and “provide both positive comments to reinforce good behavior and  
 14 constructive comments with action items to address deficiencies” [22]. Beyond such formal  
 15 mechanisms, physicians should welcome and seek out informal input from colleagues. They should  
 16 be willing to offer timely comments to colleagues as well.  
 17

18 One study among physicians and physicians in training found that participants used a dynamic,  
 19 multidimensional process to assess their own abilities. Under this process of what researchers  
 20 identified as “informed self-assessment,” participants interpreted and responded to multiple types  
 21 of information, such as cognitive and affective data, from both formal and informal sources [23].  
 22 Participants described “critically reflecting ‘in action,’ that is, during an activity or throughout the  
 23 day:”  
 24

25 I think we do a lot of it without thinking of it as reflection. We do it every day when we look at  
 26 a patient’s chart. You look back and see the last visit, “What did I do, or should I have done  
 27 something different?” I mean that’s reflection, but yet I wouldn’t have thought of that as self-  
 28 assessment or self-reflection, but we do it dozens of times a day [23].  
 29

### 30 EXPERTISE & EXPERT JUDGMENT

31  
 32 On this broad understanding of competence, physicians’ thought processes are as important as their  
 33 knowledge base or technical skills. Thus, understanding competence requires understanding  
 34 something of the nature of expertise and processes of expert reasoning, themselves topics of  
 35 ongoing exploration [24,25,26,27]. Prevailing theory distinguishes “fast” from “slow” thinking;  
 36 that is, reflexive, intuitive processes that require minimal cognitive resources versus deliberate,  
 37 analytical processes that require more conscious effort [26]. Some scholars take expertise to  
 38 involve “fast” processes, and specifically decision making that involves automatic, nonanalytic  
 39 resources acquired through experience [24]. Others argue that expertise consists in using “slow,”  
 40 effortful, analytic processes to address problems [24]. A more integrative view argues that  
 41 expertise resides in being able to transition between intuitive and analytical processes as  
 42 circumstances require. On this account, experts use automatic resources to free up cognitive  
 43 capacity so that they maintain awareness of the environment (“situational awareness”) and can  
 44 determine when to shift to effortful processes [24].  
 45

46 Expert judgment is the ability “to respond effectively in the moment to the limits of [one’s]  
 47 automatic resources and to transition appropriately to a greater reliance on effortful processes when  
 48 needed” [24], a practice described as “slowing down.” Knowing when to slow down and be  
 49 reflective has been demonstrated to improve diagnostic accuracy and other outcomes [26]. To  
 50 respond to the unexpected events that often arise in a clinical situation, the physician must  
 51 “vigilantly monitor relevant environmental cues” and use these as signals to slow down, to



transition into a more effortful state [25]. This can happen, for example, when a surgeon confronts an unexpected tumor or anatomical anomaly during a procedure. “Slowing down when you should” serves as a critical marker for intraoperative surgical judgment [24].

## INFLUENCES ON CLINICAL REASONING

Clinical reasoning is a complex endeavor. Physicians’ capabilities develop through education, training, and experiences that provide tools with which to shape their clinical reasoning. Every physician arrives at a diagnosis and treatment plan for an individual in ways that may align with or differ from the analytical and investigative processes of their colleagues in innumerable ways. When something goes wrong in the clinic, it can be difficult to discern why. Nonetheless, all physicians are open to certain common pitfalls in reasoning, including relying unduly on heuristics and habits of perception, and succumbing to overconfidence.

### *Heuristics*

Physicians often use various heuristics—i.e., cognitive short cuts—to aid decision making. While heuristics can be useful tools to help physicians identify and categorize relevant information, these time-saving devices can also derail decision making. For example, a physician may mistakenly assume that “something that seems similar to other things in a certain category is itself a member of that category” (the representative heuristic) [28], and fail to diagnose a serious health problem. Imagine a case in which a patient presents with symptoms of a possible heart attack or a stroke that the physician proceeds to discount as stress or intoxication once the physician learns that the patient is going through a divorce or smells alcohol on the patient’s breath. Or a physician may miscalculate the likelihood of a disease or injury occurring by placing too much weight “on examples of things that come to mind easily, . . . because they are easily remembered or recently encountered” (the availability heuristic) [28]. For example, amidst heavy media coverage of an outbreak of highly infectious disease thousands of miles away in a remote part of the world, a physician seeing a patient with symptoms of what is actually a more commonplace illness may misdiagnose (or over diagnose) the exotic condition because that is what is top of mind.

Clinical reasoning can be derailed by other common cognitive missteps as well. These can include misperceiving a coincidental relationship as a causal relationship (illusory bias), or the tendency to remember information transferred at the beginning (or end) of an exchange but not information transferred in the middle (primary or recency bias) [28,29,30].

### *Habits of Perception*

Like every other person, physicians can also find themselves prone to explicit (conscious) or implicit (unconscious) habits of perception or biases. Physicians may allow unquestioned assumptions based on a patient’s race or ethnicity, gender, socioeconomic status, or health behavior, among other features, to shape how they perceive the patient and how they engage with, evaluate and treat the individual. Basing one’s interactions with a patient on pre-existing expectations or stereotypes demeans the patient, undermines the patient’s relationship with the physician and the health care system, and can result in significant health disparities across entire communities [31]. This is of particular concern for patients who are members of minority and historically disadvantaged populations [31]. Physicians may fall victim to the tendency to seek out information that confirms established expectations or dismiss contradicting information that does not fit into predetermined beliefs (confirmatory bias) [28]. These often inadvertent thought processes can result in a physician pursuing an incorrect line of questioning or testing that then leads to a misdiagnosis or the wrong treatment.

1 No matter how well a patient may seem to fit a stereotype, it is imperative that the physician look  
2 beyond categories and assumptions to investigate openly the health issues experienced by the  
3 patient. Although all human beings exhibit both conscious and unconscious habits of perception,  
4 physicians must remain vigilant in not allowing preconceived or unexamined assumptions to  
5 influence their medical practice.

### 6 *Overconfidence*

9 Finally, another obstacle to strong clinical reasoning that physicians may encounter is  
10 overconfidence. Despite their extensive training, physicians, like all people, are poor at identifying  
11 the gaps in their knowledge [28,30]. Physicians may consider their skills to be excellent, when, in  
12 fact, their peers have identified areas for improvement [30]. Overconfidence in one's abilities can  
13 lead to suboptimal care for a patient, be it through mismanaging resources, failing to consider the  
14 advice of others, or not acknowledging one's limits [28,30].

16 To avoid falling into such traps, physicians must recognize that many factors can and will influence  
17 their clinical decisions [28]. They need to be aware of the information they do and do not have and  
18 they need to acknowledge that many factors can and will influence their judgment. They should  
19 keep in mind the likelihood of diseases and conditions and take the time to distinguish information  
20 that is truly essential to sound clinical judgment from the wealth of possibly relevant information  
21 available about a patient. They should consider reasons their decisions may be wrong and seek  
22 alternatives, as well as seek to disprove rather than confirm their hypotheses [28]. And they should  
23 be sensitive to the ways in which assumptions may color their reasoning and not allow expectations  
24 to govern their interactions with patients.

26 Shortcomings can be an opportunity for growth in medicine, as in any other field. By becoming  
27 aware of areas in which their skills are not at their strongest and seeking additional education or  
28 consulting with colleagues, physicians can enhance their practice and best serve their patients.

### 30 FROM INFORMED SELF-ASSESSMENT TO SELF-AWARENESS

32 Recognizing that many factors affect clinical reasoning and that self-assessment as traditionally  
33 conceived has significant shortcomings, several scholars have argued that a different understanding  
34 of self-assessment is needed, along with a different conceptualization of its role in a self-regulating  
35 profession [32]. Self-assessment, it is suggested, is a mechanism for identifying both one's  
36 weaknesses and one's strengths. One should be aware of one's weaknesses in order to self-limit  
37 practice in areas in which one has limited competence, to help set appropriate learning goals, and to  
38 identify areas that "should be accepted as forever outside one's scope of competent practice" [32].  
39 Knowing one's strengths, meanwhile, allows a physician both to "act with appropriate confidence"  
40 and to "set appropriately challenging learning goals" that push the boundaries of the physician's  
41 knowledge [32].

43 If self-assessment is to fulfill these functions, physicians need to reflect on past performance to  
44 evaluate not only their general abilities but also specific completed performances. At the same  
45 time, they must use self-assessment predictively to assess how likely they are to be able to manage  
46 new challenges and new situations. More important, physicians should understand self-assessment  
47 as an ongoing process of monitoring tasks during performance [3]. The ability to monitor oneself in  
48 the moment is critical to physicians' ethical responsibility to practice safely, at the top of their  
49 expertise but not beyond it.

Expert practitioners rely on pattern recognition and other automatic resources to be able to think and act intuitively. As noted above, an important component of expert judgment is transitioning effectively from automatic modes of thinking to more effortful modes as the situation requires. Self-awareness, in the form of attentive self-observation (metacognitive monitoring), alerts physicians when they need to direct additional cognitive resources to the immediate task. For example, among surgeons, knowing when to “slow down” during a procedure is critical to competent professional performance, whether that means actually stopping the procedure, withdrawing attention from the surrounding environment to focus more intently on the task at hand, or removing distractions from the operating environment [25].

Physicians should also be sensitive to the ways that interruptions and distractions, which are common in health care settings, can affect competence in the moment [34,35], by disrupting memory processes, particularly the “prospective memory”—i.e., “a memory performance in which a person must recall an intention or plan in the future without an agent telling them to do so”—important for resuming interrupted tasks [35,36]. Systems-level interventions have been shown to help reduce the number or type of interruptions and distractions and mitigate their impact on medical errors [37].

A key aspect of competence is demonstrating situation-specific awareness in the moment of being at the boundaries of one’s knowledge and responding accordingly [33]. Slowing down, looking things up, consulting a colleague, or deferring from taking on a case can all be appropriate responses when physicians’ self-awareness tells them they are at the limits of their abilities. The capacity for ongoing, attentive self-observation, for “mindful” practice, is an essential marker of competence broadly understood:

Safe practice in a health professional’s day-to-day performance requires an awareness of when one lacks the specific knowledge or skill to make a good decision regarding a particular patient . . . . This decision making in context is importantly different from being able to accurately rate one’s own strengths and weaknesses in an acontextual manner. . . . Safe practice requires that self-assessment be conceptualized as repeatedly enacted, situationally relevant assessments of self-efficacy and ongoing ‘reflection-in-practice,’ addressing emergent problems and continuously monitoring one’s ability to effectively solve the current problem [32].

Self-aware physicians discern when they are no longer comfortable handling a particular type of case and know when they need to obtain more information or need additional resources to supplement their own skills [32]. Self-aware physicians are also alert to how external stressors—the death of a loved one or other family crisis, or the reorganization of their practice, for example—may be affecting their ability to provide care appropriately at a given time. They recognize when they should ask themselves whether they should postpone care, arrange to have a colleague provide care, or otherwise find ways to protect the patient’s well-being.

#### MAINTAINING COMPETENCE ACROSS A PRACTICE LIFETIME

For physicians, the ideal is not simply to be “good” practitioners, but to excel throughout their professional careers. This ideal holds not just over the course of a sustained clinical practice, but equally when physicians re-enter practice after a hiatus, transition from active patient care to roles as educators or administrators, or take on other functions in health care. Self-assessment and self-awareness are central to achieving that goal.

A variety of strategies are available to physicians to support effective self-assessment and help physicians cultivate the kind of self-awareness that enables them to “know when to slow down” in

day-to-day practice. One such strategy might be to create a portfolio of materials for reflection in the form of written descriptions, audio or video recording, or photos of encounters with patients that can provide evidence of learning, achievement and accomplishment [16] or of opportunities to improve practice. A strength of portfolios as a tool for assessing one's practice is that, unlike standardized examinations, they are drawn from one's actual work and require self-reflection [15].

As noted above, to be effective, self-assessment must be joined with input from others. Well-designed multi-source feedback can be useful in this regard, particularly for providing information about interpersonal behaviors [14]. Research has shown that a four-domain tool with a simple response that elicits feedback about how well one maintains trust and professional relationships with patients, one's communication and teamwork skills, and accessibility offers a valid, reliable tool that can have practical value in helping to correct poor behavior and, just as important, consolidate good behavior [14]. Informal arrangements among colleagues to provide thoughtful feedback will not have the rigor of a validated tool but can accomplish similar ends.

Reflective practice, that is, the habit of using critical reflection to learn from experience, is essential to developing and maintaining competence across a physician's practice lifetime [38]. It enables physicians to "integrate personal beliefs, attitudes, and values in the context of professional culture," and to bridge new and existing knowledge. Studies suggest that reflective thinking can be assessed, and that it can be developed, but also that the habit can be lost over time with increasing years in practice [38].

"Mindful practice," that is, being fully present in everyday experience and aware of one's own mental processes (including those that cloud decision making) [39], sustains the attitudes and skills that are central to self-awareness. Medical training, with its fatigue, dogmatism, and emphasis on behavior over consciousness, erects barriers to mindful practice, while an individual's unexamined negative emotions, failure of imagination, and literal-mindedness can do likewise. Mindfulness can be self-taught, but for most it is most effectively learned in relationship with a mentor or guide. Nonetheless, despite challenges, there are myriad ways physicians can cultivate mindfulness. Meditation, which may come first to mind, is one, but so is keeping a journal, reviewing videos of encounters with patients, or seeking insight from critical incident reports [39].

"Exemplary physicians," one scholar notes, "seem to have a capacity for self-critical reflection that pervades all aspects of practice, including being present with the patient, solving problems, eliciting and transmitting information, making evidence-based decisions, performing technical skills, and defining their own values" [39].

## RECOMMENDATION

The Council on Ethical and Judicial Affairs recommends that the following be adopted and the remainder of this report be filed:

The expectation that physicians will provide competent care is central to medicine. It undergirds professional autonomy and the privilege of self-regulation granted by society. To this end, medical schools, residency and fellowship programs, specialty boards, and other health care organizations regularly assess physicians' technical knowledge and skills.

However, as an ethical responsibility competence encompasses more than medical knowledge and skill. It requires physicians to understand that as a practical matter in the care of actual patients, competence is fluid and dependent on context. Each phase of a medical career, from medical school through retirement, carries its own implications for what a physician should

1 know and be able to do to practice safely and to maintain effective relationships with patients  
2 and with colleagues. Physicians at all stages of their professional lives need to be able to  
3 recognize when they are and when they are not able to provide appropriate care for the patient  
4 in front of them or the patients in their practice as a whole.

5  
6 To fulfill the ethical responsibility of competence, individual physicians and physicians in  
7 training should strive to:

- 8  
9 (a) Cultivate continuous self-awareness and self-observation;  
10  
11 (b) Recognize that different points of transition in professional life can make different  
12 demands on competence;  
13  
14 (c) Take advantage of well-designed tools for self-assessment appropriate to their practice  
15 settings and patient populations;  
16  
17 (d) Seek feedback from peers and others; and  
18  
19 (e) Be attentive to environmental and other factors that may compromise their ability to  
20 bring appropriate skills to the care of individual patients and act in the patient's best  
21 interest.  
22

23 Medicine as a profession should continue to refine mechanisms for assessing knowledge and  
24 skill and should develop meaningful opportunities for physicians and physicians in training to  
25 hone their ability to be self-reflective and attentive in the moment.

(New HOD/CEJA Policy)

Fiscal Note: Less than \$500.

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# REPORT OF THE COUNCIL ON ETHICAL AND JUDICIAL AFFAIRS<sup>1\*</sup>

CEJA Report 2-A-18

Subject: Mergers of Secular and Religiously Affiliated Health Care Institutions

Presented by: Dennis S. Agliano, MD, Chair

Referred to: Reference Committee on Amendments to Constitution and Bylaws  
(Peter H. Rheinstein, MD, JD, MS, Chair)

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Mergers between secular and religiously affiliated hospitals are changing the landscape of health care across the United States. This report by the Council on Ethical and Judicial Affairs (CEJA) offers ethics guidance to address the challenges such mergers can pose for patients, physicians, health care institutions and the communities they serve.

## RELIGIOUSLY AFFILIATED HEALTH CARE INSTITUTIONS

The concept of the hospital as a facility providing inpatient care for the sick originated with the Catholic Church, with the original and enduring dual mission of healing the body and promoting spiritual well-being [1]. The mission of today's Catholic Health Association remains focused on the needs of those who are "poor, underserved, and most vulnerable" [2]. Although hospitals established by Protestant denominations and Jewish-identified facilities remain important segments of U.S. health care, Catholic facilities predominate among religiously affiliated institutions—U.S. Catholic Health Care is the largest nonprofit care provider in the country [2].

Since the 1990s, mergers between secular and religiously affiliated hospitals and health care institutions have been reshaping the landscape of health care in the United States, for both patients and physicians. Driven by economic considerations and changes in health policy, notably in recent years emphasis on accountable care organizations and bundled payments [1,3], mergers have enabled facilities in some cases simply to survive and in others to thrive within their communities. Consolidation has enabled hospitals to control a greater share of their local markets and to negotiate effectively with insurers [4].

Religiously affiliated hospitals and facilities benefit from the tax-exempt status of the religious institutions they represent and from other tax subsidies that derive from their mission to serve the poor and provide charitable care [5]. Although the majority of religiously affiliated hospitals remain nonprofit, the number of for-profit hospitals affiliated with religious institutions increased by 22 percent between 2001 and 2016 [6]. Religiously affiliated health care facilities—which encompass clinics, hospitals, and long-term care facilities—are also important employers. According to the Catholic Health Association, as of 2017 member facilities employed more than 500,000 full-time and 200,000 part time staff [2].

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In some communities, religiously affiliated health care institutions may be the only providers [6]—as of 2015, 132 of the nation’s approximately 1,300 critical access hospitals were members of U.S. Catholic Health Care [2]. In some areas, more than 40 percent of short-term, acute care beds are in Catholic facilities [6]. Nationwide, one in every six patients now receives care in a Catholic hospital [2].

## THE DILEMMA OF MERGERS

The consolidation of a religiously affiliated institution with a secular health care facility raises challenges for all stakeholders—the facilities, their communities, their patients, and the physicians and other professionals who provide care. All religiously affiliated institutions seek to remain faithful to their defining mission and values, which can place them in tension with their secular counterparts. Catholic facilities, however, are embroiled in an increasingly public debate about the implications and effects of entering into arrangements with secular institutions as they seek to retain their identity and mission and still survive in the health care market place. Thus they offer a window through which to understand the ethical dimension of health care mergers.

As the Ethical and Religious Directives that govern care in Catholic health care facilities observe:

New partnerships can be opportunities to realign the local delivery system in order to provide a continuum of health care to the community; they can witness to a responsible stewardship of limited health care resources; and they can be opportunities to provide to poor and vulnerable persons a more equitable access to basic care.

On the other hand, new partnerships can pose serious challenges to the viability of the identity of Catholic health care institutions and services, and their ability to implement these Directives in a consistent way, especially when partnerships are formed with those who do not share Catholic moral principles (§VI)[7].

From this perspective, in the contemporary health care market place Catholic hospitals “are caught in an impossible bind” [1]. Like other hospitals, financial pressures drive them to consolidate with other institutions to become more economically efficient. Yet “competing in the aggressive world of the medical business industry” can put Catholic hospitals’ historical commitment to the poor at risk [1]. At the same time, gaining financial security may risk “imperceptibly compromising their traditional Catholic witness” when compromises are made with respect to Directives [1].

From the perspective of those they serve, a merger or consolidation may help guarantee the continued presence of health care in a community, but may also limit the range of services available to patients when the consolidated entity adheres to the Directives. Certain treatment choices for care at the end of life, reproductive health care services, and, by some reports, certain services for transgender individuals may all be affected [4,8,9]. Limitations on women’s health services have been a focus of concern for obstetricians and gynecologists associated with or employed by religiously affiliated hospitals [10], with reports of conflict over both elective and clinically indicated surgical sterilization [11,12], and management of miscarriage [13]. Restricted access to services can have a disproportionate impact on poor women, and women in rural areas where religiously affiliated institutions are the only providers of care [14].

From the perspective of physicians and other health care professionals affiliated with or employed by the entity that results from a merger can challenge professional commitments. A merger that results in loss of access to services for the community and requires physicians to follow the religious guidelines embodied in the Directives may result in “conflict with prevailing medical

standards of care and ethical principles of health care professional” [15]. Physicians and other health care professionals who are not members of the faith tradition may find themselves contractually prohibited from providing care that is otherwise legal and, in their professional judgment, clinically appropriate and ethically permissible under the norms of medical professionalism.

## THE RESPONSIBILITIES OF LEADERSHIP

As challenging as mergers between secular and religiously affiliated health care facilities may be for individual patients and physicians, addressing dilemmas of mission is pre-eminently a responsibility of hospital leadership.

For Catholic facilities merging with secular facilities (or facilities associated with other religious traditions), a touchstone is the principle of cooperation [16,17]. The principle, it is argued, is a necessity for business relationships in a pluralistic world, providing a way to address the reality that, for the faithful, “it is almost impossible to bring about good without brushing up against or even becoming somewhat involved in the wrongdoing of others” [16]. The principle of cooperation is understood “as a *limiting principle*, to avoid cooperating in evil” (original emphasis) [17].

The essential goal is to ensure that institutional arrangements allow the facility and its staff to “remain as removed as possible” from violations of the Directives and “not [to] contribute anything essential to make possible the wrongdoing’s occurring” [16]—e.g., essential employed staff or equipment for the performance of what under the Directives is an immoral procedure [17]. Whether services that would be otherwise prohibited by the Directives will or may be available through the merged entity is importantly a function of how caregiving is organized in the resulting composite system. The approval of the diocesan bishop is required for mergers involving facilities subject to his governing authority, and the diocesan bishop has final authority for assessing whether a proposed merger constitutes morally licit cooperation (§VI) [7].

Analogous discussions of the ethics of trusteeship, such as that offered by The Hastings Center, offer secular insight for thinking about the responsibilities of leaders in health care institutions. Trustees of not-for-profit health care organizations “regularly make decisions that affect the lives and well-being of a large number of people who are relatively powerless, relatively vulnerable, and in need of services or assistance” [18]. In light of the mission of such organizations, service on a board of trustees entails fiduciary duties to founders, benefactors, and donors and responsibility to ensure that the organization realizes the public benefits for which it enjoys tax exempt status.

Trustees are held to principles of fidelity to mission; service to patients, ensuring that the care is high quality and provided “in an effective and ethically appropriate manner”; service to the community the hospital serves, deploying hospital resources “in ways that enhance the health and quality of life” of the community; and institutional stewardship. They have a further responsibility to ensure that when there is conflict over fundamental values and principles, “all points of view are heard and taken seriously, that reasonable compromise is explored, and that consensus has time to form” [18].

The Principles of Integrated Leadership for Hospitals and Health Care Systems, developed in collaboration by the American Hospital Association (AHA) and the American Medical Association (AMA), address responsibilities of hospital leadership in the context of rapidly evolving models of integrated physician-hospital health care systems [19]. In addition to governance and management structure and leadership development, guidance identifies “cultural adaptation” as a key element for success, observing that:

Culture is the way an organization, institution or integrated health system does business, in a way that is predictable, known to all and consonant with the mission and values of the organization, institution or integrated health system. The creation of a common shared culture that includes an integrated set of values is important to serve as a guide to the entity and will serve as a touch point to help resolve the inevitable conflicts that will arise [19].

The AHA-AMA's principles for *Integrated Leadership for Hospitals and Health Systems* urge integrated health systems to cultivate the characteristics of adaptive institutional culture, including a focus on the health of the entire population served; agreement to a common mission, vision, and values; mutual understanding and respect; and a sense of common ownership of the entity and its reputation [19].

## INSIGHT FROM THE CODE OF MEDICAL ETHICS

As frontline clinicians, physicians (and other health care professionals) regularly confront the effects on patients' lives and well-being of the institutional arrangements through which care is delivered. They have a responsibility to advocate for the resources patients need, as well as to be responsible stewards of the resources with which they are entrusted [20]. They must be able to make treatment recommendations in keeping with their best judgment as medical professionals [21]. And they are expected to uphold the ethical norms of medicine, including fidelity to patients and respect for patients as moral agents and decision makers [22].

Existing guidance on exercise of conscience by individual physicians suggests essential responsibilities of leadership in health care as well [22]. These include responsibility to engage in thoughtful consideration of the implications of institutional arrangements—whether arrangements sustain or risk undermining the personal and professional integrity of staff, cause moral distress, or compromise the ability to provide care. Leaders in health care institutions must be mindful that arrangements do not discriminate against or unduly burden individual patients or populations of patients, and of the burden arrangements may place on fellow professionals. And they must accept responsibility to take steps to ensure that services will be available to meet the patients and community the institution serves.

## RECOMMENDATION

In light of this analysis, the Council on Ethical and Judicial Affairs recommends that the following be adopted, and the remainder of this report be filed:

The merger of secular health care institutions and those affiliated with a faith tradition can benefit patients and communities by sustaining the ability to provide a continuum of care locally in the face of financial and other pressures. Yet consolidation among health care institutions with diverging value commitments and missions may also result in limiting what services are available. Consolidation can be a source of tension for the physicians and other health care professionals who are employed by or affiliated with the consolidated health care entity.

Protecting the community that the institution serves as well as the integrity of the institution, the physicians and other professionals who practice in association with it, is an essential, but challenging responsibility.

Physician-leaders within institutions that have or are contemplating a merger of secular and faith-based institutions should:

- 1 (a) Seek input from stakeholders to inform decisions to help ensure that after a consolidation  
2 the same breadth of services and care previously offered will continue to be available to the  
3 community.
- 4
- 5 (b) Be transparent about the values and mission that will guide the consolidated entity and  
6 proactively communicate to stakeholders, including prospective patients, physicians, staff,  
7 and civic leaders, how this will affect patient care and access to services.
- 8
- 9 (c) Negotiate contractual issues of governance, management, financing, and personnel that  
10 will respect the diversity of values within the community and at minimum that the same  
11 breadth of services and care remain available to the community.
- 12
- 13 (d) Recognize that physicians' primary obligation is to their patients. Physician-leaders in  
14 consolidated health systems should provide avenues for meaningful appeal and advocacy  
15 to enable associated physicians to respond to the unique needs of individual patients.
- 16
- 17 (e) Establish mechanisms to monitor the effect of new institutional arrangements on patient  
18 care and well-being and the opportunity of participating clinicians to uphold professional  
19 norms, both to identify and address adverse consequences and to identify and disseminate  
20 positive outcomes.
- 21
- 22 Individual physicians associated with secular and faith-based institutions that have or propose  
23 to consolidate should:
- 24
- 25 (f) Work to hold leaders accountable to meeting conditions for professionalism within the  
26 institution.
- 27
- 28 (g) Advocate for solutions when there is ongoing disagreement about services or arrangements  
29 for care.

(New HOD/CEJA Policy)

Fiscal note: Less than \$500

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REPORT 3 OF THE COUNCIL ON ETHICAL AND JUDICIAL AFFAIRS (A-18)  
Medical Tourism  
(Reference Committee on Amendments to Constitution and Bylaws)

EXECUTIVE SUMMARY

Every year, a growing number of “medical tourists” cross borders to receive treatments and procedures, including elective cosmetic services that are less costly than in their home countries; “medically necessary” care that is available at lower cost or in a more timely fashion; for access to nonvalidated therapies or other services that for ethical or legal reasons are not available in the health care system where the patient resides. Sometimes patients travel at the recommendation of their own physicians or under the auspices of programs initiated by their health plans or employers; sometimes patients travel on their own initiative, with or without consulting their physician, and with or without utilizing the services of commercial medical tourism companies.

Many aspects of medical tourism confound core ethical expectations regarding patients’ rights—to informed consent, continuity of care and access to their medical records (E-1.1.3)—and physicians’ responsibilities—to promote quality of care (E-1.1.6) and patient safety (E-8.6), to be prudent stewards of health care resources.

Physicians need to be aware of the implications of medical tourism for individual patients and the community. Collectively, the profession should support access to outcomes data about medical tourism and advocate for appropriate education for health care professionals as well as for appropriate oversight of medical tourism.

Individually, physicians should familiarize themselves with issues in medical tourism, including risks and possible benefits, to help support informed decision making when patients approach them about seeking care abroad and offer professional guidance as they would for any decision about care. They should advise patients who consult them in advance whether they are or are not willing to provide follow up care. Physicians should respond compassionately when patients who did not discuss traveling for care return seeking nonemergent follow-up services. Before declining to provide such care, physicians should consider carefully the nature and duration of their relationship with the patient, the likely impact on the patient’s well-being, the burden declining to provide care may impose on fellow professionals, and the likely impact on the health and resources of the community.

## REPORT OF THE COUNCIL ON ETHICAL AND JUDICIAL AFFAIRS\*

CEJA Report 3-A-18

Subject: Medical Tourism

Presented by: Dennis S. Agliano, MD, Chair

Referred to: Reference Committee on Amendments to Constitution and Bylaws  
(Peter H. Rheinstein, MD, JD, MS, Chair)

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1 Policy H-460.896(a), “Stem Cell Tourism,” adopted at the 2016 Annual meeting, calls on the  
2 American Medical Association (AMA) to encourage study of “appropriate guidance for physicians  
3 to use when advising patients who seek to engage in stem cell tourism and how to guide them in  
4 risk assessment.”

5  
6 In keeping with this policy, the Council on Ethical and Judicial Affairs (CEJA) was asked to  
7 develop ethics guidance for physicians in this area. Based on its review of relevant literature and its  
8 deliberations, the council concluded that guidance focusing on the broader phenomenon of medical  
9 tourism, of which stem cell tourism is only one example, would better serve the profession. The  
10 following report and recommendations thus provide broad guidance for physicians who interact  
11 with patients who seek or have received medical care outside the U.S.

### 12 13 EMERGENCE OF MEDICAL TOURISM

14  
15 Every year, a growing number of “medical tourists” cross borders to receive treatments and  
16 procedures, often treatments that are unaffordable or unavailable to them at home [1]. In its  
17 broadest sense, “medical tourism” refers to any occasion on which patients travel outside their  
18 home geographic area to receive medical care elsewhere—for example, traveling to a center of  
19 excellence in another city or state. As most commonly used today, however, medical tourism refers  
20 to traveling to a foreign country to receive care. It encompasses international travel by wealthy  
21 patients from lower wage countries to medical centers in higher wage countries, notably the U.S.  
22 [2]. Increasingly, however, medical tourism is understood as travel in the opposite direction, from  
23 higher wage countries to less affluent countries where medical services are available at lower cost  
24 [2,3].

25  
26 Estimations of how many patients travel abroad for care vary considerably, but appear to exceed  
27 one million [4,5]. In some instances, patients travel abroad for care at the recommendation of their  
28 own physicians or under the auspices of programs initiated by their health plans or employers  
29 [2,6,7]. In others, patients travel on their own initiative, with or without consulting their physician,  
30 and with or without utilizing the services of commercial medical tourism companies [2].

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## MEDICAL SERVICES OFFERED

Medical tourists travel to address what they deem to be unmet personal medical needs [8], prompted by issues of cost, timely access to services, higher quality of care or perceived superior services, or to access services that are not available in their country of residence [9,10]. Patients may also go outside their usual health care system to achieve other goals, for example, to preserve anonymity [11]; immigrant patients may return to their country of origin to receive care in culturally familiar settings [9]. The care medical tourists seek may be elective procedures; medically necessary standard care; or care that is unapproved or legally or ethically prohibited in their home system [12].

### *Elective Procedures: “Cosmetic Tourism”*

A significant and expanding portion of the medical tourism industry is comprised of individuals who seek cosmetic procedures that are available in their home country but are offered at often considerably lower cost elsewhere [11,13,14]. For example, 2011 data indicate that breast implants that would have cost approximately \$6,000 in the U.S. were available for about 43 percent of that cost in Thailand (approximately \$2,600) and less than 25 percent (approximately \$1,248) in Cuba [11]. Because cosmetic procedures are generally not covered by insurance plans and patients must pay out of pocket, going abroad for a desired procedure can be an attractive option. However, as Australian researchers noted, “[t]he model of care by which these services are delivered limits preoperative assessment and follow up to a few days to a week” [14].

### *Medically Necessary Care: “Transplant Tourism”*

Medical tourism also encompasses care that would be deemed “medically necessary,” such as cardiac care (coronary artery bypass grafts, heart valve replacements, angioplasty) and orthopedic surgery (hip and knee replacement, hip resurfacing, spinal fusion) [15]. Patients from publicly funded health care systems, such as Canada, Australia, or the U.K., cite long wait times at home as a primary reason for seeking care abroad [16], although they could receive needed care in their home system. Uninsured or underinsured patients in predominantly private health care systems, such as the U.S., travel to access needed care that would otherwise not be available to them [3].

Over the past decade “transplant tourism” has emerged as a particularly problematic form of medical tourism. As one critique noted, many of the patients who go abroad for an organ transplant are “middle-income Americans evading impoverishment by expensive, medically necessary operations” [17]. Self-insured employers may encourage transplant tourism in an effort to contain health care costs [18]. A study of transplant tourists who presented for follow-up care at one U.S. facility found that these patients “had a substantially lower mean dialysis time before transplantation” compared with patients who underwent transplant at the institution [19]. By one estimate, as of 2007 some 10 percent of transplants worldwide involved commercial sales of organs [20]. Organ trafficking and the exploitation of vulnerable donors in resource poor countries associated with transplant tourism led the international transplant community in 2008 to adopt principles intended to curb unethical transplant practices [20].

### *Unapproved/Investigational Therapies: “Stem Cell Tourism”*

Other than therapies for blood disorders, there is no evidence that stem-cell-based interventions are efficacious. Yet the market in stem cell tourism continues to grow—by 2012 some 700 clinics worldwide offered stem cell therapy for spinal cord injury, cardiovascular disease, Parkinson’s and

a host of other conditions [21]. For the most part, these therapies are unapproved and unregulated [21,22].

A recent case highlights the dangers of stem cell therapy. Richard Gass, a retired attorney in the U.S., suffered a stroke that left one arm paralyzed and one leg with weakness. Although he was able to live independently, he encountered a story about the miraculous physical recovery of a professional athlete who had traveled to Russia for stem cell treatments following a serious injury. Convinced of the promise stem cell treatments could bring, and undeterred by his family's concerns about the dangers of these therapies, he traveled to Mexico to receive stem-cell injections. Despite improvement in his mobility early on, within months Gass became paralyzed from the neck down. When he sought follow-up care from his U.S. health care team, they discovered that a large, rapidly growing tumor along his spine derived from foreign cells that could not be completely removed [23].

In 2013, the International Society for Stem Cell Research called on governments and professional organizations to discourage commercial provision of (autologous) stem cell interventions outside of clinical trials [24]. Governments are moving to strengthen or more stringently enforce legal regulations where they exist [25]. For example, the U.S. Food and Drug Administration has issued draft guides that increase clarity and suggest that the U.S. Food and Drug Administration is preparing to take increased regulatory action in response to stem cell interventions offered domestically [26].

#### *Proscribed Therapies: "Reproductive Tourism" ("Fertility Exile")*

As another area of medical tourism, travel for reproductive services highlights in particular issues involving access to services that for legal or ethical reasons are not available in the health care system where the patient(s) reside, or that are denied to certain categories of patients [27,28]. Hence the suggestion that such travel might better be described as "fertility exile" [29]. As reproductive tourists, patients may cross borders to receive services that are not legally available in their home health care system (e.g., pre-implantation genetic diagnosis); services for which they do not qualify in their home system by reason of age or marital status (e.g., in vitro fertilization); or services denied by their home health care institutions or health systems based on social rather than clinical considerations (e.g., gestational surrogacy for male same-sex couples) [28]. By one estimate, some 5,000 cross-border IVF treatment cycles were performed in 25 countries in 2008 [30].

Like transplant tourism, reproductive tourism raises concerns about the exploitation of vulnerable populations and the commercialization of human biological materials, as well as about discrimination against classes of patients [28,30,31]. Travel for unapproved or prohibited services can also exploit medical tourists themselves, of course, when it trades on false hope [12].

#### IMPLICATIONS FOR PATIENTS, PHYSICIANS & HEALTH CARE SYSTEMS

Many medical tourists receive excellent care, but data suggest that issues of safety and quality can loom large. Substandard surgical care, poor infection control, inadequately screening of blood products, and falsified or outdated medications in lower income settings of care can pose greater risks than patients would face at home [32,33]. Patients who develop complications may need extensive follow-up care when they return home; for those who return with infections, the differential diagnosis is often broader than in their home country, further complicating follow-up care [33]. The often short recovery periods following treatment abroad also mean medical tourists

1 can face greater risk for deep vein thrombosis, pulmonary embolism, or other travel-related  
2 complications [5,14,33].

3  
4 For example, in 2013, the Maryland Department of Health and Mental Hygiene dealt with the  
5 repercussions of medical tourists traveling outside the U.S. for cosmetic surgery. Public health  
6 officials, working with the CDC, identified 21 patients from six states who had traveled to the  
7 Dominican Republic for cosmetic procedures (liposuction, abdominoplasty, buttocks augmentation,  
8 breast augmentation, and breast reduction); 18 were confirmed to have rapidly growing  
9 *Mycobacterium abscessus* (RGM), likely because of poor sterilization procedures during their  
10 surgeries [13]. All patients were successfully treated, but their course of care was complicated.  
11 Among the nine patients for whom chart data were available, median onset of illness was 24 days  
12 after their surgical procedure. Of the five from whom RGM culture was positive, median time to  
13 laboratory confirmation was 79 days after their first presentation for care in the U.S. Eight were  
14 hospitalized in the U.S., five of them on more than two occasions. All nine underwent at least one  
15 therapeutic surgical procedure; seven required courses of antibiotics for three months or longer;  
16 seven were prescribed more than five different classes of antibiotics [13].

17  
18 Cost of post-surgical care can also be a concern. Of the patients who responded to requests for  
19 information about cost, 13 used medical insurance, although four indicated that their insurer had  
20 declined to cover some costs. Ten patients indicated the illness had caused financial problems; two  
21 reported that indirect costs, such as inability to work, compounded their financial difficulty [13]. A  
22 review of data for patients hospitalized at London's Royal Free Hospital between 2015 and 2017  
23 following plastic surgery outside the U.K. found that among 21 patients, complications led to 18  
24 in-patient admissions and 46 surgical procedures overall. The total cost of follow up care was  
25 £282,000 (U.S. \$368,600); cost per patient averaged £13,500 (slightly less than U.S. \$18,000) [34].  
26 Chart review at Gold Coast University Hospital in Queensland, Australia, similarly found that  
27 between 2012 and 2013, the facility treated 12 patients for complications following cosmetic  
28 surgery abroad—including not only infection, but also pulmonary embolism—at a cost of  
29 AU\$151,172.52 (approximately \$115,800 U.S.) [14]. Similar additional costs are reported by U.S.  
30 facilities [5].

31  
32 Medical tourism carries implications for patients' home communities as well. For example, the  
33 financial costs of needed follow-up care fall on health care institutions and health insurers  
34 [10,12,32], which may be especially problematic in publicly funded health care systems [10,14].  
35 Medical travel poses public health risks, providing means for moving bacteria and resistant genes  
36 globally [33]. The fact that patients may return to multiple home institutions from a single  
37 destination treatment center underscores the need for tracking medical travel and outcomes that  
38 currently is not being met [14,33].

39  
40 Additionally, medical tourism carries implications for destination communities and health care  
41 systems. It can foster dual systems of care, one catering to medical tourists, and one for the local  
42 population, a situation that risks exacerbating health inequity [10,32,35]. Development of  
43 commercial health care institutions to serve medical tourists risks creating, in the words of one  
44 author, "islands of medical excellence in a sea of medical neglect" [31]. Transplant and  
45 reproductive tourism in particular pose significant risk that vulnerable local populations will be  
46 exploited as donors of biological materials that benefit foreign patients [20,31].

#### 47 48 GUIDANCE FROM PROFESSIONAL ORGANIZATIONS

49  
50 In 2008, the American Medical Association adopted H-450.937, "Medical Care outside the United  
51 States," which advocates that entities that "facilitate or incentivize" medical care outside the U.S.

1 ensure that such care is voluntary, take care that financial incentives neither limit the alternatives  
 2 offered to patients nor restrict treatment or referral, and refer patients only to internationally  
 3 accredited institutions. Policy further urges that local follow-up care and financing be coordinated  
 4 prior to travel and that coverage include costs of necessary follow-up care in the U.S. Patients  
 5 should be informed about their rights and legal recourse and should have access to information  
 6 about the foreign facility and health care professionals, the potential risks of combining surgical  
 7 procedures with travel, and outcomes data for the procedure(s) they will undergo. Transfer of  
 8 medical records to and from facilities outside the U.S. should adhere to HIPAA requirements.  
 9 Policy also supports reporting and tracking safety and quality data for procedures performed  
 10 outside the U.S. Substantially similar guidelines were published by the American Society for  
 11 Metabolic and Bariatric Surgery.

12  
 13 Also in 2008, the Transplantation Society and the International Society of Nephrology jointly  
 14 developed the Declaration of Istanbul on Organ Trafficking and Transplant Tourism to promote  
 15 and uphold ethical practice in organ transplantation internationally [20]. The following year, the  
 16 American College of Surgeons issued a position statement on medical and surgical tourism that  
 17 supports patients' right to choose where and from whom they receive care and encourages College  
 18 Fellows to support informed decision making. The statement advises patients to consider not only  
 19 medical, but also "social, cultural and legal implications of seeking treatment abroad," as well as to  
 20 seek care at an accredited institution and to obtain a complete copy of their medical records before  
 21 returning to the U.S [36]. In 2013, the International Society for Stem Cell Research similarly issued  
 22 a critique of commercial stem cell therapy and called for adherence to ethical standards regarding  
 23 interventions whose clinical value has not yet been demonstrated [24].

24  
 25 Several professional medical organizations have published cautionary information for patients  
 26 about medical tourism, including the American Academy of Facial and Plastic Surgery [37], the  
 27 American Society of Hematology [38], the American Society of Plastic Surgery [39], and the  
 28 American Society for Metabolic and Bariatric Surgery [40].

## 29 30 ETHICAL CHALLENGES OF MEDICAL TOURISM

31  
 32 Medical tourism can leave home country physicians in problematic positions: Faced with the  
 33 reality that medical tourists often need follow-up when they return, even if only to monitor the  
 34 course of an uneventful recovery; confronted with the fact that returning medical tourists often  
 35 don't have records of the procedures they underwent and the medications they received, or contact  
 36 information for the foreign health care professionals who provided services; asked to make right  
 37 what went wrong when patients experience complications as a result of medical travel, often  
 38 having not been informed about, let alone part of the patient's decision to seek health care abroad  
 39 [41].

40  
 41 Many aspects of medical tourism confound core ethical expectations regarding patients' rights—to  
 42 informed consent, continuity of care and access to their medical records (E-1.1.3)—and physicians'  
 43 responsibilities—to promote quality of care (E-1.1.6) and patient safety (E-8.6), to be prudent  
 44 stewards of health care resources (E-11.1.2). Patients' decisions to seek medical care abroad may  
 45 also threaten trust [41] and the integrity of patient-physician relationships. These challenges are  
 46 fundamentally systemic, yet patients often expect individual physicians to find ways to address  
 47 them.

### *Informed Decision Making*

Ensuring that patients make informed decisions about seeking care abroad is not possible unless patients let physicians know they are considering doing so. Expecting physicians to routinely screen patients for possible interest in becoming a medical tourist is not realistic, but when a patient expresses concern about access to certain services, or a desire to receive care that is generally not available in the community, physicians should recognize the possibility that the patient is contemplating going outside the local system of care and explore the patient's concerns and wishes more fully.

When patients' responses indicate interest in medical tourism, it is reasonable to expect physicians will help ensure that patients have the information they need to make well-considered decisions. Physicians might do so by addressing the pros and cons of medical tourism themselves when they have relevant knowledge, by referring the patient to a specialist who has relevant expertise, or by directing the patient to other resources on medical tourism for the procedure, such as specialty society or government information pages.

### *Continuity of Care*

Arguably, the extent of individual physicians' ethical responsibility to provide after care for patients who have undergone a medical procedure abroad as a medical tourist will vary with the circumstances. Physicians have a responsibility to provide urgently needed care, or refer the patient appropriately (Principle VI), and to provide or refer for needed follow-up care when a current patient has received emergency medical care abroad. They are likewise expected to honor contractual obligations to provide care (E-1.1.2).

In other circumstances, however, physicians' ethical responsibility may be less stringent, particularly when patients have traveled for elective procedures. Physicians have stronger obligations to patients with whom they have a patient-physician relationship, especially one of long standing (E-1.1.7) [8]. Beyond carefully considering the likely effect on the individual patient's welfare, physicians should take into account whether they have the resources to provide the needed care safely and the likely effects providing care or declining to do so will have on their ability to meet the needs of other patients in their practice (E-1.1.2). Physicians have a further responsibility to reflect on the burden declining to provide follow-up care may impose on fellow professionals (cp. E-1.1.7), and on the likely impact on the health and resources of the community (E-1.1.2).

### *Preserving Trust*

Patients may be hesitant to discuss medical tourism, fearing their physician's reaction [41]. Physicians have a responsibility to offer their best professional guidance about a patient's decision to become a medical tourist, just as they would any other decision about care. This includes being candid when they deem a decision to obtain specific care abroad not to be in the patient's best interests and helping the patient understand why they believe that to be the case. To protect the trust on which an effective therapeutic relationship is grounded, physicians should acknowledge the patient's goal for seeking care. As patient advocates, they should help ensure that the patient has exhausted options for getting the desired care within their home health care system [42]. This includes encouraging patients who propose to travel for an unapproved therapy to enroll in appropriate clinical trials.

When patients inform them before they travel, physicians should advise the patient about the level of care they will or will not be able or willing to provide when the patient returns (cp. E-1.1.7).

When a patient who did not inform the physician in advance returns seeking follow-up care for treatment received abroad, physicians must decide whether to provide that care. The obligation of compassion does not automatically translate into a duty to treat except in an emergency. However, before declining to provide needed after care to a medical tourist, physicians should carefully consider the effect that decision is likely to have on the patient's welfare, other health care professionals, and the community.

### *Oversight*

The European Union has established formal guidelines for cross-border care among member countries [43], and entities such as the Joint Commission International and Accreditation Canada accredit international health care facilities [32], but at present, medical tourism is otherwise regulated only to the extent that medical practice in individual countries is regulated. Medical tourism companies as such are not regulated at all. Nor do medical tourism agents receive specific training or certification [32]. The absence of systematic collection and reporting of data about outcomes leaves patients, physicians, and health care systems in the dark, impeding informed decision making about medical tourism and obscuring potential risks to public health. Physicians have firsthand knowledge of the experience of individual patients who have become medical tourists and are well positioned to advocate for standards to improve quality of care and protect the interests of patients who seek care abroad.

## RECOMMENDATION

In view of these considerations, the Council on Ethical and Judicial Affairs recommends that the following be adopted and the remainder of this report filed:

Medical tourists travel to address what they deem to be unmet personal medical needs, prompted by issues of cost, timely access to services, higher quality of care or perceived superior services, or to access services that are not available in their country of residence. In many instances, patients travel on their own initiative, with or without consulting their physician, and with or without utilizing the services of commercial medical tourism companies. The care medical tourists seek may be elective procedures, medically necessary standard care, or care that is unapproved or legally or ethically prohibited in their home system.

Many medical tourists receive excellent care, but issues of safety and quality can loom large. Substandard surgical care, poor infection control, inadequately screening of blood products, and falsified or outdated medications in lower income settings of care can pose greater risks than patients would face at home. Medical tourists also face heightened travel-related risks. Patients who develop complications may need extensive follow-up care when they return home. They may pose public health risks to their home communities as well.

Medical tourism can leave home country physicians in problematic positions: Faced with the reality that medical tourists often need follow-up when they return, even if only to monitor the course of an uneventful recovery; confronted with the fact that returning medical tourists often do not have records of the procedures they underwent and the medications they received, or contact information for the foreign health care professionals who provided services, asked to make right what went wrong when patients experience complications as a result of medical travel, often having not been informed about, let alone part of the patient's decision to seek health care abroad.

1 Physicians need to be aware of the implications of medical tourism for individual patients and  
2 the community.

3  
4 Collectively, through their specialty societies and other professional organizations, physicians  
5 should:

- 6  
7 (a) Support collection of and access to outcomes data from medical tourists to enhance  
8 informed decision making.  
9  
10 (b) Advocate for education for health care professionals about medical tourism.  
11  
12 (c) Advocate for appropriate oversight of medical tourism and companies that facilitate it to  
13 protect patient safety and promote high quality care.  
14  
15 (d) Advocate against policies that would require patients to accept care abroad as a condition  
16 of access to needed services.  
17

18 Individually, physicians should:

- 19  
20 (e) Be alert to indications that a patient may be contemplating seeking care abroad and explore  
21 with the patient the individual's concerns and wishes about care.  
22  
23 (f) Seek to familiarize themselves with issues in medical tourism to enable them to support  
24 informed decision making when patients approach them about getting care abroad.  
25  
26 (g) Help patients understand the special nature of risk and limited likelihood of benefit when  
27 they desire an unapproved therapy. Physicians should help patients frame realistic goals for  
28 care and encourage a plan of care based on scientifically recognized interventions.  
29  
30 (h) Advise patients who inform them in advance of a decision to seek care abroad whether the  
31 physician is or is not willing to provide follow-up care for the procedure(s), and refer the  
32 patient to other options for care.  
33  
34 (i) Offer their best professional guidance about a patient's decision to become a medical  
35 tourist, just as they would any other decision about care. This includes being candid when  
36 they deem a decision to obtain specific care abroad not to be in the patient's best interests.  
37 Physicians should encourage patients who seek unapproved therapy to enroll in an  
38 appropriate clinical trial.  
39  
40 (j) Physicians should respond compassionately when a patient who has undergone treatment  
41 abroad without the physician's prior knowledge seeks nonemergent follow-up care. Those  
42 who are reluctant to provide such care should carefully consider  
43  
44 (i) the nature and duration of the patient-physician relationship;  
45  
46 (ii) the likely impact on the individual patient's well-being;  
47  
48 (iii) the burden declining to provide follow-up care may impose on fellow professionals;  
49  
50 (iv) the likely impact on the health and resources of the community.

- 1 Physicians who are unable or unwilling to provide care in these circumstances have a
- 2 responsibility to refer the patient to appropriate services.

(NEW HOD/CEJA POLICY)

Fiscal Note: Less than \$500.



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# REPORT OF THE COUNCIL ON ETHICAL AND JUDICIAL AFFAIRS\*

CEJA Report 4-A-18

Subject: Expanded Access to Investigational Therapies

Presented by: Dennis S. Agliano, MD, Chair

Referred to: Reference Committee on Amendments to Constitution and Bylaws  
(Peter H. Rheinstein, MD, JD, MS, Chair)

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Policy D-460.967(2), “Study of the Current Uses and Ethical Implications of Expanded Access Programs,” instructs our American Medical Association (AMA) to “study the ethics of expanded access programs, accelerated approval mechanisms, and payment reform models meant to increase access to investigational therapies, including access for infants and children.” This report by the Council on Ethical and Judicial Affairs (CEJA) examines ethical issues in relation to expanded access and offers guidance for physicians.

## ACCESS TO INVESTIGATIONAL THERAPY

For some patients who face serious life-threatening or life-limiting conditions there are few or no approved therapies. For others, existing therapies are unlikely or have failed to be effective. In such situations, patients and their physicians may turn to as yet unapproved treatments as a last hope.

From a societal perspective, participating in a clinical trial is the most desirable way for patients to obtain access to therapies still in development [1,2]. But from the perspective of individual patients, enrolling in a randomized trial cannot guarantee access to the treatment they seek; some will not meet inclusion criteria to be accepted as trial participants even if they are willing to take the chance of being randomized to a control arm rather than the investigational therapy; still others may be unable to participate for other reasons. The expanded access program of the US Food and Drug Administration (FDA) allows patients in such circumstances to seek access to treatment with an investigational therapy outside a clinical trial.

### *Expanded Access (“Compassionate Use”)*

“Expanded access” refers “the use of an investigational drug when the primary purpose is to diagnose, monitor, or treat a patient rather than to obtain the kind of information about the drug that is generally derived from clinical trials [3].

Following the thalidomide scandal of the late 1950s and early 1960s, in 1962 the US Congress mandated that the FDA validate the safety and effectiveness of new drugs based on substantial evidence collected from controlled clinical trials, which significantly lengthened the timelines for development of new drugs [4]. The FDA began allowing patients and physicians to petition for access to unapproved drugs [4], and in 1987 recognized “treatment IND [investigational new

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\* Reports of the Council on Ethical and Judicial Affairs are assigned to the Reference Committee on Amendments to Constitution and Bylaws. They may be adopted, not adopted, or referred. A report may not be amended, except to clarify the meaning of the report and only with the concurrence of the Council

1 drug]” protocols in response to the HIV/AIDS crisis as dying AIDS patients sought access to the  
2 then-unapproved drug AZT [5].

3  
4 With the push from advocacy groups such as ACT UP, the FDA agreed to allow pharmaceutical  
5 companies to offer access to other promising AIDS drugs through an “expanded access” (or  
6 “compassionate use”) protocol; Alzheimer and cancer patients and their advocates soon followed  
7 with similar demands for access to unproven therapies [5]. In 2009, the FDA substantially revised  
8 federal regulations (at 21 CFR 312), creating three categories for access to investigational  
9 therapies: use by individual patients, use by intermediate-sized patient populations (tens to  
10 hundreds), and widespread use after a clinical trial has been successfully completed but prior to  
11 FDA approval of the therapy [4,6].

12  
13 Before a patient can legally receive an investigational therapy outside of a clinical trial, the FDA  
14 must approve the expanded access application submitted by the physician who will oversee  
15 treatment (21 CFR 312.305). To be granted, a request must demonstrate that the patient(s) for  
16 whom access is requested has a “serious or immediately life-threatening” condition for which there is  
17 no satisfactory alternative therapy; that the potential benefit to the patient justifies the risk of the  
18 investigational therapy; and that the potential risks of the investigational therapy “are not  
19 unreasonable in the context of the disease or condition to be treated” (21 CFR 312.305). To protect  
20 the scientific integrity of clinical trials, it must also be shown that providing the investigational  
21 therapy “will not interfere with the initiation, conduct, or completion of clinical investigations that  
22 could support marketing approval of the expanded access use or otherwise compromise the  
23 potential development of the expanded access use” (21 CFR 312.305).

24  
25 The regulations further set evidentiary thresholds for risk that are more stringent the greater  
26 number of patients involved and the less serious the condition. For single patient use, a physician  
27 need only conclude that the investigational therapy poses no greater risk than the disease itself (21  
28 CFR 312.310), while for intermediate-size patient populations, there must be evidence that the drug  
29 is safe “at the dose and duration” proposed for expanded access use and that there is “at least  
30 preliminary clinical evidence of effectiveness” (or plausible pharmacologic effect) to make use  
31 under expanded access “a reasonable therapeutic option” for the intended patient population (21  
32 CFR 312.315). Thus, patients who receive investigational therapies outside clinical trials don’t  
33 have the same protections as do enrolled participants, such as monitoring by institutional review  
34 boards and data and safety monitoring boards, which can halt trials when significant concerns arise  
35 [7]. Because patients receiving investigational therapies under expanded access are not connected  
36 to a particular trial site, “the potential for rigorous safety monitoring is greatly reduced” [7].

37  
38 Under the 2009 regulations, the treating physician must determine that the proposed use meets  
39 FDA criteria for expanded access and is also responsible for obtaining IRB approval for use of the  
40 investigational therapy for the patient, which can be particularly challenging for physicians outside  
41 academic medical centers [4]. Physicians who treat patients with investigational therapies under  
42 expanded access must comply with the responsibilities for investigators set out elsewhere in federal  
43 regulations governing clinical trials. In 2017, the FDA took steps to streamline the process of  
44 applying for expanded access, simplifying the single patient application form and modifying the  
45 requirement for IRB approval to allow review by a single member of the IRB rather than the fully  
46 convened board [8]. FDA has indicated that further simplification is being considered [8].

47  
48 Sponsors are not required to provide investigational therapies for use under expanded access, and  
49 FDA has no authority to mandate that a drug be made available by an unwilling sponsor [7].  
50 Sponsors decline to participate in expanded access for a variety of reasons, including limited  
51 supply of the investigational therapy, limited capacity to produce additional supplies, or the cost of

1 making the therapy available outside an ongoing clinical trial [1,4]. Sponsors who provide an  
2 investigational therapy under expanded access face additional administrative burdens—among  
3 other requirements, regulations mandate that they ensure that physicians are qualified to administer  
4 the therapy and submit investigational new drug safety reports for the expanded access use,  
5 including reporting adverse events (21 CFR 312.305).

6  
7 One concern is that adverse events reported for expanded access use may in fact not be associated  
8 with the investigational therapy and could jeopardize development of it [1,9]. Patients who receive  
9 an investigational therapy outside clinical trials may have more advanced disease than trial  
10 participants, have other concurrent medical conditions, or be receiving other concurrent treatment,  
11 which can make it more difficult to determine the cause of an adverse event. Responding to this  
12 concern, the FDA recently clarified expectations for reporting negative effects, permitting sponsors  
13 to report only those events for which “there is evidence to suggest a causal relationship between the  
14 drug and the adverse event” [8].

### 15 16 *Impact of Expanded Access*

17  
18 Applications for expanded access use for both drugs and biologics have grown steadily—from just  
19 under 1,100 in 2010 to more than 1,700 in 2016 (with a high total of 1,999 in 2014) [10]. Overall,  
20 the Center for Drug Evaluation and Research received nearly 11,000 applications between 2005  
21 and 2014, of which 99.7% were approved [1]. The majority of requests were in “therapeutic areas  
22 where products were being developed to treat life-threatening illness with significant unmet  
23 medical need,” such as hematologic and solid organ malignancies [1].

24  
25 Less is known about whether requests for expanded access use are granted by sponsors or whether  
26 investigational therapies provided through expanded access have received FDA approval. A review  
27 of found 398 expanded access programs registered at ClinicalTrials.gov as of July 2016 [11]. Of  
28 the 210 unique experimental drugs for which data were reviewed, 76 percent had ultimately  
29 received approval. As the authors note, this suggests that “we cannot entirely eliminate safety and  
30 efficacy questions in expanded access and compassionate use” [11].

### 31 32 *The Future of Expanded Access*

33  
34 Provisions of the 21<sup>st</sup> Century Cures Act enacted in December 2016 address the challenges patients  
35 and physicians face in obtaining information about investigational therapies that may be available  
36 through expanded access. The act requires manufacturers and distributors of investigational drugs  
37 intended to treat serious diseases to “make public and readily available” their policies for  
38 evaluating and responding to requests for expanded access use (Pub L 114-255). The act further  
39 requires that such policies include contact information for the manufacturer or distributor,  
40 procedures for making requests and general criteria used to evaluate requests for individual  
41 patients, and a link or other reference to clinical trial information about the investigational therapy.  
42 The act does not, however, require a manufacturer or distributor to guarantee access to an  
43 investigational therapy in development.

44  
45 In addition to simplifying application forms for single patient use and procedures for IRB approval,  
46 in July 2017 FDA launched a new online [Expanded Access Navigator](#) in conjunction with the  
47 Reagan-Udall Foundation to assist patients and physicians in finding information about expanded  
48 access [8].

## ETHICAL CHALLENGES IN EXPANDED ACCESS

Although ongoing efforts to simplify expanded access programs will likely enable more patients to receive treatment with investigational therapies, ethical concerns remain. Key among them are issues of informed consent and decision making, fairness in access to investigational therapies, and possible negative effects for the conduct of clinical trials.

### *Informed Consent*

Informed consent to medical treatment is fundamental in both ethics and law. Patients have the right to receive information and to ask questions about recommended treatments so that they can make well-considered decisions about care ([E-2.1.1](#)). Treatment with an investigational therapy poses special challenges in this regard. Patients who face serious, life-threatening illnesses for which approved therapies have not been effective or for which there are no approved therapies may be particularly vulnerable to holding out false hope for investigational therapy [12]. Promoting truly informed decisions about whether to request expanded access is critical, but can be difficult, both because information about an investigational therapy is often incomplete or difficult to obtain, and because patients may be prone to misinterpreting what information is available.

In the early stages of development, relatively little may be known about an investigational therapy's efficacy or possible adverse effects [4,13]. Information about therapies still in development is often proprietary and thus not readily available, making it difficult for patients and physicians to assess whether the risk of disease outweighs the risk of the investigational therapy for purposes of requesting expanded access [4]. Moreover, terminally ill patients do not always evaluate risks and benefits objectively—they tend to overestimate likely benefit and underestimate the burdens of as yet unproven therapies [12,14]. They may be under a “therapeutic misconception” and fail to appreciate that the therapy has not been demonstrated to be effective [15], or be “unrealistically optimistic” and expect that their personal outcomes will be more positive than the outcomes of others in similar situations [14,16].

FDA acknowledges that patients who are candidates for expanded access use “are a particularly vulnerable population” and “should be afforded a rigorous informed consent process that effectively communicates the risks and potential benefits of any investigational therapy to be used for treatment use [sic] in a way that does not raise false expectations about a positive outcome from treatment and makes clear what is unknown about the drug” [6]. Expanded access regulations mandate that the treating physician (“investigator” in the language of the regulations) ensure that the consent requirements of the Common Rule are met (21 CFR 305(c)(4)), including informing the patient that the therapy is investigational and that there is uncertainty as to its safety and effectiveness [3].

FDA also mandates that the sponsor of an investigational therapy provide the treating physician “with the information needed to minimize the risk and maximize the potential benefits of the investigational drug (the investigator’s brochure must be provided if one exists for the drug)” (21 CFR 312.305(c)(5)) as a requirement for expanded access use. It is essential that the treating physician have as much information as possible about an investigational therapy to provide appropriate patient care. An investigator’s brochure “provides insight to support the clinical management of the study subject” [17]—or, in the instant case, the patient receiving the investigational therapy under expanded access—by compiling both clinical and nonclinical information about the therapy.

### *Financial Barriers to Expanded Access*

Issues of equity also arise with respect to expanded access programs. Sponsors may provide investigational therapies at no cost for expanded access use, but they are not required to do so. Current FDA regulations permit sponsors to recover direct costs of providing an investigational therapy for expanded access use (21 CFR 312.8(d)(1)) , either directly from patients or by billing third-party payers. For the most part, insurance plans do not reimburse the costs of therapies not yet approved for marketing [14,18]. Although most sponsors shoulder the cost burden, when they do not patients may be unable to afford to pay out of pocket, even when they have been approved for expanded access use. It has been argued that expanded access “favors the rich or well-connected” [4].

### *Effects on Clinical Trials/Implications for Public Health*

Expanded access programs may also adversely affect the successful completion of clinical trials and marketing approval of clinical trials. Permitting patients to obtain not yet approved therapies by means of expanded access may delay enrollment in trials of the therapy or jeopardize retention of participants, undermining efforts to demonstrate the safety and efficacy of the investigational therapy [9]. This in turn thwarts society’s interest in the development and approval of new therapies for populations of patients [2,9]. The extent to which expanded access programs in fact have this effect is not clear. Before FDA will approve a request for expanded access use, patients and physicians must demonstrate that the patient is not a candidate for a clinical trial, for example, because the individual fails to meet inclusion criteria or existing trials are geographically inaccessible to the individual.

## RECOMMENDATION

In light of these considerations, the Council on Ethical and Judicial Affairs recommends that Policy D-460.967(2), “Study of the Current Uses and Ethical Implications of Expanded Access Programs,” be rescinded, the following be adopted, and the remainder of the report be filed:

Physicians who care for patients with serious, life-threatening illness for whom standard therapies have failed, are unlikely to be effective, or do not exist should determine whether questions about access to investigational therapy through the U.S. Food and Drug Administration’s “expanded access” program are likely to arise in their clinical practice. If so, physicians should familiarize themselves with the program to be better able to engage in shared decision making with patients.

When a patient requests expanded access to an investigational therapy, physicians should:

- (a) Assess the patient’s individual clinical situation to determine whether an investigational therapy would be appropriate, including:
  - (i) whether there is a satisfactory alternative therapy available to diagnose, monitor, or treat the patient’s disease or condition;
  - (ii) the nature of potential risks of the investigational therapy and whether those risks are not unreasonable in the context of the patient’s disease or condition;
  - (iii) whether the potential benefit to the patient justifies the risks of the investigational therapy;



- 1 (iv) whether the patient meets inclusion criteria for an existing clinical trial of the  
2 investigational therapy.  
3
- 4 (b) As part of the informed consent process, advise the patient (or parent/guardian if the  
5 patient is a minor) that the investigational therapy has not yet been demonstrated to be  
6 effective in treating the patient's condition and may pose as yet unknown risks. Physicians  
7 should explain the importance of clinical trials, encourage patients who meet inclusion  
8 criteria to participate in an existing trial rather than seek access to investigational therapy  
9 through the FDA expanded access program, and direct patients who wish to participate in  
10 research to appropriate resources.  
11
- 12 (c) Decline to support an application for expanded access to an investigational therapy when:  
13
- 14 (i) the physician judges the treatment with the investigational therapy not to be in the  
15 patient's best interest, and explain why; or  
16
- 17 (ii) the physician does not have appropriate resources and ability to safely supervise the  
18 patient's care under expanded access.  
19
- 20 In such cases, physicians should refer the patient to another physician with whom to discuss  
21 possible application for expanded access.  
22
- 23 (d) Discuss the implications of expanded access for the patient and family and help them form  
24 realistic expectations about what it will mean to be treated with the investigational therapy  
25 outside a clinical trial. Physicians should alert patients:  
26
- 27 (i) to the possibility of financial or other responsibilities associated with receiving an  
28 investigational therapy through expanded access;  
29
- 30 (ii) to the lack of infrastructure to systematically monitor and evaluate the effects of the  
31 investigational therapy outside a clinical trial;  
32
- 33 (iii) that they need information about how to contact the manufacturer for guidance if they  
34 seek emergency care from a health care professional who is not affiliated with a  
35 clinical trial of the investigational therapy;  
36
- 37 (iv) that the physician has a responsibility to collect and share clinical information about  
38 the patient's course of treatment with the investigational therapy, as well as to report  
39 any adverse events that may occur over the course of treatment;  
40
- 41 (v) to the conditions under which the physician would recommend stopping treatment with  
42 the investigational therapy.

(NEW HOD/CEJA POLICY)

Fiscal Note: Less than \$500

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## REPORT OF THE COUNCIL ON ETHICAL AND JUDICIAL AFFAIRS\*

CEJA Report 5-A-18

Subject: Study Aid-in-Dying as End-of-Life Option  
(Resolution 15-A-16)  
The Need to Distinguish “Physician-Assisted Suicide” and “Aid in Dying”  
(Resolution 14-A-17)

Presented by: Dennis S. Agliano, MD, Chair

Referred to: Reference Committee on Amendments to Constitution and Bylaws  
(Peter H. Rheinstein, MD, JD, MS, Chair)

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1 At the 2016 Annual Meeting, the House of Delegates referred Resolution 15-A-16, “Study Aid-in-  
2 Dying as End-of-Life Option,” presented by the Oregon Delegation, which asked:

3  
4 That our American Medical Association and its Council on Judicial and Ethical Affairs, study  
5 the issue of medical aid-in-dying with consideration of (1) data collected from the states that  
6 currently authorize aid-in-dying, and (2) input from some of the physicians who have provided  
7 medical aid-in-dying to qualified patients, and report back to the HOD at the 2017 Annual  
8 Meeting with recommendation regarding the AMA taking a neutral stance on physician “aid-  
9 in-dying.”

10  
11 At the following Annual Meeting in June 2017, the House similarly referred Resolution 14-A-17,  
12 The Need to Distinguish between ‘Physician-Assisted Suicide’ and ‘Aid in Dying’” (presented by  
13 M. Zuhdi Jasser, MD), which asked that our AMA:

14  
15 (1) as a matter of organizational policy, when referring to what it currently defines as  
16 ‘*Physician Assisted Suicide*’ avoid any replacement with the phrase ‘*Aid in Dying*’ when  
17 describing what has long been understood by the AMA to specifically be ‘*Physician Assisted*  
18 *Suicide*’; (2) develop definitions and a clear distinction between what is meant when the AMA  
19 uses the phrase ‘*Physician Assisted Suicide*’ and the phrase ‘*Aid in Dying*’; and (3) fully utilize  
20 these definitions and distinctions in organizational policy, discussions, and position statements  
21 regarding both ‘*Physician Assisted Suicide*’ and ‘*Aid in Dying*.’

22  
23 This report by the Council on Ethical and Judicial Affairs (CEJA) addresses the concerns expressed  
24 in Resolutions 15-A-16 and 14-A-17. In carrying out its review of issues in this area, CEJA  
25 reviewed the philosophical and empirical literature, sought input from the House of Delegates  
26 through an I-16 educational program on physician-assisted suicide, an informal “open house” at A-  
27 17, and its I-17 Open Forum. The council wishes to express its sincere appreciation for  
28 participants’ contributions during these sessions and for additional written communications  
29 received from multiple stakeholders, which have enhanced its deliberations.

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\* Reports of the Council on Ethical and Judicial Affairs are assigned to the Reference Committee on Amendments to Constitution and Bylaws. They may be adopted, not adopted, or referred. A report may not be amended, except to clarify the meaning of the report and only with the concurrence of the Council.

The council observes that the ethical arguments advanced today supporting and opposing “physician-assisted suicide” or “aid in dying” are fundamentally unchanged from those examined in CEJA’s 1991 report on this topic [1]. The present report does not rehearse these arguments again as such. Rather, it considers the implications of the legalization of assisted suicide in the United States since the adoption of Opinion E-5.7, “Physician-Assisted Suicide,” in 1994.

“ASSISTED SUICIDE,” “AID IN DYING,” OR “DEATH WITH DIGNITY”?

Not surprisingly, the terms stakeholders use to refer the practice of physicians prescribing lethal medication to be self-administered by patients in many ways reflect the different ethical perspectives that inform ongoing societal debate. Proponents of physician participation often use language that casts the practice in a positive light. “Death with dignity” foregrounds patients’ values and goals, while “aid in dying” invokes physicians’ commitment to succor and support. Such connotations are visible in the titles of relevant legislation in states that have legalized the practice: “Death with Dignity” (Oregon, Washington, District of Columbia), “Patient Choice and Control at the End of Life” (Vermont), “End of Life Options” (California, Colorado), and in Canada’s “Medical Aid in Dying.”

Correspondingly, those who oppose physician provision of lethal medications refer to the practice as “physician-assisted suicide,” with its negative connotations regarding patients’ psychological state and its suggestion that physicians are complicit in something that, in other contexts, they would seek to prevent. The language of dignity and aid, critics contend, are euphemisms [2]; their use obscures or sanitizes the activity. In their view such language characterizes physicians’ role in a way that risks construing an act that is ethically unacceptable as good medical practice [3].

The council recognizes that choosing one term of art over others can carry multiple, and not always intended messages. However, in the absence of a perfect option, CEJA believes ethical deliberation and debate is best served by using plainly descriptive language. In the council’s view, despite its negative connotations [4], the term “physician assisted suicide” describes the practice with the greatest precision. Most importantly, it clearly distinguishes the practice from euthanasia [1]. The terms “aid in dying” or “death with dignity” could be used to describe either euthanasia or palliative/ hospice care at the end of life and this degree of ambiguity is unacceptable for providing ethical guidance.

## COMMON GROUND

Beneath the seemingly incommensurate perspectives that feature prominently in public and professional debate about writing a prescription to provide patients with the means to end life if they so choose, CEJA perceives a deeply and broadly shared vision of what matters at the end of life. A vision that is characterized by hope for a death that preserves dignity, a sense of the sacredness of ministering to a patient at the end of life, recognition of the relief of suffering as the deepest aim of medicine, and fully voluntary participation on the part of both patient and physician in decisions about how to approach the end of life.

Differences lie in the forms these deep commitments take in concrete decisions and actions. CEJA believes that thoughtful, morally admirable individuals hold diverging, yet equally deeply held, and well-considered perspectives about physician-assisted suicide that govern how these shared commitments are ultimately expressed. For one patient, dying “with dignity” may mean accepting the end of life however it comes as gracefully as one can; for another, it may mean being able to exercise some measure of control over the circumstances in which death occurs. For some physicians, the sacredness of ministering to a terminally ill or dying patient and the duty not to

abandon the patient preclude the possibility of supporting patients in hastening their death. For others, not to provide a prescription for lethal medication in response to a patient's sincere request violates that same commitment and duty. Both groups of physicians base their view of ethical practice on the guidance of Principle I of the AMA *Principles of Medical Ethics*: "A physician shall be dedicated to providing competent medical care, with compassion and respect for human dignity and rights."

So too, how physicians understand and act on the goals of relieving suffering, respecting autonomy, and maintaining dignity at the end of life is directed by identity-conferring beliefs and values that may not be commensurate. Where one physician understands providing the means to hasten death to be an abrogation of the physician's fundamental role as healer that forecloses any possibility of offering care that respects dignity, another in equally good faith understands supporting a patient's request for aid in hastening a foreseen death to be an expression of care and compassion.

#### IRREDUCIBLE DIFFERENCES IN MORAL PERSPECTIVES ON PHYSICIAN-ASSISTED SUICIDE

How to respond when coherent, consistent, and deeply held beliefs yield irreducibly different judgments about what is an ethically permissible course of action is profoundly challenging. With respect to physician-assisted suicide, some professional organizations—for example, the American Academy of Hospice and Palliative Medicine [5]—have adopted a position of "studied neutrality." Positions of studied neutrality neither endorse nor oppose the contested practice, but instead are intended to respect that there are irreducible differences among the deeply held beliefs and values that inform public and professional perspectives [5,6], and to leave space open for ongoing discussion. Nonetheless, as a policy position, studied neutrality has been criticized as being open to unintended consequences, including stifling the very debate it purports to encourage or being read as little more than acquiescence with the contested practice [7].

CEJA approaches the condition of irreducible difference from a different direction. In its 2014 report on exercise of conscience, the Council noted that "health care professionals may hold very different core beliefs and thus reach very different decisions based on those core beliefs, yet equally act according to the dictates of conscience. For example, a physician who chooses to provide abortions on the basis of a deeply held belief in protecting women's autonomy makes the same kind of moral claim to conscience as does a physician who refuses to provide abortion on the basis of respect for the sanctity of life of the fetus" [8].

Importantly, decisions taken in conscience are not simply idiosyncratic; they do not rest on intuition or emotion. Rather, such decisions are based on "substantive, coherent, and reasonably stable" values and principles [8]. Physicians must be able to articulate how those values and principles justify the action in question.

The ethical arguments offered for more than two decades by those who support and those who oppose physician participation in assisted suicide reflect the diverging "substantive, coherent, and reasonably stable" values and principles within the profession and the wider moral community. While supporters and opponents of physician-assisted suicide share a common commitment to "compassion and respect for human dignity and rights" (AMA Principles of Medical Ethics, I), they draw different moral conclusions from the underlying principle they share. As psychiatrist Harvey Chochinov observed with respect to the stakeholders interviewed by Canadian Supreme Court's advisory panel on physician-assisted death, "neither those who are strongly supportive nor those who are opposed hold a monopoly on integrity and a genuine concern for the well-being of

1 people contemplating end of life. Equally true: neither side is immune from impulses shaped more  
2 by ideology than a deep and nuanced understanding of how to best honor and address the needs of  
3 people who are suffering” [9].

#### 4 5 THE RISK OF UNINTENDED CONSEQUENCES

6  
7 From the earliest days of the debate, a prominent argument raised against permitting physician-  
8 assisted suicide has been that doing so will have adverse consequences for individual patients, the  
9 medical profession, and society at large. Scholars have cited the prospect that boundaries will be  
10 eroded and practice will be extended beyond competent, terminally ill adult patients; to patients  
11 with psychiatric disorders, children; or that criteria will be broadened beyond physical suffering to  
12 encompass existential suffering; or that stigmatized or socioeconomically disadvantaged patients  
13 will be coerced or encouraged to end their lives. Concerns have also been expressed that permitting  
14 the practice will compromise the integrity of the profession, undermine trust, and harm the  
15 physicians and other health care professionals who participate; and that forces outside medicine  
16 will unduly influence decisions.

17  
18 The question whether safeguards—which in the U.S. jurisdictions that permit assisted suicide,  
19 restrict the practice to terminally ill adult patients who have decision-making capacity and who  
20 voluntarily request assisted suicide, along with procedural and reporting requirements—can  
21 actually protect patients and sustain the integrity of medicine remains deeply contested. Some  
22 studies have “found no evidence to justify the grave and important concern often expressed about  
23 the potential for abuse—namely, the fear that legalized physician-assisted dying will target the  
24 vulnerable or pose the greatest risk to people in vulnerable groups” [10], others question whether  
25 the available data can in fact support any such conclusions, finding the evidence cited variously  
26 flawed [11], inadequate [12], or distorted [13].

27  
28 Although cross-cultural comparisons are problematic [14], current evidence from Europe does tell  
29 a cautionary tale. Recent findings from studies in Belgium and the Netherlands, both countries that  
30 permit euthanasia as well as physician-assisted suicide, mitigate some fears but underscore others  
31 [15]. For example, research in the Netherlands has found that “requests characterized by  
32 psychological as opposed to physical suffering were more likely to be rejected, as were requests by  
33 individuals who lived alone,” mitigating fears that “solitary, depressed individuals with potentially  
34 reversible conditions might successfully end their lives.” At the same time, however, among  
35 patients who obtained euthanasia or assisted suicide, nearly 4 percent “reported only psychological  
36 suffering.” At the level of anecdote, a description of a case of euthanasia in Belgium elicited  
37 widespread concern about the emergence of a “slippery slope” [16].

38  
39 Studies have also raised questions about how effective retrospective review of decisions to provide  
40 euthanasia/assisted suicide is in policing practice [17,18]. A qualitative analysis of cases that Dutch  
41 regional euthanasia committees determined had not met legal “due care criteria” found that such  
42 reviews focus on procedural considerations and do not “directly assess the actual eligibility” of the  
43 patients who obtained euthanasia [17]. A separate study of cases in which psychiatric patients  
44 obtained euthanasia found that physicians’ reports “stated that psychosis or depression did or did  
45 not affect capacity but provided little explanation regarding their judgments” and that review  
46 committees “generally accepted the judgment of the physician performing EAS [euthanasia or  
47 physician-assisted suicide]” [18]. It remains an open question whether reviews that are not able to  
48 assess physicians’ reasoning truly offer the protection they are intended to provide. To the extent  
49 that reporting and data collection in states that permit physician-assisted suicide have similar  
50 limitations, oversight of practice may not be adequate.

Medicine must learn from this experience. Where physician-assisted suicide is legalized, safeguards can and should be improved—e.g., “[t]o increase safeguards, states could consider introducing multidisciplinary panels to support patients through the entire process, including verifying consent and capacity, ensuring appropriate psychosocial counseling, and discussing all palliative and end-of-life options” [19]. Both the state and the medical profession have a responsibility to monitor ongoing practice in a meaningful way and to address promptly compromises in safeguards should any be discovered. It is equally important that strong practices be identified and encouraged across all jurisdictions that permit physicians to assist suicide. Health care organizations in California and Canada, for example, have shared richly descriptive reports of practices adopted in response to the recent legalization of “aid in dying” in those jurisdictions that seek to address concerns about quality of practice and data collection [20,21].

Medicine must also acknowledge, however, that evidence (no matter how robust) that there have not yet been adverse consequences cannot guarantee that such consequences would not occur in the future. As a recent commentary noted, “[p]art of the problem with the slippery slope is you never know when you are on it” [15].

#### SAFEGUARDING DECISIONS AT THE END OF LIFE

CEJA has found that just as there are shared commitments behind deep differences regarding physician-assisted suicide, there are also shared concerns about how to understand the available evidence. For example, in the council’s recent Open Forum, both proponents and opponents of physician-assisted suicide observed that in the U.S., debate occurs against the backdrop of a health care system in which patients have uneven access to care, including access to high quality end-of-life care. They also noted that patients and physicians too often still do not have the conversations they should about death and dying, and that too few patients are aware of the range of options for end-of-life care, raising concern that many patients may be led to request assisted suicide because they don’t understand the degree of relief of suffering state-of-the-art palliative care can offer. Participants who in other respects held very different views concurred as well that patients may be vulnerable to coercion, particularly patients who are in other ways disadvantaged; and expressed concern in common that forces external to medicine could adversely influence practice.

These are much the same concerns the Institute of Medicine identified in its 2015 report, *Dying in America* [22]. They are concerns echoed in a February 2018 workshop on physician-assisted death convened by the National Academies of Science, Engineering and Medicine [23]. They underscore how important it is to understand *why* a patient requests assisted suicide as a starting point for care.

Patient requests for assisted suicide invite physicians to have the kind of difficult conversations that are too often avoided. They open opportunities to explore the patient’s goals and concerns, to learn what about the situation the individual finds intolerable and to respond creatively to the patient’s needs other than providing the means to end life—by such means as better managing symptoms, arranging for psychosocial or spiritual support, treating depression, and helping the patient to understand more clearly how the future is likely to unfold [4,24]. Medicine as a profession must ensure that physicians are skillful in engaging in these difficult conversations and knowledgeable about the options available to terminally ill patients [25]. The profession also has a responsibility to advocate for adequate resources for end-of-life care [14,25], particularly for patients from disadvantaged groups. The availability of assisted suicide where it is legal must not be allowed to interfere with excellent care at the end of life.

1 CONCLUSION  
2

3 At the core of public and professional debate, the council believes, is the aspiration that every  
4 patient come to the end of life as free as possible from suffering that does not serve the patient's  
5 deepest self-defining beliefs and in the presence of trusted companions, including where feasible  
6 and when the patient desires, the presence of a trusted physician. As Timothy Quill noted more  
7 than 20 years ago, "dying patients do not have the luxury of choosing not to undertake the journey,  
8 or of separating their person from their disease" [24]. Decisions about how to approach the end of  
9 life are among the most intimate that patients, families, and their physicians make. Respecting the  
10 intimacy and the authenticity of those relationships is essential if our common ideal is to be  
11 achieved.  
12

13 RECOMMENDATION  
14

15 Over the past two years, the Council on Ethical and Judicial Affairs has reviewed the literature and  
16 received thoughtful input from numerous individuals and organizations to inform its deliberations,  
17 and is deeply grateful to all who shared their insights. CEJA engaged in extensive, often passionate  
18 discussion about how to interpret the *Code of Medical Ethics* in light of ongoing debate and the  
19 irreducible differences in moral perspectives identified above. After careful consideration, CEJA  
20 concludes that in its current form the *Code* offers guidance to support physicians and the patients  
21 they serve in making well-considered, mutually respectful decisions about legally available options  
22 for care at the end of life in the intimacy of a patient-physician relationship. The Council on Ethical  
23 and Judicial Affairs therefore recommends that the *Code of Medical Ethics* not be amended, that  
24 Resolutions 15-A-16 and 14-A-17 not be adopted and that the remainder of the report be filed.

Fiscal Note: None.



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## REPORT OF THE COUNCIL ON ETHICAL AND JUDICIAL AFFAIRS\*

CEJA Report 6-A-18

Subject: CEJA's Sunset Review of 2008 House Policies

Presented by: Dennis S. Agliano, MD, Chair

Referred to: Reference Committee on Amendments to Constitution and Bylaws  
(Peter H. Rheinstein, MD, JD, MS, Chair)

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At its 1984 Interim Meeting, the House of Delegates (HOD) established a sunset mechanism for House policies (Policy G-600.110). Under this mechanism, a policy established by the House ceases to be viable after 10 years unless action is taken by the House to retain it.

The objective of the sunset mechanism is to help ensure that the American Medical Association (AMA) policy database is current, coherent, and relevant. By eliminating outmoded, duplicative, and inconsistent policies, the sunset mechanism contributes to the ability of the AMA to communicate and promote its policy positions. It also contributes to the efficiency and effectiveness of HOD deliberations.

At its 2012 Annual Meeting, the House modified Policy G-600.110 to change the process through which the policy sunset review is conducted. The process now includes the following steps:

- Each year the House policies that are subject to review under the policy sunset mechanism are identified.
- Policies are assigned to appropriate Councils for review.
- For the Annual Meeting of the House, each Council develops a separate policy sunset report that recommends how each policy assigned to it should be handled. For each policy it reviews, a Council may recommend one of the following actions: (a) retain the policy; (b) sunset the policy; (c) retain part of the policy; d) reconcile the policy with more recent and like policy. A justification must be provided for the recommended action to retain a policy.
- A policy will typically sunset after ten years unless action is taken by the House of Delegates to retain it. A reaffirmation or amendment to policy by the House of Delegates resets the sunset clock, making the reaffirmed or amended policy viable for another 10 years.

Although the policy sunset review mechanism may not be used to change the meaning of AMA policies, minor editorial changes can be accomplished through the sunset review process.

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\* Reports of the Council on Ethical and Judicial Affairs are assigned to the reference committee on Amendments to Constitution and Bylaws. They may be adopted, not adopted, or referred. A report may not be amended, except to clarify the meaning of the report and only with the concurrence of the Council.

1 2008 POLICIES

2  
3 In this report, the Council on Ethical and Judicial Affairs presents its recommendations regarding  
4 the disposition of 2008 House policies that were assigned to or originated from CEJA.

5  
6 DUPLICATIVE POLICIES

7  
8 On the model of the Council on Long Range Planning & Development (CLRPD)/CEJA Joint  
9 Report I-01 and of subsequent reports of CEJA's sunset review of House policies, this report  
10 recommends the rescission of House policies issued since June 2008. As noted previously, the  
11 intent of this process is the elimination of duplicative ethics policies from PolicyFinder. The  
12 process does not diminish the substance of AMA policy in any sense. Indeed, CEJA Opinions are a  
13 category of AMA policy.

14  
15 MECHANISM TO ELIMINATE DUPLICATIVE ETHICS POLICIES

16  
17 The Council continues to present reports to the HOD. If adopted, the recommendations of these  
18 reports continue to be recorded in PolicyFinder as House policy. After the corresponding CEJA  
19 Opinion is issued, CEJA utilizes its annual sunset report to rescind the duplicative House policy.

20  
21 For example, at the 2007 Interim Meeting, the HOD adopted the recommendations of CEJA Report  
22 8-I-07, "Pediatric Decision-Making." It was recorded in PolicyFinder as Policy H-140.865. At the  
23 2008 Annual Meeting, CEJA filed the corresponding Opinion E-2.026, thereby generating a  
24 duplicative policy. Under the mechanism to eliminate duplicative ethics policies, CEJA  
25 recommended the rescission of Policy H-140.865 as part of the Council's 2009 sunset report.

26  
27 The Appendix provides recommended actions and their rationale on House policies from 2008, as  
28 well as on duplicate policies.

29  
30 RECOMMENDATION

31  
32 The Council on Ethical and Judicial Affairs recommends that the House of Delegates policies that  
33 are listed in the Appendix to this report be acted upon in the manner indicated and the remainder of  
34 this report be filed. (Directive to Take Action)

Fiscal Note: Less than \$500.

## APPENDIX - RECOMMENDED ACTIONS

Policy No.	Title	Recommended Action & Rationale
H-15.997	Elderly's Eligibility for Automobile Insurance and Licensure	Retain: Policy remains relevant.
H-160.961	Caring for the Poor	Rescind: Policy is superseded by Opinion <a href="#">E-11.1.4, Financial Barriers to Health Care Access</a> adopted as modernized in June 2016.
H-160.998 H-25.997	Health Care Dignity and Self Respect	Rescind: Policies have been superseded by the following:  <a href="#">H-165.838 Health System Reform Legislation</a>  <a href="#">H-165.888 Evaluating Health System Reform Proposals</a>  <a href="#">H-165.920 Individual Health Insurance</a>
H-230.962	Subspecialists Functioning as Primary Care Physicians	Retain: Policy remains relevant; edit to remain timely  It is the policy of the AMA that clinical privileges in primary care be granted to physicians that have demonstrated capability through education, training, experience and current competence, and that the practice of <del>managed care organizations to arbitrarily deny</del> <u>denying</u> primary care privileges to physicians because of subspecialty or second specialty training be opposed by the AMA.
H-265.997	AMA-ABA Statement on Interprofessional Relations for Physicians and Attorneys	Retain: Policy remains relevant.
H-315.981	Privacy of a Physician's Personal Medical Records	Retain: Policy remains relevant.
H-35.999	Medicine and Pharmacy Relations	Retain: Policy remains relevant
H-350.971 H-350.975	Initiatives Regarding Minorities Improving Healthcare of Hispanic Populations in the United States	Defer recommendation to 2018 Interim meeting pending report on consolidation of AMA policy addressing issues of disparities and the health of minority populations:

		<p><a href="#"><u>H-160.991 Health Care Needs of Gay, Lesbian, Bisexual and Transgender Populations</u></a></p> <p><a href="#"><u>H-295.878 Eliminating Health Disparities—Promoting Awareness and Education of Lesbian, Gay, Bisexual and Transgender (LGBT) Issues in Medical Education</u></a></p> <p><a href="#"><u>H-350.957 Addressing Immigrant Health Disparities</u></a></p> <p><a href="#"><u>H-350.958 Hispanic Population and Access to the US Healthcare System</u></a></p> <p><a href="#"><u>H-350.959 Guiding Principles for Eliminating Racial and Ethnic Health Care Disparities</u></a></p> <p><a href="#"><u>H-350.961 Improving the Health of Minority Populations</u></a></p> <p><a href="#"><u>H-350.966 Health Initiatives on Asian-Americans and Pacific Islanders</u></a></p> <p><a href="#"><u>H-350.971 AMA Initiatives Regarding Minorities</u></a></p> <p><a href="#"><u>H-350.972 Improving the Health of Black and Minority Populations</u></a></p> <p><a href="#"><u>H-350.974 Racial and Ethnic Disparities in Health Care</u></a></p> <p><a href="#"><u>H-350.976 Improving Health Care of American Indians</u></a></p> <p><a href="#"><u>H-440.869 Establishment of State Commission/Task Force to Eliminate Racial and Ethnic Health Care Disparities</u></a></p> <p><a href="#"><u>D-350.996 Strategies for Eliminating Minority Health Care disparities</u></a></p>
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		<a href="#">D-55.997 Cancer and Health Care Disparities among Minority Women</a>  <a href="#">D-65.995 Health Care Disparities among Gay, Lesbian, Bisexual and Transgender Families</a>
H-350.978	Minorities in the Health Professions	Retain: Policy remains relevant.
H-370.967	Ethical Procurement of Organs for Transplantation	Retain: Policy remains relevant.
H-375.965	Principles for Incident-Based Peer Review and Disciplining at Health Care Organizations	Retain: Policy remains relevant.
H-375.969	Physician Access to Performance Profile Data	Retain: Policy remains relevant.
H-375.970	Professional Review Organization Peer Review	Retain: Policy remains relevant.
H-405.999	Physicians in Public Affairs	Retain: Policy remains relevant.
H-465.988	Educational Strategies for Meeting Rural Health Physician Shortage	Retain: Policy remains relevant
H-465.994	Committee on Rural Health	Retain: Policy remains relevant; revise title for clarity "Improving Rural Health Care"
H-475.987	Freedom of Speech in Medical Information	Rescind: Policy addresses litigation concluded in 1997 and is outdated.
D-478.992	Health Information Technology Purchasing Guidance	Rescind: Directive is accomplished through extensive resources available online at: <a href="https://www.ama-assn.org/practice-management/improving-digital-health">https://www.ama-assn.org/practice-management/improving-digital-health</a>

## AMERICAN MEDICAL ASSOCIATION HOUSE OF DELEGATES

Resolution: 001  
(A-18)

Introduced by: New York

Subject: Discriminatory Policies that Create Inequities in Health Care

Referred to: Reference Committee on Amendments to Constitution and Bylaws  
(Peter H. Rheinstein, MD, JD, MS, Chair)

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1 Whereas, President Trump's administration has created a new conscience and religious  
2 freedom division within the Health and Human Services department, with the intent of allowing  
3 all health professionals to opt out of providing services that violate their moral or religious  
4 beliefs; and

5  
6 Whereas, The Acting Health and Human Services Secretary Eric D. Hargan has stated that the  
7 creation of this office, "represents a rollback of policies that had prevented many Americans from  
8 practicing their profession and following their conscience at the same time, and that Americans  
9 of faith should feel at home in our health system, not discriminated against, and that states  
10 should have the right to take reasonable steps in overseeing their Medicaid programs, and  
11 being good stewards of public funds"; and

12  
13 Whereas, A number of women's groups, LGBT rights groups and physicians have expressed  
14 that the creation of this office and policy would further discriminate against vulnerable  
15 populations and worsen inequities within the health care system; and

16  
17 Whereas, To impose a broad religious refusal policy that will allow individuals and institutions to  
18 deny basic care for women, transgender people and people of diverse ethnic backgrounds; and

19  
20 Whereas, This policy reverses years of policies that have been put in place under previous  
21 administrations that had narrowed conscience protections; and

22  
23 Whereas, This new office and policy appears to go against the oath that health care providers  
24 take when they enter their professions, to provide basic care to those who need it; and

25  
26 Whereas, The MSSNY Committee on Health Disparities believes that religious liberty gives a  
27 person the right to their beliefs, but it does not give a person the right to impose those beliefs on  
28 others, or harm others, including by discriminating against others; therefore be it

29  
30 RESOLVED, That our American Medical Association speak against policies that are  
31 discriminatory and create even greater health disparities in medicine (Directive to Take Action);  
32 and be it further

33  
34 RESOLVED, That our AMA be a voice for our most vulnerable populations, including sexual,  
35 gender, racial and ethnic minorities, who will suffer the most under such policies, further  
36 widening the gaps that exist in health and wellness in our nation. (Directive to Take Action)

Fiscal Note: Minimal - less than \$1,000.  
Received: 04/25/18



**RELEVANT AMA POLICY****Racial and Ethnic Disparities in Health Care H-350.974**

1. Our AMA recognizes racial and ethnic health disparities as a major public health problem in the United States and as a barrier to effective medical diagnosis and treatment. The AMA maintains a position of zero tolerance toward racially or culturally based disparities in care; encourages individuals to report physicians to local medical societies where racial or ethnic discrimination is suspected; and will continue to support physician cultural awareness initiatives and related consumer education activities. The elimination of racial and ethnic disparities in health care is an issue of highest priority for the American Medical Association.
  2. The AMA emphasizes three approaches that it believes should be given high priority:
    - A. Greater access - the need for ensuring that black Americans without adequate health care insurance are given the means for access to necessary health care. In particular, it is urgent that Congress address the need for Medicaid reform.
    - B. Greater awareness - racial disparities may be occurring despite the lack of any intent or purposeful efforts to treat patients differently on the basis of race. The AMA encourages physicians to examine their own practices to ensure that inappropriate considerations do not affect their clinical judgment. In addition, the profession should help increase the awareness of its members of racial disparities in medical treatment decisions by engaging in open and broad discussions about the issue. Such discussions should take place in medical school curriculum, in medical journals, at professional conferences, and as part of professional peer review activities.
    - C. Practice parameters - the racial disparities in access to treatment indicate that inappropriate considerations may enter the decision making process. The efforts of the specialty societies, with the coordination and assistance of our AMA, to develop practice parameters, should include criteria that would preclude or diminish racial disparities.
  3. Our AMA encourages the development of evidence-based performance measures that adequately identify socioeconomic and racial/ethnic disparities in quality. Furthermore, our AMA supports the use of evidence-based guidelines to promote the consistency and equity of care for all persons.
  4. Our AMA: (a) actively supports the development and implementation of training regarding implicit bias, diversity and inclusion in all medical schools and residency programs; (b) will identify and publicize effective strategies for educating residents in all specialties about disparities in their fields related to race, ethnicity, and all populations at increased risk, with particular regard to access to care and health outcomes, as well as effective strategies for educating residents about managing the implicit biases of patients and their caregivers; and (c) supports research to identify the most effective strategies for educating physicians on how to eliminate disparities in health outcomes in all at-risk populations.
- CLRPD Rep. 3, I-98 Appended and Reaffirmed: CSA Rep.1, I-02 Reaffirmed: BOT Rep. 4, A-03 Reaffirmed in lieu of Res. 106, A-12 Appended: Res. 952, I-17

## AMERICAN MEDICAL ASSOCIATION HOUSE OF DELEGATES

Resolution: 002  
(A-18)

Introduced by: Medical Student Section

Subject: FMLA-Equivalent for LGBT Workers

Referred to: Reference Committee on Amendments to Constitution and Bylaws  
(Peter H. Rheinstein, MD, JD, MS, Chair)

Whereas, The Family and Medical Leave Act (FMLA) requires employers with 50 or more employees to grant up to 12 weeks of unpaid annual leave to allow workers to care for a spouse, child, or parent (except in-laws) with a serious health condition, to take leave for personal health conditions, or to care for newly born or adopted children;<sup>1</sup> and

Whereas, LGBT persons report poorer health as compared to their heterosexual counterparts, including earlier age at disability, increased risk of sexually transmitted infection among MSM, decreased likelihood to obtain preventive cervical cancer screening among lesbian women, and increased incidence of obesity among lesbian and bisexual women;<sup>2,3,4,5</sup> and

Whereas, Results from the 2008 National Health Interview Survey indicated workers with paid leave are significantly more likely to see healthcare providers and to receive preventative screenings independent of insured or uninsured status and health status;<sup>6</sup> and

Whereas, In 2016, a study from the *American Journal of Orthopsychiatry* asserted that affirming the chosen family of LGBT individuals in family and medical leave policies improved mental well-being;<sup>7</sup> and

Whereas, In 2010, the United States Office of Personnel Management issued regulations to modify its definitions of *family member* and *immediate relative* to include “domestic partner and parents thereof” and “any individual related *by blood or affinity* whose close association with the employee is the equivalent of a family relationship” in order to expand the categories of individuals for whom an employee may use leave;<sup>8</sup> and

Whereas, Arizona<sup>9</sup>, the District of Columbia<sup>10</sup>, Hawaii<sup>11</sup>, Maine<sup>12</sup>, New York<sup>13</sup>, and Oregon<sup>14</sup> have expanded upon the federal FMLA regulations in favor of the “blood or affinity” model,

<sup>1</sup> (2017) “Family & Medical Leave.” United States Department of Labor.

<sup>2</sup> Fredriksen-Goldsen, K.I., Kim, H.J., Barkan, S.E. Disability among lesbian, gay, and bisexual adults: disparities in prevalence and risk. *Am J Public Health*. 2012 Jan; 102:e16-21

<sup>3</sup> Ranji, U. *et al*. Health and access to care and coverage for lesbian, gay, bisexual, and transgender individuals in the U.S. Menlo Park, CA: Kaiser Family Foundation; 2014.

<sup>4</sup> Buchmueller, T. & Carpenter, C.S. Disparities in health insurance coverage, access, and outcomes for individuals in same-sex versus different-sex relationships, 2000-2007. *Am J Public Health*. 2010 Jan;100:489-95

<sup>5</sup> Ard, K.L., Makadon, H.J. Improving the health care of lesbian, gay, bisexual and transgender people: understanding and eliminating health disparities. Boston: The Fenway Institute; 2012.

<sup>6</sup> Peipens, L. *et al*. The lack of paid sick leave as a barrier to cancer screening and medical care-seeking: results from the National Health Interview Survey. *BMC Public Health*. 2012 Jul;12:520

<sup>7</sup> Blosnich, J. *et al*. Social support networks among diverse sexual minority populations. *American Journal of Orthopsychiatry*. 2016 Jan; 86(1):91-102.

<sup>8</sup> 75 FR § 33491 – Absence and Leave; Definitions of Family Member, Immediate Relative, and Related Terms. 2010.

<sup>9</sup> Ariz. Rev. Stat. § 23-371(H)(5) (2016)

<sup>10</sup> D.C. Code § 32-501(4)

<sup>11</sup> N.Y. Workers' Comp. Law §§ 4; 201(20)

<sup>12</sup> Me. Rev. Stat. Ann. tit. 26 § 843(7).

<sup>13</sup> Wis. Stat. Ann. §§ 103.10(1)(ar); 40.02(21c)-21(d)

<sup>14</sup> D.C. Code Ann. § 32-131.01(C)

- 1 which allows FMLA-equivalent benefits for chosen family, domestic partners, and individuals  
2 who are dependent or mutually interdependent on the employed individual; therefore be it  
3  
4 RESOLVED, That our American Medical Association advocate that Family and Medical Leave  
5 Act policies include any individual related by blood or affinity whose close association with the  
6 employee is the equivalent of a family relationship. (New HOD Policy)

Fiscal note: Minimal - less than \$1,000.

Received: 04/26/18

#### **RELEVANT AMA POLICY:**

##### **Nondiscriminatory Policy for the Health Care Needs of LGBTQ Populations H-65.976**

Our AMA encourages physician practices, medical schools, hospitals, and clinics to broaden any nondiscriminatory statement made to patients, health care workers, or employees to include "sexual orientation, sex, or gender identity" in any nondiscrimination statement.

Res. 414, A-04 Modified: BOT Rep. 11, A-07 Modified: Res. 08, A-16 Modified: Res. 903, I-17

##### **Clarification of Medical Necessity for Treatment of Gender Dysphoria H-185.927**

Our AMA: (1) recognizes that medical and surgical treatments for gender dysphoria, as determined by shared decision making between the patient and physician, are medically necessary as outlined by generally-accepted standards of medical and surgical practice; and (2) will advocate for federal, state, and local policies to provide medically necessary care for gender dysphoria.

Res. 05, A-16

##### **Health Care Disparities in Same-Sex Partner Households H-65.973**

Our American Medical Association: (1) recognizes that denying civil marriage based on sexual orientation is discriminatory and imposes harmful stigma on gay and lesbian individuals and couples and their families; (2) recognizes that exclusion from civil marriage contributes to health care disparities affecting same-sex households; (3) will work to reduce health care disparities among members of same-sex households including minor children; and (4) will support measures providing same-sex households with the same rights and privileges to health care, health insurance, and survivor benefits, as afforded opposite-sex households.

CSAPH Rep. 1, I-09 BOT Action in response to referred for decision Res. 918, I-09: Reaffirmed in lieu of Res. 918, I-09 BOT Rep. 15, A-11 Reaffirmed in lieu of Res. 209, A-12

##### **Health Disparities Among Gay, Lesbian, Bisexual and Transgender Families D-65.995**

Our AMA supports reducing the health disparities suffered because of unequal treatment of minor children and same sex parents in same sex households by supporting equality in laws affecting health care of members in same sex partner households and their dependent children.

Res. 445, A-05 Modified: CSAPH Rep. 1, A-15

## AMERICAN MEDICAL ASSOCIATION HOUSE OF DELEGATES

Resolution: 003  
(A-18)

Introduced by: Medical Student Section

Subject: Proposing Consent for De-identified Patient Information

Referred to: Reference Committee on Amendments to Constitution and Bylaws  
(Peter H. Rheinstein, MD, JD, MS, Chair)

Whereas, The Health Insurance Portability and Accountability Act (HIPAA) placed “limitations on the sale of medical information to third parties for marketing purposes” and prevents medical information from being disclosed unless permitted or required;<sup>1,2,3</sup> and

Whereas, Secondary use of health data entails the use of protected health information (PHI) outside of direct healthcare delivery including strictly commercial activities;<sup>1</sup> and

Whereas, Under HIPAA, patient consent is not required to use and disclose PHI for treatment, payment, and healthcare operations (TPO); meanwhile, patient authorization is required when “voluntary consent is not sufficient to permit a use or disclosure of protected health information” which largely consists of any use outside of TPO, unless an exception applies;<sup>4</sup> and

Whereas, HIPAA does not apply after data is de-identified nor does it prohibit selling or sharing of de-identified data without prior patient authorization for “research, public health, law enforcement, judicial proceedings, and other ‘public interest and benefit activities’”;<sup>2,5,6,7,8</sup> and

Whereas, The extent to which patient data collection and use for purposes not directly related to patient care and public health such as for pure commercial intent is not well understood or regulated;<sup>9,10</sup> and

Whereas, A multimillion-dollar industry has been established based on sales of patient health-related information;<sup>10</sup> and

Whereas, In US courts, transactions involving de-identified patient data irrespective of their purpose have come to be labeled as expressions of free speech;<sup>11,12</sup> and

<sup>1</sup>Department of Health and Human Services. Summary of the HIPAA Security Rule. Health Information Privacy. <https://www.hhs.gov/hipaa/for-professionals/security/laws-regulations/index.html>. Published 2013.

<sup>2</sup>Goldstein MM, Pewen WF. The HIPAA Omnibus Rule: implications for public health policy and practice. *Public Health Rep.* 2013;128(6):554-558. doi:10.1177/003335491312800615.

<sup>3</sup>Rothstein MA. Access to Information in Segmented Electronic Health Records. *J Law, Med Ethics.* 2012;40(2):394-400. doi:10.1111/j.1748-720X.2012.00673.x.

<sup>4</sup>Department of Health and Human Services. What is the difference between “consent” and “authorization” under the HIPAA Privacy Rule? Health Information Privacy. <https://www.hhs.gov/hipaa/for-professionals/faq/264/what-is-the-difference-between-consent-and-authorization/index.html>. Published 2013.

<sup>5</sup>Cornell Law Legal Information Institute. 45 CFR 164.512 Uses and disclosures for which an authorization or opportunity to agree or object is not required. <https://www.law.cornell.edu/cfr/text/45/164.512%0D>. Published 2016.

<sup>6</sup>Cambridge University Press. How should health data be used? *Cambridge Q Healthc Ethics.* 2016;25:312-329.

<sup>7</sup>Cornell Law Legal Information Institute. 45 CFR 164.502 - Uses and disclosures of protected health information: General rules.

<sup>8</sup>Department of Health and Human Services. May a health information organization (HIO), acting as a business associate of a HIPAA covered entity, de-identify information and then use it for its own purposes? 2008. <https://www.hhs.gov/hipaa/for-professionals/faq/544/may-a-health-information-organization-de-identify-information/index.html>.

<sup>9</sup>Safran C. Reuse of clinical data. *Yearb Med Inform.* 2014;9(1):52-54. doi:10.15265/IY-2014-0013.

<sup>10</sup>Tanner A. *Our Bodies, Our Data*. Penguin Random House; 2017.

<sup>11</sup>Bambaur J. Is Data Speech? *Stanford Law Rev.* 2014;(January). [http://www.stanfordlawreview.org/wp-content/uploads/sites/3/2014/01/66\\_Stan\\_L\\_Rev\\_57\\_Bambauer.pdf](http://www.stanfordlawreview.org/wp-content/uploads/sites/3/2014/01/66_Stan_L_Rev_57_Bambauer.pdf).

<sup>12</sup>Supreme Court of the United States. WILLIAM H. SORRELL, ATTORNEY GENERAL OF VERMONT, ET AL., PETITIONERS v. IMS HEALTH INC. ET AL. 2011. <https://www.law.cornell.edu/supct/pdf/10-779P.ZO>.

Whereas, PHI ownership rights, whether it be the patient, provider, government or another entity, is unclear and has yet to be formally settled;<sup>13</sup> and

Whereas, As individuals continue to divulge personal information in areas outside of healthcare, it becomes easier to consolidate data and identify those individuals in aggregated pools of anonymized health data;<sup>3,6,14,15</sup> and

Whereas, AMA Policy H-315.983 states that only de-identified and/or aggregate data should be used for "business decisions," including sales, mergers, and similar business transactions when ownership or control of medical records changes hands; and

Whereas, AMA Code of Ethics Section 3.2.4 Paragraph 2 states, "Disclosing information to third parties for commercial purposes without consent undermines trust, violates principles of informed consent and confidentiality, and may harm the integrity of the patient-physician relationship";<sup>16</sup> and

Whereas, AMA Code of Ethics Section 3.2.4 enables the release of patient information so long as it is de-identified and only recommends that patients be informed of the impending release without providing patients an avenue to prevent third parties from utilizing their PHI for commercial purposes; and

Whereas, AMA Code of Ethics Section 3.2.4 is conflicting as it emphasizes patient consent in Paragraph 2 while Paragraph 3 immediately defers to patients only needing to be informed about use of their de-identified information rather than providing consent; and

Whereas, AMA Code of Ethics Section 3.2.4 may conflict with HIPAA in that patient authorization, rather than consent, is sometimes mandated for release of identifiable patient information to third parties for reasons other than TPO; and

Whereas, A lack of accountability and transparency on how a patient's own health data will be used beyond their immediate care undermines both the informed consent process and the patient-physician relationship, and impairs future efforts in healthcare, research, and public health;<sup>6,16,17</sup> therefore be it

RESOLVED, That our American Medical Association study the handling of de-identified patient information and report findings and recommendations back to the AMA House of Delegates. (Directive to Take Action)

Fiscal Note: Modest - between \$1,000 - \$5,000.

Date Received: 04/26/18

**RELEVANT AMA POLICY:** [Patient Privacy and Confidentiality H-315.983](#); [Police, Payer, and Government Access to Patient Health Information H-315.975](#); [Interim Report of the Inter-Council Task Force on Privacy and Confidentiality D-460.991](#); [Work of the Task Force on the Release of Physician Data H-406.990](#); [Guiding Principles, Collection and Warehousing of Electronic Medical Record Information H-315.974](#)

<sup>13</sup> Gliklich R, Dreyer N, Leavy M. Registries for Evaluating Patient Outcomes: A User's Guide. 2014. <https://www.ncbi.nlm.nih.gov/books/NBK208620/>.

<sup>14</sup> Committee on the Recommended Social and Behavioral Domains and Measures for Electronic Health Records; Board on Population Health and Public Health Practice; Institute of Medicine. *Capturing Social and Behavioral Domains in Electronic Health Records: Phase 1.*; 2014. <http://www.ncbi.nlm.nih.gov/pubmed/24757748>.

<sup>15</sup> Committee on the Recommended Social and Behavioral Domains and Measures for Electronic Health Records; Board on Population Health and Public Health Practice; Institute of Medicine. *Capturing Social and Behavioral Domains and Measures in Electronic Health Records: Phase 2.*; 2015. <http://www.ncbi.nlm.nih.gov/pubmed/25590118>.

<sup>16</sup> American Medical Association. Code of Ethics - Chapter 3: opinions on privacy, confidentiality & medical records. 2016:1-10.

<sup>17</sup> McGraw D. Building public trust in uses of Health Insurance Portability and Accountability Act de-identified data. *J Am Med Inform Assoc.* 2013;20(1):29-34. doi:10.1136/amiajnl-2012-000936.

AMERICAN MEDICAL ASSOCIATION HOUSE OF DELEGATES

Resolution: 004  
(A-18)

Introduced by: Medical Student Section

Subject: Patient-Reported Outcomes in Gender Confirmation Surgery

Referred to: Reference Committee on Amendments to Constitution and Bylaws  
(Peter H. Rheinstein, MD, JD, MS, Chair)

Whereas, There were 3200 gender confirmation surgeries performed in 2016 in the United States, which represents a 20% increase from the previous year;<sup>1</sup> and

Whereas, Gender confirmation surgeries include a variety of surgical procedures such as transfeminine and transmasculine genital reconstruction, breast surgery, and facial reconstruction;<sup>2</sup> and

Whereas, While numerous safe and reliable surgical options exist for patients undergoing gender confirmation surgery, there is currently no standard for patient selection and education about the various techniques available;<sup>3,4</sup> and

Whereas, Patient-reported outcomes are emerging as a standard in the evaluation of and research into surgical quality and outcomes;<sup>5</sup> and

Whereas, A questionnaire that assesses a patient's perspective on their physical, sexual, and social well-being following breast reconstructive surgery has been validated for use in assessing procedure outcomes and quality;<sup>6</sup> and

Whereas, Current research in gender confirmation surgery outcomes utilizes patient questionnaires related to sexual function and bowel and urinary issues that were not originally designed for the transgender population;<sup>7</sup> and

Whereas, Information gathered from patient-reported outcomes could improve techniques used by surgeons, provide better training, and help new patients better understand how these operations impact overall well-being and quality of life;<sup>8</sup> therefore be it

<sup>1</sup> "Gender Confirmation Surgeries Rise 20% in First Ever Report." American Society of Plastic Surgeons website. <https://www.plasticsurgery.org/news/press-releases/gender-confirmation-surgeries-rise-20-percent-in-first-ever-report>. Updated May 22, 2017. Accessed September 1, 2017.

<sup>2</sup> "Gender Confirmation Surgeries." American Society of Plastic Surgeons website. <https://www.plasticsurgery.org/reconstructive-procedures/gender-confirmation-surgeries>. Accessed September 1, 2017.

<sup>3</sup> Papadopoulos N. *et al.* Quality of Life and Patient Satisfaction Following Male-to-Female Sex Reassignment Surgery. *J Sex Med.* 2017; 14(5):721-730.

<sup>4</sup> Manrique O. *et al.* "Gender Confirmation Surgery Using the Pedicle Transverse Colon Flap for Vaginal Reconstruction: A Clinical Outcome and Sexual Function Evaluation Study." *Plastic Reconstr Surg.* 2017; 140 (2): 144-145.

<sup>5</sup> Vyas, K. *et al.* The Role of Patient-Centered Outcomes Research in Plastic Surgery. *Annals of Plast Surgery.* 2016; 77(6):585-586

<sup>6</sup> Pusic, A. *et al.* Development of a New Patient-Reported Outcome Measure for Breast Surgery: The BREAST-Q. *Plast Reconstr Surg.* 2009; 124(2):345-353.

<sup>7</sup> Massie J. *et al.* Letter to Editor Regarding "Surgical Outcomes After Penile Inversion Vaginoplasty: Retrospective Review of 475 Transgender Women" By Buncamper *et al.* *Plast Reconstr Surg.* 2017; 140 (1): 236-237.

<sup>8</sup> Buncamper M. *et al.* Aesthetic and functional outcomes of neovaginoplasty using penile skin in male-to female transsexuals. *J Sex Med.* 2015; 12(7):1626-34.

- 1 RESOLVED, That our American Medical Association support initiatives and research to
- 2 establish standardized protocols for patient selection, surgical management, and preoperative
- 3 and postoperative care for transgender patients undergoing gender confirmation surgeries (New
- 4 HOD Policy); and be it further
- 5
- 6 RESOLVED, That our AMA support development and implementation of standardized tools,
- 7 such as questionnaires to evaluate outcomes of gender confirmation surgeries. (New HOD
- 8 Policy)

Fiscal Note: Minimal - less than \$1,000.

Received: 04/26/18

**RELEVANT AMA POLICY:**

**Removing Financial Barriers to Care for Transgender Patients H-185.950**

Our AMA supports public and private health insurance coverage for treatment of gender dysphoria as recommended by the patient's physician.

Citation: Res. 122; A-08; Modified: Res. 05, A-16;

See also:

[H-160.991 Health Care Needs of Lesbian Gay Bisexual and Transgender Populations](#)

[H-460.907 Encouraging Research Into the Impact of Long-Term Administration of Hormone Replacement Therapy in Transgender Patients](#)

[D-345.994 Increasing Detection of Mental Illness and Encouraging Education](#)

## AMERICAN MEDICAL ASSOCIATION HOUSE OF DELEGATES

Resolution: 005  
(A-18)

Introduced by: Medical Student Section

Subject: Decreasing Sex and Gender Disparities in Health Outcomes

Referred to: Reference Committee on Amendments to Constitution and Bylaws  
(Peter H. Rheinstein, MD, JD, MS, Chair)

Whereas, Numerous studies have demonstrated the widespread existence of sex and gender bias and disparities in the provision and outcomes of health care, and that awareness of gender bias does not negate its effect;<sup>1,2,3,4,5,6,7,8</sup> and

Whereas, These disparities have been attributed to provider bias, physiologic and pathophysiologic sex differences, or a combination of both;<sup>1,4,9,10</sup> and

Whereas, Patients with a feminine gender identity or presentation are at risk for gender-bias in health care regardless of biological sex;<sup>6,8</sup> and

Whereas, Gender disparities exist in treatments, invasive therapies, referral patterns and wait times which often leads to worsened outcomes including increased mortality rates;<sup>1-4,6</sup> and

Whereas, Clinical Decision Support (CDS) tools, which provide electronic alerts and computerized order sets, are recognized methods to minimize gender bias and decrease disparities through automatization of treatment and diagnostic protocols;<sup>10,11,12,13,14</sup> and

<sup>1</sup> Shah, T. *et al.* An Update on Gender Disparities in Coronary Heart Disease Care. *Current Atherosclerosis Reports*. 2016 May; 18(5), 28.

<sup>2</sup> Bogaev, R. Gender Disparities Across the Spectrum of Advanced Cardiac Therapies: Real or Imagined? *Current Cardiology Reports*. 2016 Nov.; 18(11), 108.

<sup>3</sup> Choi K, Shofer FS, Mills AM. Sex differences in STEMI activation for patients presenting to the ED 1939. *The American Journal of Emergency Medicine*. 2016 Oct.; 34(10), 1939-1943.

<sup>4</sup> Razmjou, H. *et al.* Sex and gender disparity in pathology, disability, referral pattern, and wait time for surgery in workers with shoulder injury. *BMC Musculoskeletal Disorders*. 2016 Sep.; 17, 401.

<sup>5</sup> Agency for Healthcare Research and Quality. Healthcare Quality and Disparities in Women: Selected Findings From the 2010 National Healthcare Quality and Disparities Reports. 2014 Oct.

<sup>6</sup> Pelletier, R. *et al.* Sex-related differences in access to care among patients with premature acute coronary syndrome. *CMAJ: Canadian Medical Association Journal*. 2014, Apr.; 186(7), 497–504.

<sup>7</sup> Torain MJ, Maragh-Bass AC, Dankwa-Mullen I, *et al.* Surgical Disparities: A Comprehensive Review and New Conceptual Framework. *Journal of the American College of Surgeons*. 2016 Aug.; 223(2), 408-418.

<sup>8</sup> Anstey ED, Li S, Thomas L, *et al.* Race and Sex Differences in Management and Outcomes of Patients After ST-Elevation and Non-ST-Elevation Myocardial Infarct: Results From the NCDR. *Clinical Cardiology*. 2016 Oct.; 39(10), 585-595.

<sup>9</sup> Bushnell, *et al.* Guidelines for the Prevention of Stroke in Women. American Heart Association/American Stroke Association. 6 Feb 2014.

<sup>10</sup> Lau, B. D. *et al.* Eliminating Healthcare Disparities Via Mandatory Clinical Decision Support: The Venous Thromboembolism (VTE) Example. *Medical Care*. 2015 Jan.; 53(1), 18–24.

<sup>11</sup> Wei, Janet *et al.* Sex-Based Differences in Quality of Care and Outcomes in a Health System Using a Standardized STEMI Protocol. *American Heart Journal*. 2017 Sept.; 191: 30–36.

<sup>12</sup> United States. Commission to End Health Care Disparities. Addressing Health Care Disparities: Recommended Goal, Guiding Principles, and Key Strategies for Comprehensive Policies. Cong. Rept. 2007.

<sup>13</sup> McMurray, R. J. *et al.* Council on Ethical and Judicial Affairs, American Medical Association. Gender Disparities in Clinical Decision Making. *Journal of the American Medical Association*. 1991 Jul.; 266(4), 559-562. Print.

<sup>14</sup> Kraus, L. J. An Expanded Definition of Women's Health. Council on Science and Public Health. Report. 2016.



1 Whereas, The AMA's Commission to End Health Care Disparities sought "to ensure equitable,  
2 appropriate, effective, safe, and high quality care for all, with no gaps in services based on any  
3 medically irrelevant factor;" yet conclusions from the Commission refer only to racial and ethnic  
4 disparities;<sup>15</sup> and

5  
6 Whereas, The Council on Ethical and Judicial Affairs recommended in 1991 encouraging the  
7 development and implementation of procedures and techniques that preclude or minimize the  
8 negative impact of gender bias;<sup>13</sup> and

9  
10 Whereas, A 2016 report from the AMA's Council on Science and Public Health acknowledged  
11 both biological and social factors leading to disparities in women's health, but only suggested  
12 improving medical education and including women in clinical research as solutions;<sup>14</sup> and

13  
14 Whereas, The AMA has existing policy declaring a commitment to eliminating health care  
15 disparities with a specific mention of racial and ethnic health disparities, but does not have a  
16 policy directly targeting gender-based health care disparities;<sup>12</sup> therefore be it

17  
18 RESOLVED, That our American Medical Association encourage the use of guidelines,  
19 treatment protocols, and decision support tools specific to biological sex for conditions in which  
20 physiologic and pathophysiologic differences exist between sexes (New HOD Policy); and be it  
21 further

22  
23 RESOLVED, That our AMA support the use of gender-neutral decision support tools that aim to  
24 mitigate gender bias in diagnosis and treatment. (New HOD Policy)

Fiscal note: Minimal - less than \$1,000.

Received: 04/26/17

#### **RELEVANT AMA POLICY**

[D-478.995 National Health Information Technology](#)

[H-350.971 AMA Initiatives Regarding Minorities](#)

[D-350.995 Reducing Racial and Ethnic Disparities in Health Care](#)

[An Expanded Definition of Women's Health H-525.976](#)

[Medical Education and Training in Women's Health H-295.890](#)

[Sex and Gender Differences in Medical Research H-525.988](#)

[8.5 Disparities in Health Care](#)

[Principles of the Patient-Centered Medical Home H-160.919](#)

[Medicare Physician Payment Reform D-390.961](#)

AMERICAN MEDICAL ASSOCIATION HOUSE OF DELEGATES

Resolution: 006  
(A-18)

Introduced by: American Society of Transplant Surgeons

Subject: Living Donor Protection Act of 2017 (HR 1270)

Referred to: Reference Committee on Amendments to Constitution and Bylaws  
(Peter H. Rheinstein, MD, JD, MS, Chair)

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1 Whereas, Living donor organ transplantation is often the best and most cost effective treatment  
2 option for patients with end stage organ failure; and  
3

4 Whereas, Living organ donors have faced discrimination in obtaining life, disability, and long-  
5 term care insurance due to company policy prohibitions, coverage denial, or premium price  
6 increases; and  
7

8 Whereas, Clarification is needed regarding live organ donation surgery in qualifying as a serious  
9 health condition under the Family Medical Leave Act; and  
10

11 Whereas, Educational materials on the benefits of live organ donation are not universally  
12 available; and  
13

14 Whereas, The "Living Donor Protection Act of 2017" (HR 1270) addresses each of these  
15 burdens related to living organ donation; and  
16

17 Whereas, Transplant professional and patient-centered organizations have publicly supported  
18 the Living Donor Protection Act of 2017; therefore be it  
19

20 RESOLVED, That our American Medical Association strongly and actively support the Living  
21 Donor Protection Act of 2017 (HR 1270). (Directive to Take Action)

References: <https://www.congress.gov/bill/115th-congress/house-bill/1270>

Fiscal Note: Modest - between \$1,000 - \$5,000.

Received: 04/27/18

## AMERICAN MEDICAL ASSOCIATION HOUSE OF DELEGATES

Resolution: 007  
(A-18)

Introduced by: Women Physicians Section

Subject: Oppose the Criminalization of Self-Induced Abortion

Referred to: Reference Committee on Amendments to Constitution and Bylaws  
(Peter H. Rheinstein, MD, JD, MS, Chair)

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1 Whereas, Self-induced abortion involves women attempting to induce abortion without medical  
2 assistance<sup>1</sup>; and  
3

4 Whereas, Laws criminalizing self-induced abortion increase health risks and deter patients from  
5 seeking necessary healthcare services related to self-induced abortion or miscarriage<sup>2</sup>; and  
6

7 Whereas, Laws criminalizing patients who self-induce abortion lead to increased suspicion  
8 towards patients presenting to healthcare providers for miscarriage<sup>3</sup>; and  
9

10 Whereas, From the beginning of 2011 through July 2016, states enacted 334 new legal  
11 restrictions on abortion, further limiting access to abortion care. In 2018 alone, 695 provisions  
12 have already been introduced to further restrict abortion<sup>4</sup>; and  
13

14 Whereas, National studies of abortion patients have shown that approximately 2% of patients  
15 attempted to self-induce an abortion at some point in their lives. That number is higher in states  
16 such as Texas with stricter legal restrictions on abortion, where one study showed that 7% of  
17 patients attempted some method to end their pregnancy before presenting to the clinic<sup>5</sup>; and  
18

19 Whereas, Google search trends from 2005 and 2015 have shown a relative increase in  
20 searches for self-induced abortion that correlate with state-based abortion restrictions<sup>6</sup>; and  
21

22 Whereas, There were more than 700,000 Google searches looking into self-induced abortions  
23 in 2015<sup>7</sup>; and  
24

25 Whereas, A recent online study of 1,235 people who google searched “self-abortion” revealed  
26 that almost three-quarters (73%) indicated that they were searching for information because  
27 they were pregnant and did not or may not want to be<sup>8</sup>; and  
28

29 Whereas, Self-induced abortion is significantly associated with post-abortion complications,  
30 maternal morbidity and mortality<sup>9</sup>; and  
31

32 Whereas, The ability and willingness to access medical care if complications relating to self-  
33 induced abortion arise are essential for patient safety<sup>10</sup>; and  
34

35 Whereas, People of color are disproportionately targeted for prosecution and criminalization  
36 related to pregnancy outcomes<sup>11</sup>; and

Whereas, The American College of Obstetricians and Gynecologists (ACOG) has taken a very strong position that women should not be prosecuted for trying to end their own pregnancies. ACOG additionally opposes forcing physicians to share information about patients due to its burdensome interference in the patient-provider relationship<sup>12</sup>; therefore be it

RESOLVED, That our American Medical Association oppose the criminalization of self-induced abortion as it increases patients' medical risks and deters patients from seeking medically necessary services (New HOD Policy); and be it further

RESOLVED, That our AMA advocate against any legislative efforts to criminalize self-induced abortion. (New HOD Policy)

Fiscal note: Minimal - less than \$1,000.

Received: 05/01/18

#### References:

1. Criminalization of Self-Induced Abortion Intimidates and Shames Women Unnecessarily. Available at <https://www.acog.org/About-ACOG/News-Room/News-Releases/2018/Criminalization-of-Self-Induced-Abortion-Intimidates-and-Shames-Women-Unnecessarily>.
2. Rowan, Andrea. "Prosecuting women for self-inducing abortion: Counterproductive and lacking compassion." *Guttmacher Policy Review* 18.3 (2015): 70-76.
3. *Ibid*.
4. Abortion. Available at <https://www.guttmacher.org/united-states/abortion>.
5. Decriminalization of Self-Induced Abortion. Available at <https://www.acog.org/Clinical-Guidance-and-Publications/Position-Statements/Decriminalization-of-Self-Induced-Abortion>.
6. MAP: Google Searches For 'Self-Induced Abortion' Track Almost Perfectly With Anti-Choice States. Available at <https://thinkprogress.org/map-google-searches-for-self-induced-abortion-track-almost-perfectly-with-anti-choice-states-c6c01db3e692/>.
7. Stephens-Davidowitz S. The return of the D.I.Y. abortion. *New York Times*. March 6, 2016:SR2. Available at [https://www.nytimes.com/2016/03/06/opinion/sunday/the-return-of-the-diy-abortion.html?\\_r=0](https://www.nytimes.com/2016/03/06/opinion/sunday/the-return-of-the-diy-abortion.html?_r=0). Retrieved March 20, 2018.
8. What are people looking for when they google "self-abortion"? Available at [http://www.contraceptionjournal.org/article/S0010-7824\(18\)30068-4/fulltext#ac0005](http://www.contraceptionjournal.org/article/S0010-7824(18)30068-4/fulltext#ac0005).
9. Halt Criminalization. Available at <https://www.sjalegalteam.org/halt-criminalization>.
10. Melese T, Habte D, Tsima BM, et al. High Levels of Post-Abortion Complication in a Setting Where Abortion Service Is Not Legalized. Gebhardt S, ed. *PLoS ONE*. 2017;12(1):e0166287. doi:10.1371/journal.pone.0166287.
11. Mississippi Woman Criminally Charged for Pregnancy Outcome After Home Birth. Available at <https://rewire.news/article/2018/02/06/mississippi-woman-criminally-charged-pregnancy-outcome-home-birth/>.
12. Criminalization of Self-Induced Abortion Intimidates and Shames Women Unnecessarily. Available at <https://www.acog.org/About-ACOG/News-Room/News-Releases/2018/Criminalization-of-Self-Induced-Abortion-Intimidates-and-Shames-Women-Unnecessarily>.

#### Relevant AMA Policy:

[Right to Privacy in Termination of Pregnancy H-5.993](#)

[Pregnancy Termination H-5.983](#)

[Opinion 4.2.7 Abortion](#)

[H-5.995 Abortion](#)

[H-160.946 The Criminalization of Health Care Decision Making](#)

AMERICAN MEDICAL ASSOCIATION HOUSE OF DELEGATES

Resolution: 008  
(A-18)

Introduced by: Women Physicians Section

Subject: Health Care Rights of Pregnant Minors

Referred to: Reference Committee on Amendments to Constitution and Bylaws  
(Peter H. Rheinstein, MD, JD, MS, Chair)

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1 Whereas, Some states require parental consent or parental notice for pregnant minors to  
2 receive prenatal care tests and procedures such as prenatal genetic testing, epidural block and  
3 cesarean section; and  
4

5 Whereas, In some cases, states allow only certain groups of minors--such as those who are  
6 married or already parents--to consent to related prenatal care tests and procedures<sup>1</sup>; and  
7

8 Whereas, Four states (Kansas, Nevada, New Hampshire, West Virginia) allow a minor who is  
9 considered "mature" to consent to related prenatal care tests and procedures<sup>1</sup>; and  
10

11 Whereas, One state (North Dakota) allows a minor to consent to prenatal care during the first  
12 trimester while requiring parental consent for prenatal care during the second and third  
13 trimesters<sup>1</sup>; and  
14

15 Whereas, Thirteen states (Arizona, Connecticut, Indiana, Iowa, Louisiana, Maine, Nebraska,  
16 Ohio, Rhode Island, South Dakota, Vermont, Wisconsin, and Wyoming) have no relevant policy  
17 or case law regarding minors' authority to consent to prenatal care<sup>1</sup>; and  
18

19 Whereas, In some states, such as Indiana and Ohio, without relevant policy or case law, people  
20 under age 18 who are in labor cannot consent to their own health care or anything considered to  
21 be elective, such as an epidural block<sup>2,3</sup>; and  
22

23 Whereas, An epidural block is the most common type of pain relief used for childbirth in the  
24 United States<sup>4</sup>; and  
25

26 Whereas, There are reports of parents withholding consent for interventions such as epidural  
27 blocks as a form of punishment for minors becoming pregnant<sup>5</sup>, and  
28

29 Whereas, Current AMA policy does not oppose restrictions on consent-related rights<sup>6</sup>; therefore  
30 be it  
31

32 RESOLVED, That our American Medical Association work with appropriate stakeholders to  
33 support legislation allowing pregnant minors to consent to related tests and procedures from the  
34 prenatal stage through postpartum care (Directive to Take Action); and be it further  
35

36 RESOLVED, That our AMA oppose any law or policy that prohibits a pregnant minor to consent  
37 to prenatal and other pregnancy related care, including, but not limited to, prenatal genetic  
38 testing, epidural block, and Cesarean section. (Directive to Take Action)

Fiscal note: Modest - between \$1,000 - \$5,000.

Received: 05/01/18

**References:**

1. An Overview of Minors' Consent Law. Available at <https://www.guttmacher.org/state-policy/explore/overview-minors-consent-law>.
2. Treat Teenage Moms Like Moms, Not Children. Available at <https://www.nytimes.com/2018/02/13/opinion/teenage-mothers-children.html>.
3. State laws put teenage moms in a double-bind. Available at <http://www.idsnews.com/article/2017/10/editorial-state-laws-put-teenage-moms-in-a-double-bind>.
4. Medications for Pain Relief during Labor and Delivery. Available at <https://www.acog.org/Patients/FAQs/Medications-for-Pain-Relief-During-Labor-and-Delivery#what>.
5. Some States Make It Hard for Teen Moms to Get Pain Relief in Childbirth. Available at <https://www.npr.org/sections/health-shots/2017/09/28/554033177/some-states-make-it-hard-for-teen-moms-to-get-pain-relief-in-childbirth>.
6. AMA Code of Medical Ethics. Available at <https://www.ama-assn.org/delivering-care/confidential-health-care-minors>.

**Relevant AMA Policy:**

Confidential Health Services for Adolescents H-60.965

Our AMA:

- (1) reaffirms that confidential care for adolescents is critical to improving their health;
- (2) encourages physicians to allow emancipated and mature minors to give informed consent for medical, psychiatric, and surgical care without parental consent and notification, in conformity with state and federal law;
- (3) encourages physicians to involve parents in the medical care of the adolescent patient, when it would be in the best interest of the adolescent. When, in the opinion of the physician, parental involvement would not be beneficial, parental consent or notification should not be a barrier to care;
- (4) urges physicians to discuss their policies about confidentiality with parents and the adolescent patient, as well as conditions under which confidentiality would be abrogated. This discussion should include possible arrangements for the adolescent to have independent access to health care (including financial arrangements);
- (5) encourages physicians to offer adolescents an opportunity for examination and counseling apart from parents. The same confidentiality will be preserved between the adolescent patient and physician as between the parent (or responsible adult) and the physician;
- (6) encourages state and county medical societies to become aware of the nature and effect of laws and regulations regarding confidential health services for adolescents in their respective jurisdictions. State medical societies should provide this information to physicians to clarify services that may be legally provided on a confidential basis;
- (7) urges undergraduate and graduate medical education programs and continuing education programs to inform physicians about issues surrounding minors' consent and confidential care, including relevant law and implementation into practice;
- (8) encourages health care payers to develop a method of listing of services which preserves confidentiality for adolescents; and
- (9) encourages medical societies to evaluate laws on consent and confidential care for adolescents and to help eliminate laws which restrict the availability of confidential care.

Citation: (CSA Rep. A, A-92; Reaffirmed by BOT Rep. 24, A-97; Reaffirmed by BOT Rep. 9, A-98; Reaffirmed: Res. 825, I-04; Reaffirmation A-08; Reaffirmed: CMS Rep. 2, I-14)

See also:

[2.2.1 Pediatric Decision Making](#)

[2.2.2 Confidential Health Care for Minors](#)

## AMERICAN MEDICAL ASSOCIATION HOUSE OF DELEGATES

Resolution: 009  
(A-18)

Introduced by: Women Physicians Section

Subject: Improving and Increasing Clarity and Consistency Among AMA Induced  
Abortion Policies

Referred to: Reference Committee on Amendments to Constitution and Bylaws  
(Peter H. Rheinstein, MD, JD, MS, Chair)

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1 Whereas, In recent years our AMA has affirmed the medical relevance of induced abortion;  
2 and  
3

4 Whereas, There are several AMA policies that are directly or indirectly related to induced  
5 abortion; and  
6

7 Whereas, Amendments and revisions of policies have sometimes resulted in use of imprecise  
8 and inconsistent language; and  
9

10 Whereas, This may result in inaccurate perceptions, and reporting of AMA policies on induced  
11 abortion; and  
12

13 Whereas, A review of these policies reveals language inconsistencies that cause AMA policy  
14 misunderstandings by the public, as evidenced in the need for and premise for policy H-5.988,  
15 "Accurate Reporting on AMA Abortion Policy"; and  
16

17 Whereas, Legal induced abortion is defined by the Centers for Disease Control and Prevention  
18 (CDC), for the purpose of CDC surveillance, as an intervention performed by a specially  
19 trained and licensed clinician (e.g., a physician, nurse-midwife, nurse practitioner, or physician  
20 assistant) that is intended to terminate an ongoing pregnancy<sup>1</sup>; and  
21

22 Whereas, The AMA has previously only recognized abortion performed by duly licensed  
23 physicians; and  
24

25 Whereas, In certain states, other licensed and specially trained clinicians perform abortion; and  
26

27 Whereas, The American College of Obstetricians and Gynecologists encourages expanding  
28 the trained pool of non-obstetrician-gynecologist providers to include family physicians, nurse  
29 practitioners, physician assistants, and certified nurse-midwives, thereby supporting access to  
30 safe abortion care<sup>2</sup>; and  
31

32 Whereas, Clinical evidence suggests that outcomes are equivalent between physician and  
33 other trained clinicians<sup>2</sup>; therefore be it  
34

35 RESOLVED, That our American Medical Association review its policies on abortion to ensure  
36 use of appropriate terminology and that such policies are reflective of appropriate practice  
37 standards (Directive to Take Action); be it further

1 RESOLVED, That AMA Policy H-5.988, "Accurate Reporting on AMA Abortion Policy," be  
2 amended by addition to read as follows:

3  
4 Accurate Reporting on AMA Abortion Policy H-5.988

5 Our AMA House of Delegates (HOD) cautions members of the Board of Trustees,  
6 Councils, employees and members of the ~~House of Delegates~~ HOD to precisely  
7 state current AMA policy on abortion and related issues in an effort to minimize  
8 public misperception of AMA policy and urges that our AMA continue efforts to refute  
9 misstatements and misquotes by the media with reference to AMA abortion policy.

10 (Amend HOD Policy)

Fiscal note: Minimal - less than \$1,000.

Received: 05/01/18

**References:**

1. CDC Abortion Surveillance FAQs. Available at [https://www.cdc.gov/reproductivehealth/data\\_stats/abortion.htm](https://www.cdc.gov/reproductivehealth/data_stats/abortion.htm).
2. Abortion training and education. Committee Opinion No. 612. American College of Obstetricians and Gynecologists. Obstet Gynecol 2014;124:1055–9.
3. Weitz TA, Taylor D, Desai S, Upadhyay UD, Waldman J, Battistelli MF, Drey EA. Safety of aspiration abortion performed by nurse practitioners, certified nurse midwives, and physician assistants under a California legal waiver. Am J Public Health. 2013 Mar;103(3):454-61.
4. Freedman MA, Jillson DA, Coffin RR, Novick LF. Comparison of complication rates in first trimester abortions performed by physician assistants and physicians. Am J Public Health 1986;76:550–4.
5. Goldman MB, Occhiuto JS, Peterson LE, Zapka JG, Palmer RH. Physician assistants as providers of surgically induced abortion services. Am J Public Health 2004;94:1352–7.

**RELEVANT AMA POLICY**

**Accurate Reporting on AMA Abortion Policy H-5.988**

Our AMA HOD cautions members of the Board of Trustees, Councils, employees and members of the House of Delegates to precisely state current AMA policy on abortion and related issues in an effort to minimize public misperception of AMA policy and urges that our AMA continue efforts to refute misstatements and misquotes by the media with reference to AMA abortion policy.

Citation: (Sub. Res. 21, A-91; Reaffirmed: Sunset Report, I-01; Reaffirmed: CEJA Rep. 8, A-11)

**Pregnancy Termination H-5.983**

The AMA adopted the position that pregnancy termination be performed only by appropriately trained physicians (MD or DO).

Citation: (Res. 520, A-95; Reaffirmed: CSA Rep. 8, A-03; Modified: CSAPH Rep. 1, A-13)

**Freedom of Communication Between Physicians and Patients H-5.989**

It is the policy of the AMA: (1) to strongly condemn any interference by the government or other third parties that causes a physician to compromise his or her medical judgment as to what information or treatment is in the best interest of the patient;

(2) working with other organizations as appropriate, to vigorously pursue legislative relief from regulations or statutes that prevent physicians from freely discussing with or providing information to patients about medical care and procedures or which interfere with the physician-patient relationship;

(3) to communicate to HHS its continued opposition to any regulation that proposes restrictions on physician-patient communications; and

(4) to inform the American public as to the dangers inherent in regulations or statutes restricting communication between physicians and their patients.

Citation: (Sub. Res. 213, A-91; Reaffirmed: Sub. Res. 232, I-91; Reaffirmed by Rules & Credentials Cmt., A-96; Reaffirmed by Sub. Res. 133 and BOT Rep. 26, A-97; Reaffirmed by Sub. Res. 203 and 707, A-98; Reaffirmed: Res. 703, A-00; Reaffirmed in lieu of Res. 823, I-07; Reaffirmation I-09; Reaffirmation: I-12; Reaffirmed in lieu of Res. 5, I-13)

See also: [Policy on Abortion H-5.990](#); [Right to Privacy in Termination of Pregnancy H-5.993](#); [Abortion H-5.995](#); [E-4.2.7 Abortion](#); [E-4.1.2 Genetic Testing for Reproductive Decision Making](#)



## AMERICAN MEDICAL ASSOCIATION HOUSE OF DELEGATES

Resolution: 010  
(A-18)

Introduced by: American College of Cardiology

Subject: Gender Equity in Compensation and Professional Advancement

Referred to: Reference Committee on Amendments to Constitution and Bylaws  
(Peter H. Rheinstein, MD, JD, MS, Chair)

Whereas, Recent data demonstrate that significant differences in salary and compensation exist between male and female physicians, despite improvements in explicit gender discrimination<sup>1-5</sup>; and

Whereas, Women physicians in academic medicine and in practice earn less than men even after adjustment for factors such as age, years of experience, specialty, reported work hours, clinical productivity, research productivity, and faculty rank<sup>1-5</sup>; and

Whereas, A recently published analysis of salary differences at 24 US public medical schools found that the annual salaries of female physicians were \$19,879 (8%) lower than the salaries of male physicians; this difference persisted through all faculty ranks<sup>5</sup>; and

Whereas, This gender compensation gap is likely to only widen over the course of a woman's career; and

Whereas, Explicit gender bias in academic medicine has largely decreased since the passage of the Education Amendment to the Civil Rights Act (Title IX), however implicit biases persist and cultural stereotypes continue to disadvantage women in male dominated fields<sup>6-8</sup>; therefore be it

RESOLVED, That our American Medical Association advocate for institutional and departmental policies that promote transparency in defining the criteria for initial and subsequent physician compensation (New HOD Policy); and be it further

RESOLVED, That our AMA advocate for equal base pay based on objective criteria (New HOD Policy); and be it further

RESOLVED, That our AMA advocate for implicit bias and compensation determination training for those in positions to determine salary and bonuses, with a focus on how subtle differences in the evaluation of male and female physicians may impede compensation and career advancement (New HOD Policy); and be it further

RESOLVED, That our AMA encourage a specified approach, sufficient to identify gender disparity, to oversight of compensation models, metrics, and actual total compensation for all employed physicians (New HOD Policy); and be it further

RESOLVED, That our AMA establish educational programs to help empower all genders to negotiate equitable compensation. (Directive to Take Action)

Fiscal Note: Not yet determined

Received: 05/01/18

<sup>1</sup> Association of Women Surgeons. Association of Women Surgeons Statement on Gender Salary Equity. Available at: [www.womensurgeons.org/](http://www.womensurgeons.org/). Accessed 2/14/18/

<sup>2</sup> American College of Physicians. Position Statement on Compensation Equity and Transparency in the Field of Medicine. [https://www.acponline.org/acp\\_policy/policies/compensation\\_equity\\_and\\_transparency\\_position\\_statement\\_2017.pdf](https://www.acponline.org/acp_policy/policies/compensation_equity_and_transparency_position_statement_2017.pdf) accessed 2/15/18.

<sup>3</sup> American College of Physicians. Research on Compensation Equity and Transparency in the Field of Medicine. [https://www.acponline.org/system/files/documents/newsroom/research\\_on\\_compensation\\_equity\\_and\\_transparency\\_in\\_the\\_field\\_of\\_medicine\\_2017.pdf](https://www.acponline.org/system/files/documents/newsroom/research_on_compensation_equity_and_transparency_in_the_field_of_medicine_2017.pdf) accessed 2/15/18.

<sup>4</sup> Jaggi R, Biga C, Poppas A, et al. Work Activities and Compensation of Male and Female Cardiologists. J Am Coll Cardiol. 2016;67(5):529-541

<sup>5</sup> Jena, AB; et al. Sex Differences in Physician Salary in US Public Medical Schools. JAMA Intern Med. 2016;176(9):1294-1304

<sup>6</sup> Yedidia, MJ, et al. Why aren't there more women leaders in academic medicine? The views of clinical department chairs. Acad Med. 2001; 76(5): 453-465

<sup>7</sup> Carnes, M. Why Is John More Likely to Become Department Chair than Jennifer? Transactions of The American Clinical and Climatological Association, Vol. 126, 2015

<sup>8</sup> Eagly, AH; et al. Role congruity theory of prejudice toward female leaders. Psychol Rev 2002; 109(3):573.

## RELEVANT AMA POLICY

### Gender Disparities in Physician Income and Advancement D-200.981

Our AMA:

- (1) encourages medical associations and other relevant organizations to study gender differences in income and advancement trends, by specialty, experience, work hours and other practice characteristics, and develop programs to address disparities where they exist;
- (2) supports physicians in making informed decisions on work-life balance issues through the continued development of informational resources on issues such as part-time work options, job sharing, flexible scheduling, reentry, and contract negotiations;
- (3) urges medical schools, hospitals, group practices and other physician employers to institute and monitor transparency in pay levels in order to identify and eliminate gender bias and promote gender equity throughout the profession;
- (4) will collect and publicize information on best practices in academic medicine and non academic medicine that foster gender parity in the profession; and
- (5) will provide training on leadership development, contract and salary negotiations and career advancement strategies, to combat gender disparities as a member benefit.

Citation: (BOT Rep. 19, A-08; Reaffirmed: CCB/CLRPD Rep. 4, A-13)

## AMERICAN MEDICAL ASSOCIATION HOUSE OF DELEGATES

Resolution: 011  
(A-18)

Introduced by: American College of Gastroenterology

Subject: Women Physician Workforce and Gender Gap in Earnings-Measures to Improve Equality

Referred to: Reference Committee on Amendments to Constitution and Bylaws  
(Peter H. Rheinstein, MD, JD, MS, Chair)

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Whereas, The American Medical Association and AMA's Women Physicians Section have made concerted efforts to highlight the disparity of physician payment by gender in the United States today, and to increase the influence of women physicians in leadership roles in medicine;<sup>i</sup> and

Whereas, In 2015, while women comprised 34% of the active physician workforce in the United States, and an estimated 46% of all physicians-in-training as well as more than half of all medical students are women, much remains to be done to improve equity and parity among physician payment and to increase opportunities for promotion and leadership;<sup>ii</sup> and

Whereas, Studies have historically found a payment disparity gap among male and female physicians within the same specialty,<sup>iii</sup> and this payment disparity continues to exist in all specialties of medicine in 2018;<sup>iv</sup> and

Whereas, Among cohorts of equal training and experience, adjusting for variables including workhours, calls, vacation, gender, academic versus non-academic practice, women held less advanced academic positions, earning significantly less compensation ten years after graduation;<sup>v</sup> and

Whereas Significant differences in salary also exist among male and female physicians with faculty appointments at U.S. public medical schools, even after accounting for age, experience, specialty faculty rank, and measures of research productivity and clinical revenue;<sup>vi</sup> and

Whereas, Female physicians in early and mid-career may opt for flexibility in schedules in their child-bearing and child-rearing years; and

Whereas, The U.S. will face a significant shortage of physicians, fueled by population growth, an increase in the number of aging Americans, and retirement of practicing doctors, a shortage of between 40,800 and 104,900 physicians by 2030<sup>vii</sup>, and the AMA has prioritized confronting this shortage in previous AMA House of Delegates meetings;<sup>viii</sup> and

Whereas, The city of Chicago can no longer ask about salary history on employment applications, part of a growing effort nationwide to improve pay equality between men and women;<sup>ix</sup> and

Whereas, On January 29, 2009 the Lilly Ledbetter Fair Pay Act was signed into law to reinforce the protection against pay discrimination under the Equal Pay Act of 1963 (EPA), which prohibits sex-based wage discrimination between men and women in the same establishment

1 who perform jobs that require substantially equal skill, effort, and responsibility under similar  
2 working conditions;<sup>x</sup> therefore be it  
3

4 RESOLVED, That our American Medical Association, together with the assistance of  
5 professional medical societies, create an awareness campaign to inform physicians about their  
6 rights under the Lilly Ledbetter Fair Pay Act and Equal Pay Act (Directive to Take Action); and  
7 be it further  
8

9 RESOLVED, That our AMA, together with the assistance of professional medical societies, help  
10 U.S. public medical schools and facilities create guidance for institutional transparency of  
11 compensation, and regular gender-based pay audits, in order to narrow the gender inequity in  
12 pay and promotion (Directive to Take Action); and be it further  
13

14 RESOLVED, That our AMA recommend to eliminate the question of prior salary information  
15 from job applications for physician recruitment in academic and private practice. (Directive to  
16 Take Action)

Fiscal Note: Not yet determined

Received: 05/02/18

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<sup>i</sup> American Medical Association: <https://www.ama-assn.org/about/women-physicians-section-wps>

<sup>ii</sup> Achieving Gender Equity in Physician Compensation and Career Advancement: A Position Paper of the American College of Physicians. April 2018. <http://annals.org/aim/fullarticle/2678630/achieving-gender-equity-physician-compensation-career-advancement-position-paper-american>

<sup>iii</sup> MEDSCAPE 2017 Physician Compensation Report: [www.medscape.com/slideshow/compensation-2017-overview-6008547](http://www.medscape.com/slideshow/compensation-2017-overview-6008547); MEDSCAPE 2016 Physician Compensation Report: <https://www.medscape.com/features/slideshow/compensation/2016/public/overview>;

<sup>iv</sup> MEDSCAPE 2018 Physician Compensation Report: <https://www.medscape.com/slideshow/2018-compensation-overview-6009667>; Doximity: Second Annual Physician Compensation Report. March 2018

[https://www.doximity.com/press\\_releases/national\\_research\\_study\\_finds\\_large\\_gaps\\_in\\_us\\_physician\\_compensation](https://www.doximity.com/press_releases/national_research_study_finds_large_gaps_in_us_physician_compensation)

<sup>v</sup> Singh A, Sastri S, Burke C. Do Gender Disparities Persist in Gastroenterology after Ten Years of Practice? Am J Gastroenterol. Vol. 103, pages1589–1595 (2008)

<sup>vi</sup> Jena AB, Olenski AR, Blumenthal DM. Sex Differences in salary in US Public Medical Schools. JAMA Intern Med. 2016;176(9):1294-1304. doi:10.1001/jamainternmed.2016.3284

<sup>vii</sup> American Association of Medical Colleges. March 2017: Research Shows Shortage of More Than 100,000 Doctors by 2030. <https://news.aamc.org/medical-education/article/new-aamc-research-reaffirms-looming-physician-shortage>

<sup>viii</sup> American Medical Association: Council on Medical Education Report – executive Summary. <https://www.ama-assn.org/sites/default/files/media-browser/public/about-ama/councils/Council%20Reports/council-on-medical-education/cme-rpt7-a-14.pdf>

<sup>ix</sup> Chicago Tribune: “Emanuel moves to boost gender pay equity.” April 12, 2018.

<sup>x</sup> U.S. Equal Employment Opportunity Commission: EQUAL PAY ACT OF 1963 AND LILLY LEDBETTER FAIR PAY ACT OF 2009. [https://www.eeoc.gov/eeoc/publications/brochure-equal\\_pay\\_and\\_ledbetter\\_act.cfm](https://www.eeoc.gov/eeoc/publications/brochure-equal_pay_and_ledbetter_act.cfm)

## RELEVANT AMA POLICY

### Gender Disparities in Physician Income and Advancement D-200.981

Our AMA:

- (1) encourages medical associations and other relevant organizations to study gender differences in income and advancement trends, by specialty, experience, work hours and other practice characteristics, and develop programs to address disparities where they exist;
- (2) supports physicians in making informed decisions on work-life balance issues through the continued development of informational resources on issues such as part-time work options, job sharing, flexible scheduling, reentry, and contract negotiations;
- (3) urges medical schools, hospitals, group practices and other physician employers to institute and monitor transparency in pay levels in order to identify and eliminate gender bias and promote gender equity throughout the profession;
- (4) will collect and publicize information on best practices in academic medicine and non academic medicine that foster gender parity in the profession; and
- (5) will provide training on leadership development, contract and salary negotiations and career advancement strategies, to combat gender disparities as a member benefit.

Citation: (BOT Rep. 19, A-08; Reaffirmed: CCB/CLRPD Rep. 4, A-13)

[See also: E-9.5.5 Gender Discrimination in Medicine: Eliminating Questions Regarding Marital Status, Dependents, Plans for Marriage or Children, Sexual Orientation, Gender Identity, Age, Race, National Origin and Religion During the Residency and Fellowship Application Process H-310.919](#)

## AMERICAN MEDICAL ASSOCIATION HOUSE OF DELEGATES

Resolution: 012  
(A-18)

Introduced by: Illinois

Subject: Costs to Kidney Donors

Referred to: Reference Committee on Amendments to Constitution and Bylaws  
(Peter H. Rheinstein, MD, JD, MS, Chair)

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1 Whereas, Some 100,000 Americans are awaiting a kidney transplant at any given time; and

2  
3 Whereas, Kidney donations can be made by living donors; and

4  
5 Whereas, Paying donors for organs is currently illegal; and

6  
7 Whereas, Costs directly related to organ donation are paid by the recipient, but living kidney  
8 donors still typically incur significant expenses both before and after donation – a disincentive to  
9 donating; therefore be it

10  
11 RESOLVED, That our American Medical Association seek legislation to ensure that living  
12 kidney donors are reimbursed for expenses associated with donation of their kidney. (Directive  
13 to Take Action)

Fiscal Note: Modest - between \$1,000 - \$5,000.

Received: 05/02/18

## AMERICAN MEDICAL ASSOCIATION HOUSE OF DELEGATES

Resolution: 013  
(A-18)

Introduced by: Michigan

Subject: Opposing Surgical Sex Assignment of Infants with Differences of Sex Development

Referred to: Reference Committee on Amendments to Constitution and Bylaws  
(Peter H. Rheinstein, MD, JD, MS, Chair)

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Whereas, Differences of sex development (DSD), also known as intersex, are defined as congenital development of ambiguous genitalia (e.g., 46,XX virilizing congenital adrenal hyperplasia), congenital disjunction of sex anatomy (e.g., Complete Androgen Insensitivity Syndrome), incomplete development of sex anatomy (e.g., gonadal agenesis), sex chromosome anomalies (e.g., Turner Syndrome), and disorders of gonadal development (e.g., ovotestes)<sup>1</sup>; and

Whereas, Sex (the biological state of being male or female), gender (a person's self-representation as male or female), and sexual orientation (direction(s) of erotic interest -- heterosexual, bisexual, homosexual) are three separate categories existing on a spectrum<sup>2</sup>; and

Whereas, For many decades research has supported the idea that our experience of our bodies and gender identity is inherent in us and not something that can be assigned<sup>3,4,5,6,7,8,9,10</sup>; and

Whereas, DSD is currently presented as a pathological condition requiring medical attention rather than biological variance outside of the hegemonic sex binary<sup>11</sup>; and

Whereas, There is little research on the incidence of DSD, but estimates range from 1 in 5000 ambiguous genitalia to 1 in 1,500 for atypical genitalia<sup>12,13</sup>; and

Whereas, The frequency of DSD from 1955 to 2000 was estimated to be as high as 2 percent of live births worldwide; and the frequency of individuals receiving corrective genital surgery was estimated to be 0.1-0.2 percent of all live births<sup>14</sup>; and

Whereas, No straightforward recommendations exist in the U.S. for sex assignment in Neonates with DSD; however, there is a growing consensus that any surgical intervention in neonates and infants leading to irreversible changes should be done with the utmost caution<sup>15</sup>; and

Whereas, The majority of reconstructive surgeries for DSD in the U.S. are typically performed during the first year; however, this timing is controversial and there is limited data on the long term psychological outcomes for patients<sup>16,17,18</sup>; and

Whereas, A survey of young adults found that 93 percent of women would not have wanted their parents to agree to a genitoplasty surgery for an enlarged clitoris unless the condition were life threatening and almost all men would not have wanted sex reassignment for a micropenis if it might have impacted their sexual pleasure<sup>19</sup>; and

1 Whereas, Medical professionals (including three former U.S. Surgeons General: Doctor  
2 Joycelyn Elders, Doctor David Satcher, and Doctor Richard Carmona) as well as national  
3 organizations such as United Nations, Amnesty International and Human Rights Watch have  
4 recommended against and are devoted to ending unnecessary surgeries on infants with  
5 DSD<sup>11,19,20,21</sup>; and

6  
7 Whereas, The human rights organization Amnesty International documented numerous  
8 examples of human rights violations during instances of "invasive and irreversible 'normalizing'  
9 surgeries" for children with DSD<sup>21</sup>; and

10  
11 Whereas, The 2015 European Union Report on the current legal state of affairs regarding  
12 intersex rights of member states found that at least 18 member states legally require patient  
13 (rather than parental) consent for surgical intervention in DSD<sup>22</sup>; and

14  
15 Whereas, Medically unnecessary DSD surgery is defined as, "all surgical procedures that seek  
16 to alter the gonads, genitals, or internal sex organs of children with atypical sex characteristics  
17 too young to participate in the decision, when those procedures both carry a meaningful risk of  
18 harm and can be safely deferred"<sup>18</sup>; and

19  
20 Whereas, The court case *MC v. Aaronson*, concerning the potential violation of constitutional  
21 rights of a person who underwent intersex genital mutilation without consent at age one while a  
22 ward of the state, was later dismissed by the Court of Appeals for the Fourth Circuit since there  
23 was "no fair warning to those involved in the decision regarding M.C.'s surgery that they were  
24 violating his clearly established constitutional rights;"<sup>23</sup> and

25  
26 Whereas, There are minimal studies examining the long-term impact of these surgeries, but  
27 those studies found that persons with DSD that did not have surgical intervention as infants  
28 primarily experienced psychological stress from feelings of isolation from other individuals,  
29 communities, and support groups, rather than from the absence of early surgical  
30 intervention<sup>11,24</sup>; and

31  
32 Whereas, Attempting to alter a person's sexual identity or sexual orientation through any type of  
33 therapy may cause psychological harm<sup>25</sup>; and

34  
35 Whereas, Chronic juvenile stress has been associated with the development of neuropsychiatric  
36 illness in adulthood; much like the stress caused by having one's biological sex assigned for  
37 them at birth<sup>26</sup>; and

38  
39 Whereas, Permanent alterations to genitalia before a patient can consent may result in the child  
40 being assigned a gender incongruent with their gender identity and lead to adverse outcomes  
41 including loss of sensitivity, orgasmic function, and fertility<sup>2,12,27</sup>; therefore be it

42  
43 RESOLVED, That our American Medical Association oppose the assignment of gender binary  
44 sex to infants with differences in sex development through surgical intervention outside of the  
45 necessity of physical functioning for an infant and believes children should have meaningful  
46 input into any gender assignment surgery. (New HOD Policy)

Fiscal Note: Minimal - less than \$1,000.

Received: 05/02/18

- <sup>1</sup> Consortium on the Management of Disorders of Sex Development. Clinical Guidelines for the Management of Disorders of Sex Development in Childhood.; 2006. <http://www.dsdguidelines.org/files/clinical.pdf>. Accessed December 28, 2017.
- <sup>2</sup> Ainsworth C. Sex redefined. *Nature*. 2015;518(7539):288-291. doi:10.1038/518288a.
- <sup>3</sup> Hines M. Gender Development and the Human Brain. *Annu Rev Neurosci*. 2011;34(1):69-88. doi:10.1146/annurev-neuro-061010-113654.
- <sup>4</sup> Case LK, Brang D, Landazuri R, Viswanathan P, Ramachandran VS. Altered White Matter and Sensory Response to Bodily Sensation in Female-to-Male Transgender Individuals. *Arch Sex Behav*. 2017;46(5):1223-1237. doi:10.1007/s10508-016-0850-z.
- <sup>5</sup> Hines M, Constantinescu M, Spencer D. Early androgen exposure and human gender development. *Biol Sex Differ*. 2015;6:3. doi:10.1186/s13293-015-0022-1.
- <sup>6</sup> Nota NM, Kreukels BPC, den Heijer M, et al. Brain functional connectivity patterns in children and adolescents with gender dysphoria: Sex-atypical or not? *Psychoneuroendocrinology*. 2017;86:187-195. doi:10.1016/J.PSYNEUEN.2017.09.014.
- <sup>7</sup> Koolschijn PCMP, Crone EA. Sex differences and structural brain maturation from childhood to early adulthood. *Dev Cogn Neurosci*. 2013;5:106-118. doi:10.1016/J.DCN.2013.02.003.
- <sup>8</sup> Ruigrok ANV, Salimi-Khorshidi G, Lai M-C, et al. A meta-analysis of sex differences in human brain structure. *Neurosci Biobehav Rev*. 2014;39:34-50. doi:10.1016/J.NEUBIOREV.2013.12.004.
- <sup>9</sup> Kruijver FPM, Zhou J-N, Pool CW, Hofman MA, Gooren LJG, Swaab DF. Male-to-Female Transsexuals Have Female Neuron Numbers in a Limbic Nucleus. *J Clin Endocrinol Metab*. 2000;85(5):2034-2041. doi:10.1210/jcem.85.5.6564.
- <sup>10</sup> Rametti G, Carrillo B, Gómez-Gil E, et al. White matter microstructure in female to male transsexuals before cross-sex hormonal treatment. A diffusion tensor imaging study. *J Psychiatr Res*. 2011;45(2):199-204. doi:10.1016/j.jpsychires.2010.05.006.
- <sup>11</sup> Davis G. Contesting Intersex : The Dubious Diagnosis. <https://nyupress.org/books/9781479887040/>. Accessed December 28, 2017.
- <sup>12</sup> Leidolf EM, Curran M, Scout, Bradford J. Intersex Mental Health and Social Support Options in Pediatric Endocrinology Training Programs. *J Homosex*. 2008;54(3):233-242. doi:10.1080/00918360801982074.
- <sup>13</sup> Thyen U, Lanz K, Holterhus P-M, Hiort O. Epidemiology and Initial Management of Ambiguous Genitalia at Birth in Germany. *Horm Res Paediatr*. 2006;66(4):195-203. doi:10.1159/000094782.
- <sup>14</sup> Blackless M, Charuvastra A, Derruck A, Fausto-Sterling A, Lauzanne K, Lee E. How sexually dimorphic are we? Review and synthesis. *Am J Hum Biol*. 2000;12(2):151-166. doi:10.1002/(SICI)1520-6300(200003/04)12:2<151::AID-AJHB1>3.0.CO;2-F.
- <sup>15</sup> Hiort O, Birnbaum W, Marshall L, et al. Management of disorders of sex development. *Nat Rev Endocrinol*. 2014;10(9):520-529. doi:10.1038/nrendo.2014.108.
- <sup>16</sup> Wolffebuttel KP, Crouch NS. Timing of feminising surgery in disorders of sex development. *Endocr Dev*. 2014;27:210-221. doi:10.1159/000363665.
- <sup>17</sup> Mouriquand PDE, Gorduza DB, Gay C-L, et al. Surgery in disorders of sex development (DSD) with a gender issue: If (why), when, and how? *J Pediatr Urol*. 2016;12(3):139-149. doi:10.1016/j.jpuro.2016.04.001.
- <sup>18</sup> Advocates for Intersex Youth. "I Want to Be Like Nature Made Me" Medically Unnecessary Surgeries on Intersex Children in the US. *Hum Rights Watch*. 2017.
- <sup>19</sup> Diamond M, Garland J. Evidence regarding cosmetic and medically unnecessary surgery on infants. *J Pediatr Urol*. 2014;10(1):2-6. doi:10.1016/J.JPUROL.2013.10.021.
- <sup>20</sup> Dalke K. A Changing Paradigm: US Medical Provider Discomfort with Intersex Care Practices. *Hum Rights Watch*. 2017.
- <sup>21</sup> Amnesty International. First, Do No Harm: Ensuring the Rights of Children with Variations of Sex Characteristics in Denmark and Germany. London; 2017. <https://www.amnesty.org/en/documents/eur01/6086/2017/en/>. Accessed December 28, 2017.
- <sup>22</sup> European Union Agency for Fundamental Rights. The Fundamental Rights Situation of Intersex People. Austria; 2015. <http://fra.europa.eu/en/publication/2015/fundamentalrightssituation-intersex-people>. Accessed December 28, 2017.
- <sup>23</sup> CA4. MC vs Amrhein.(2006). doi:No. 13-2178.
- <sup>24</sup> Bougnères P, Bouvattier C, Cartigny M, Michala L. Deferring surgical treatment of ambiguous genitalia into adolescence in girls with 21-hydroxylase deficiency: a feasibility study. *Int J Pediatr Endocrinol*. 2016. doi:10.1186/s13633-016-0040-8.
- <sup>25</sup> Ansara YG, Hegarty P. Cisgenderism in psychology: pathologising and misgendering children from 1999 to 2008. *Psychol Sex*. 2012;3(2):137-160. doi:10.1080/19419899.2011.576696.
- <sup>26</sup> Watt MJ, Weber MA, Davies SR, Forster GL. Impact of juvenile chronic stress on adult cortico-accumbal function: Implications for cognition and addiction. *Prog Neuro-Psychopharmacology Biol Psychiatry*. 2017;79:136-154. doi:10.1016/J.PNPBP.2017.06.015.
- <sup>27</sup> Lee P, Schober J, Nordenström A, et al. Review of recent outcome data of disorders of sex development (DSD): Emphasis on surgical and sexual outcomes. *J Pediatr Urol*. 2012;8(6):611-615. doi:10.1016/j.jpuro.2012.10.017.



AMERICAN MEDICAL ASSOCIATION HOUSE OF DELEGATES

Resolution: 014  
(A-18)

Introduced by: Michigan

Subject: Promotion of LGBTQ-Friendly and Gender-Neutral Intake Forms

Referred to: Reference Committee on Amendments to Constitution and Bylaws  
(Peter H. Rheinstein, MD, JD, MS, Chair)

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Whereas, The LGBTQ+ (per the Urban Dictionary – lesbian, gay, bisexual, transgender, questioning and + meaning other sexualities such as pansexual, asexual and omnisexual extra) population in the United States is estimated to be over 10 million people (4.1 percent of the population)<sup>i</sup>; and

Whereas, LGBTQ+ populations are vulnerable and often marginalized in society and in the medical system<sup>ii</sup>; and

Whereas, LGBTQ+ focus groups have established that distinguishing their identity within the medical system is often a source of great discomfort<sup>iii</sup>; and

Whereas, LGBTQ+ focus groups have also identified normalization of their gender identities as a major component of their recommendations to improve health care experiences<sup>3</sup>; and

Whereas, Intake forms in medical facilities (i.e., clinics, hospitals) often have only binary gender options, and only 5 percent of forms are gender inclusive in able to identify transgender patients<sup>4</sup>; and

Whereas, The Institute of Medicine recommends the collection of data on sexual orientation and gender identity as part of the electronic health record, but 14 percent of intake forms confuse gender and sexual orientation<sup>4,5</sup>; and

Whereas, An LGBTQ+ friendly intake form establishes a comfortable and welcoming atmosphere for the LGBTQ+ patient in the office; and

Whereas, The Gay and Lesbian Medical Association offers various guidelines for improving the care of LGBTQ+ patients, including the use of gender-neutral forms<sup>6</sup>; and

Whereas, Twenty-four percent of transgender and gender nonconforming patients reported denial of equal treatment in the while seeking healthcare<sup>7</sup>; and

Whereas, The American Medical Association has an established stance on and commitment to the ongoing improvement of nonjudgmental, nondiscriminatory, and culturally competent care of LGBTQ+ patients<sup>8</sup>; therefore be it

RESOLVED, That our American Medical Association distribute and promote the adoption of the recommendations pertaining to medical documentation and related forms in AMA policy H-315.967, “Promoting Inclusive Gender, Sex, and Sexual Orientation Options on Medical Documentation,” to our membership. (Directive to Take Action)

Fiscal Note: Not yet determined

Received: 05/02/18

## RELEVANT AMA POLICY

### Promoting Inclusive Gender, Sex, and Sexual Orientation Options on Medical Documentation H-315.967

Our AMA: (1) supports the voluntary inclusion of a patient's biological sex, current gender identity, sexual orientation, and preferred gender pronoun(s) in medical documentation and related forms, including in electronic health records, in a culturally-sensitive and voluntary manner; and (2) will advocate for collection of patient data that is inclusive of sexual orientation/gender identity for the purposes of research into patient health.

Citation: Res. 212, I-16; Reaffirmed in lieu of: Res. 008, A-17;

### Health Care Needs of Lesbian, Gay, Bisexual and Transgender Populations H-160.991

1. Our AMA: (a) believes that the physician's nonjudgmental recognition of patients' sexual orientations, sexual behaviors, and gender identities enhances the ability to render optimal patient care in health as well as in illness. In the case of lesbian, gay, bisexual, transgender, queer/questioning, and other (LGBTQ) patients, this recognition is especially important to address the specific health care needs of people who are or may be LGBTQ; (b) is committed to taking a leadership role in: (i) educating physicians on the current state of research in and knowledge of LGBTQ Health and the need to elicit relevant gender and sexuality information from our patients; these efforts should start in medical school, but must also be a part of continuing medical education; (ii) educating physicians to recognize the physical and psychological needs of LGBTQ patients; (iii) encouraging the development of educational programs in LGBTQ Health; (iv) encouraging physicians to seek out local or national experts in the health care needs of LGBTQ people so that all physicians will achieve a better understanding of the medical needs of these populations; and (v) working with LGBTQ communities to offer physicians the opportunity to better understand the medical needs of LGBTQ patients; and (c) opposes, the use of "reparative" or "conversion" therapy for sexual orientation or gender identity.

2. Our AMA will collaborate with our partner organizations to educate physicians regarding: (i) the need for sexual and gender minority individuals to undergo regular cancer and sexually transmitted infection screenings based on anatomy due to their comparable or elevated risk for these conditions; and (ii) the need for comprehensive screening for sexually transmitted diseases in men who have sex with men; (iii) appropriate safe sex techniques to avoid the risk for sexually transmitted diseases; and (iv) that individuals who identify as a sexual and/or gender minority (lesbian, gay, bisexual, transgender, queer/questioning individuals) experience intimate partner violence, and how sexual and gender minorities present with intimate partner violence differs from their cisgender, heterosexual peers and may have unique complicating factors.

3. Our AMA will continue to work alongside our partner organizations, including GLMA, to increase physician competency on LGBTQ health issues.

4. Our AMA will continue to explore opportunities to collaborate with other organizations, focusing on issues of mutual concern in order to provide the most comprehensive and up-to-date education and information to enable the provision of high quality and culturally competent care to LGBTQ people.

Citation: CSA Rep. C, I-81; Reaffirmed: CLRPD Rep. F, I-91; CSA Rep. 8 - I-94; Appended: Res. 506, A-00; Modified and Reaffirmed: Res. 501, A-07; Modified: CSAPH Rep. 9, A-08; Reaffirmation A-12; Modified: Res. 08, A-16; Modified: Res. 903, I-17; Modified: Res. 904, I-17;

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<sup>i</sup> Gates, G. "LGBT Data Collection Amid Social and Demographic Shifts of the US LGBT Community." American Journal of Public Health. 2017. <http://ajph.aphapublications.org/doi/full/10.2105/AJPH.2017.303927>

<sup>ii</sup> Canestraro LM. Disparities in Care: LGBT Patients Often Are Vulnerable, Marginalized. Journal of the Catholic Health Association of the United States. July-August 2015. <https://www.chausa.org/publications/health-progress/article/july-august-2015/disparities-in-care-lgbt-patients-often-are-vulnerable-marginalized>

<sup>iii</sup> Smith SK, Turell SC. Perceptions of Healthcare Experiences: Relational and Communicative Competencies to Improve Care for LGBT People. Journal of Social Issues. 2017;73:637-657.

<sup>4</sup> Carabez, R, et al. "Does Your Organization Use Gender Inclusive Forms? Nurses' Confusion about Trans\* Terminology." Journal of Clinical Nursing, vol. 24, no. 21-22, Dec. 2015, pp. 3306-3317.

<sup>5</sup> Institute of Medicine Committee on Lesbian, G.B., et al., The National Academies Collection: reports funded by National Institutes of Health. In: The Health of Lesbian, Gay, Bisexual, and Transgender People: Building a Foundation for Better Understanding. National Academies Press (US) National Academy of Sciences, Washington (DC), 2011.

<sup>6</sup> Guidelines for Care of Lesbian, Gay, Bisexual, and Transgender Patients. Gay and Lesbian Medical Association. [http://www.glma.org/\\_data/n\\_0001/resources/live/GLMA%20guidelines%202006%20FINAL.pdf](http://www.glma.org/_data/n_0001/resources/live/GLMA%20guidelines%202006%20FINAL.pdf)

<sup>7</sup> Grant, Jaime M., Lisa A. Mottet, Justin Tanis, Jody L. Herman, and Jack Harrison. "National transgender discrimination survey report on health and health care." Washington, DC: National Center for Transgender Equality and the National Gay and Lesbian Task Force, 2010 [http://www.thetaskforce.org/static\\_html/downloads/resources\\_and\\_tools/ntds\\_report\\_on\\_health.pdf](http://www.thetaskforce.org/static_html/downloads/resources_and_tools/ntds_report_on_health.pdf)

<sup>8</sup> Health Care Needs of Lesbian, Gay, Bisexual and Transgender Populations H-160.991.

## AMERICAN MEDICAL ASSOCIATION HOUSE OF DELEGATES

Resolution: 015  
(A-18)

Introduced by: Oklahoma

Subject: Human Trafficking/Slavery Awareness

Referred to: Reference Committee on Amendments to Constitution and Bylaws  
(Peter H. Rheinstein, MD, JD, MS, Chair)

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1 Whereas, The United Nations has defined human trafficking as “the recruitment, transportation,  
2 transfer, harboring or receipt of persons, by means of threat or use of force or other forms of  
3 coercion, of abduction, of fraud, or deception, of the abuse of power or of a position of  
4 vulnerability or of the giving or receiving of payments or benefits to achieve the consent of a  
5 person having control over another person, for the purpose of exploitation. Exploitation shall  
6 include, as a minimum, the exploitation of the prostitution of others or other forms of sexual  
7 exploitation, forced labour or services, slavery or practices similar to slavery, servitude or the  
8 removal of organs;” and  
9

10 Whereas, All 50 states have enacted laws criminalizing human trafficking activities; and  
11

12 Whereas, AMA Board of Trustee Report 20, A-13, encourages its member groups and sections  
13 as well as the Federation of Medicine, to raise awareness about human trafficking and of  
14 resources available to help them identify and address the needs of victims; and  
15

16 Whereas, The Polaris Project operates a 24-hour national human trafficking hotline which also  
17 provides assessment tools for healthcare professionals and on-line training; and  
18

19 Whereas, Current AMA Policy H-65.966 will help encourage the education of physicians about  
20 human trafficking and how to report cases of suspected human trafficking to appropriate  
21 authorities to provide a conduit to resources to address the victim’s medical, legal, and social  
22 needs; and  
23

24 Whereas, The January 2017 American Medical Association *Journal of Ethics* featured  
25 numerous perspectives on how physicians can respond for effectively to this vulnerable  
26 population and has brought awareness; and  
27

28 Whereas, According to the US Department of State, Human Trafficking is the fastest growing  
29 criminal activity in the world, second only to drug trafficking. This modern-day slavery generates  
30 over \$150 billion annually for organized crime; and  
31

32 Whereas, Human trafficking continues to be an increasing substantial societal problem in  
33 Oklahoma and nationally; and  
34

35 Whereas, Physicians are first responders in this epidemic and their education has been  
36 underwhelming compared to the rate of increase of this problem; and  
37

38 Whereas, Health care providers are key stakeholders in the abolitionist movement. An  
39 estimated 28% of trafficked persons encounter the health care system while in captivity but

1 virtually none are ever detected. Only 1 in 100 trafficked victims are ever rescued. Recognizing  
 2 red flags is absolutely essential. Without an awareness of human trafficking, victims will  
 3 continue to go undetected by health care professionals; therefore be it  
 4

5 RESOLVED, That our American Medical Association study the effectiveness of physician  
 6 education to ensure that physicians are trained to report suspected cases of human  
 7 trafficking/slavery to the appropriate authorities while assuring victims have the medical, legal,  
 8 and social resources they need and develop a plan of action to improve recognition of victims of  
 9 human trafficking/slavery to increase the identification, referral, and rescue rate. (Directive to  
 10 Take Action)

Fiscal Note: Not yet determined

Received: 05/01/18

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- United Nations Office on Drugs and Crime. Human Trafficking. Available at [www.unodc.org/unodc/en/human-trafficking/what-is-human-trafficking.html](http://www.unodc.org/unodc/en/human-trafficking/what-is-human-trafficking.html) Accessed January 31, 2013.
- Health Care Providers' Training Needs Related to Human Trafficking: Maximizing the Opportunity to Effectively Screen and Intervene. Isaac R, Solak J, and Giardino A. The Journal of Applied Research on Children
- Human Trafficking: The Fastest-Growing Criminal Industry Worldwide and the Role of the Physician in Turning the Tide. Isaac R. Texas Children's Hospital.
- Trafficking in Persons Report. Department of State. United States of America. Jun 2013.
- Human Trafficking Into and Within the United States: A Review of the Literature. US Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation.

## RELEVANT AMA POLICY

### Physicians Response to Victims of Human Trafficking H-65.966

1. Our AMA encourages its Member Groups and Sections, as well as the Federation of Medicine, to raise awareness about human trafficking and inform physicians about the resources available to aid them in identifying and serving victims of human trafficking.

Physicians should be aware of the definition of human trafficking and of resources available to help them identify and address the needs of victims.

The US Department of State defines human trafficking as an activity in which someone obtains or holds a person in compelled service. The term covers forced labor and forced child labor, sex trafficking, including child sex trafficking, debt bondage, and child soldiers, among other forms of enslavement. Although it's difficult to know just how extensive the problem of human trafficking is, it's estimated that hundreds of thousands of individuals may be trafficked every year worldwide, the majority of whom are women and/or children.

The Polaris Project -

In addition to offering services directly to victims of trafficking through offices in Washington, DC and New Jersey and advocating for state and federal policy, the Polaris Project:

- Operates a 24-hour National Human Trafficking Hotline
- Maintains the National Human Trafficking Resource Center, which provides
  - a. An assessment tool for health care professionals
  - b. Online training in recognizing and responding to human trafficking in a health care context
  - c. Speakers and materials for in-person training
  - d. Links to local resources across the country

The Rescue & Restore Campaign -

The Department of Health and Human Services is designated under the Trafficking Victims Protection Act to assist victims of trafficking. Administered through the Office of Refugee Settlement, the Department's Rescue & Restore campaign provides tools for law enforcement personnel, social service organizations, and health care professionals.

2. Our AMA will help encourage the education of physicians about human trafficking and how to report cases of suspected human trafficking to appropriate authorities to provide a conduit to resources to address the victim's medical, legal and social needs.

Citation: (BOT Rep. 20, A-13; Appended: Res. 313, A-15)

AMERICAN MEDICAL ASSOCIATION HOUSE OF DELEGATES

Resolution: 016  
(A-18)

Introduced by: GLMA: Health Professionals Advancing LGBT Equality

Subject: Utilization of "LGBTQ" in Relevant Past and Future AMA Policies

Referred to: Reference Committee on Amendments to Constitution and Bylaws  
(Peter H. Rheinstein, MD, JD, MS, Chair)

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Whereas, The term "queer" is defined by the Human Rights Campaign (HRC) as "an umbrella term that encompasses many people as it intersects with sexual orientation and gender identity," and "LGBTQ" has formally been adopted by the organization as a broader representation of individuals for whom its work focuses; and

Whereas, The word "queer" includes anyone who does not associate with typical classifications of gender, gender identity, and sexual orientation; rather, they have non-binary or gender expansive identities; and

Whereas, In the HRC's 2012 survey of 50,000 self-identified LGBTQ youth age 13-18, eight (8) percent of respondents identified as a gender other than male or female; and

Whereas, According to the HRC, when asked to label their gender and sexual orientation, hundreds of respondents used "queer," "genderqueer," or other responses; and many others wrote in their own descriptions of more fluid identities; and

Whereas, In 2016, the AMA Board of Trustees recognized the importance of a more expansive definition of sexual and gender minorities and officially renamed the AMA Advisory Committee on LGBTQ Issues; and

Whereas, Recent AMA policies passed by the AMA House of Delegates have utilized the abbreviation "LGBTQ" and the expanded language "lesbian, gay, bisexual, transgender, and queer" (H-160.991, H-60.927); and

Whereas, The use of "LGBTQ" has come to replace "LGBT" in many aspects of culture, medicine, academics, and advocacy; and

Whereas, It is important for the AMA to recognize those within the LGBTQ population who identify as queer so that they will be fully embraced and empowered within our AMA and the healthcare community; therefore be it

RESOLVED, That our American Medical Association utilize the terminology "lesbian, gay, bisexual, transgender, and queer" and the abbreviation "LGBTQ" in all future policies and publications when broadly addressing this population, (New HOD Policy); and be it further

RESOLVED, That our AMA revise all relevant and active policies to utilize the abbreviation "LGBTQ" in place of the abbreviations "LGBT" and "GLBT" where such text appears (Modify Current HOD Policy); and be it further

- 1 RESOLVED, That our AMA revise all relevant and active policies to utilize the terms “lesbian,
- 2 gay, bisexual, transgender, and queer” to replace “lesbian, gay, bisexual, and transgender”
- 3 where such text appears. (Modify Current HOD Policy)

Fiscal Note: Minimal - less than \$1,000.

Received: 05/10/18

References:

<https://www.hrc.org/blog/hrc-officially-adopts-use-of-lgbtq-to-reflect-diversity-of-own-community>

Human Rights Campaign Post-election Survey of Youth [www.hrc.org/youth](http://www.hrc.org/youth)

[https://assets2.hrc.org/files/assets/resources/HRC\\_PostElectionSurveyofYouth.pdf?\\_ga=2.1866225.1552857023.1523827449-1196525142.1505150368](https://assets2.hrc.org/files/assets/resources/HRC_PostElectionSurveyofYouth.pdf?_ga=2.1866225.1552857023.1523827449-1196525142.1505150368)

## RELEVANT AMA POLICY

### **Reducing Suicide Risk Among Lesbian, Gay, Bisexual, Transgender, and Questioning Youth Through Collaboration with Allied Organizations H-60.927**

Our AMA will partner with public and private organizations dedicated to public health and public policy to reduce lesbian, gay, bisexual, transgender, and questioning (LGBTQ) youth suicide and improve health among LGBTQ youth.

Citation: (Res. 402, A-12)

### **Health Disparities Among Gay, Lesbian, Bisexual and Transgender Families D-65.995**

Our AMA supports reducing the health disparities suffered because of unequal treatment of minor children and same sex parents in same sex households by supporting equality in laws affecting health care of members in same sex partner households and their dependent children.

Citation: (Res. 445, A-05; Modified: CSAPH Rep. 1, A-15)

### **Health Care Needs of Lesbian, Gay, Bisexual and Transgender Populations H-160.991**

1. Our AMA: (a) believes that the physician's nonjudgmental recognition of patients' sexual orientations, sexual behaviors, and gender identities enhances the ability to render optimal patient care in health as well as in illness. In the case of lesbian, gay, bisexual, transgender, queer/questioning, and other (LGBTQ) patients, this recognition is especially important to address the specific health care needs of people who are or may be LGBTQ; (b) is committed to taking a leadership role in: (i) educating physicians on the current state of research in and knowledge of LGBTQ Health and the need to elicit relevant gender and sexuality information from our patients; these efforts should start in medical school, but must also be a part of continuing medical education; (ii) educating physicians to recognize the physical and psychological needs of LGBTQ patients; (iii) encouraging the development of educational programs in LGBTQ Health; (iv) encouraging physicians to seek out local or national experts in the health care needs of LGBTQ people so that all physicians will achieve a better understanding of the medical needs of these populations; and (v) working with LGBTQ communities to offer physicians the opportunity to better understand the medical needs of LGBTQ patients; and (c) opposes, the use of "reparative" or "conversion" therapy for sexual orientation or gender identity.

2. Our AMA will collaborate with our partner organizations to educate physicians regarding: (i) the need for sexual and gender minority individuals to undergo regular cancer and sexually transmitted infection screenings based on anatomy due to their comparable or elevated risk for these conditions; and (ii) the need for comprehensive screening for sexually transmitted diseases in men who have sex with men; (iii) appropriate safe sex techniques to avoid the risk for sexually transmitted diseases; and (iv) that individuals who identify as a sexual and/or gender minority (lesbian, gay, bisexual, transgender, queer/questioning individuals) experience intimate partner violence, and how sexual and gender minorities present with intimate partner violence differs from their cisgender, heterosexual peers and may have unique complicating factors.

3. Our AMA will continue to work alongside our partner organizations, including GLMA, to increase physician competency on LGBTQ health issues.

4. Our AMA will continue to explore opportunities to collaborate with other organizations, focusing on issues of mutual concern in order to provide the most comprehensive and up-to-date education and information to enable the provision of high quality and culturally competent care to LGBTQ people.

Citation: CSA Rep. C, I-81; Reaffirmed: CLRPD Rep. F, I-91; CSA Rep. 8 - I-94; Appended: Res. 506, A-00; Modified and Reaffirmed: Res. 501, A-07; Modified: CSAPH Rep. 9, A-08; Reaffirmation A-12; Modified: Res. 08, A-16; Modified: Res. 903, I-17; Modified: Res. 904, I-17

[See also: D-65.996 Nondiscriminatory Policy for the Health Care Needs of LGBT Populations; H-170.968 Sexuality Education, Sexual Violence Prevention, Abstinence, and Distribution of Condoms in Schools; H-215.965 Hospital Visitation Privileges for GLBT Patients; H-295.878 Eliminating Health Disparities - Promoting Awareness and Education of Lesbian, Gay, Bisexual, and Transgender \(LGBT\) Health Issues in Medical Education](#)

AMERICAN MEDICAL ASSOCIATION HOUSE OF DELEGATES

Resolution: 017  
(A-18)

Introduced by: New Jersey

Subject: Revised Mission Statement of the AMA

Referred to: Reference Committee on Amendments to Constitution and Bylaws  
(Peter H. Rheinstein, MD, JD, MS, Chair)

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1 Whereas, The Mission Statement of our AMA for many years has been to “Promote the art and  
2 science of medicine and the betterment of public health”; and  
3

4 Whereas, Our AMA has been spending an increasing amount of time discussing physician  
5 suicide, burn out and general malaise with practicing medicine; and  
6

7 Whereas, Darwin has taught that survival depends on adaptation; and  
8

9 Whereas, It is vital for its survival that our AMA adapt to changing times by updating its Mission  
10 Statement; therefore be it  
11

12 RESOLVED, That our American Medical Association consider its current mission statement to  
13 read: *The AMA promotes professionalism, the art and science of medicine, physician wellness*  
14 *and the betterment of public health.* (Directive to Take Action)

Fiscal Note: Minimal - less than \$1,000.

Received: 05/10/18