Whereas, organ transplantation is a live-saving treatment for individuals with end-stage organ failure; and1

Whereas, existing AMA policy recognizes that organ donation is crucial for treating end-stage diseases, views organs as a national resource, and supports equitable access to transplantation; and2,3,4

Whereas, The National Organ Transplant Act established the Organ Procurement and Transplantation Network (OPTN) to govern organ procurement, allocation, and transplantation, and to increase access to donor organs; and5

Whereas, on March 22, 2023, Health Resources and Services Administration (HRSA) launched the OPTN Modernization Initiative to enhance transparency, equity, and modernization in the U.S. transplant system.; and

Whereas, the Initiative would include the “creation of a separate legal entity to serve as the OPTN, with its own independent Board of Directors, to facilitate independent, transparent, and accountable OPTN governance”; and6

Whereas, the OPTN Board of Directors established the OPTN Transition Task Force to collaborate with HRSA and contractors to create a fully independent OPTN and Board of Directors by June 28, 2024; and

Whereas, in May 2024, HRSA has reneged and stated that it no longer supports the idea that the new legal entity will serve as the OPTN; and

Whereas, HRSA has created a new structure without input from relevant stakeholders which is solely a Board of Directors with very limited authority and a vague association of government and non-government organizations; and7

Whereas, this new structure diminishes the role of patients, transplant physicians and providers, OPO representatives, and other key stakeholders; and

Whereas, the new HRSA proposed structure threatens a governmental/OPTN public-private partnership that required for the Modernization Initiative; therefore be it

RESOLVED, that our American Medical Association (AMA) seek congressional and regulatory support for the establishment of a separate legal entity that will serve as the OPTN; and be it further
RESOLVED, that our AMA support the involvement of key stakeholders (patients, physicians, advanced practice providers, transplant centers, OPOs, and professional societies) in the OPTN modernization Initiative.

Fiscal Note: Modest

Received: 5/30/24

References:

2. Increasing Organ Donation H-370.971
3. Transplantable Organs as a National Resource H-370.990
4. Equal Access to Organ Transplantation for Medicaid Beneficiaries H-370.962
5. Organ procurement and transplantation network 42 U.S.C. § 274
6. Letter from Suma Nair PhD, MS, RD, Associate Administrator, Health Systems Bureau, to Dianne LaPointe-Rudow ANP-BC,DNP, FAA, OPTN President, United Network for Organ Sharing (Mar. 27, 2024)
7. Letter from OPTN Board of Directors Transition Work Group (May 28, 2024)

Relevant RFS Position Statements:

360.001R Removing Barriers to Organ Donation: That our AMA-RFS support the AMA working with legislators to remove financial barriers to living organ donation to pass laws which include: (1) provisions for expenses involved in the donation incurred by the organ donor, (2) providing access to health care coverage for any medical expense or disability related to the donation, (3) prohibiting employment discrimination on the basis of living donor status, and (4) prohibiting the use of living donor status as the sole basis for denying health and life insurance coverage. (Resolution 4, A-11)

Relevant AMA Policy:
H-370.971 Increasing Organ Donation.

H-370.990 Transplantable Organs as a National Resource
Our AMA: (1) supports the United Network of Organ Sharing (UNOS) policy calling for regional allocation of livers to status 1 (most urgent medical need) patients as an effort to more equitably distribute a scarce resource; (2) opposes any legislation, regulations, protocols, or policies directing or allowing governmental agencies to favor residents of a particular geo-political jurisdiction as recipients of transplantable organs or tissues; (3) reaffirms its position that organs and tissues retrieved for transplantation should be treated as a national, rather than a regional, resource; and (4) supports the findings and recommendations of the Institute of Medicine Committee on Organ Procurement and Transplantation Policy. [Res. 94, I-87Reaffirmed: Sunset Report, I-97Appended and Reaffirmed CSA Rep. 12, I-99Reaffirmed: CSA Rep. 4, I-02Reaffirmed: CSAPH Rep. 1, A-12]

H-370.962 Equal Access to Organ Transplantation for Medicaid Beneficiaries