REPORT OF THE BOARD OF TRUSTEES

Subject: Update on TruthinRx Grassroots Campaign

Presented by: Jack Resneck, Jr., MD, Chair

INTRODUCTION

At the 2017 Interim Meeting, the House of Delegates adopted Policy D-110.988[2] “Prescription Drug Price and Cost Transparency,” which asked for a report back to the House of Delegates at the 2018 Interim Meeting on the progress and impact of the TruthinRx grassroots campaign. This report, which is presented for the information of the House, summarizes the creation of the TruthinRx grassroots campaign, its evolution, and its progress and impact. The report also summarizes relevant American Medical Association (AMA) policy and advocacy, which is reflected in the TruthinRx grassroots campaign.

BACKGROUND

In 2015, Policy H-110.987, “Pharmaceutical Costs,” directed the AMA to convene a task force of appropriate AMA Councils, state medical societies, and national medical specialty societies to develop principles to guide advocacy and grassroots efforts aimed at addressing pharmaceutical costs and improving patient access and adherence to medically necessary prescription drug regimens. Accordingly, the AMA convened a Task Force on Pharmaceutical Costs, which met four times in the first six months of 2016 to develop principles to guide advocacy and grassroots efforts aimed at addressing pharmaceutical costs. The Task Force agreed that increasing transparency among pharmaceutical companies, health plans, and pharmacy benefit managers (PBMs) should be the initial focus of the campaign, which led to the launch of a grassroots campaign in the third quarter of 2016, and the launch of the TruthinRx website, TruthinRx.org, on November 1, 2016.

EVOLUTION OF THE TRUTHINRX GRASSROOTS CAMPAIGN

The goal of the TruthinRx campaign has been to mobilize the AMA Physician Grassroots Network (PGN), the AMA Patient Action Network (PAN), the public, and thought leaders around the challenges posed by the lack of transparency surrounding prescription drug pricing and costs. TruthinRx.org engages physicians, patients/consumers, and health care policy influencers by:

(a) providing critical information about prescription drug price and cost challenges, as well as the lack of drug price and cost transparency, and (b) facilitating grassroots action in support of improving prescription drug price and cost transparency. Since its launch in November 2016, TruthinRx.org has evolved through two key stages. In its first stage, the TruthinRx.org landing page focused on informing visitors about how drug price negotiations happen behind closed doors and how pharmaceutical companies, PBMs, and health insurance companies participate in these negotiations. The page concludes that “when patients are left out, health care suffers.” This landing page directs visitors to four main website subsections:

- “Your Stories” – invites visitors to read and contribute their own stories about how the lack of transparency in drug pricing impacts our health care system.
• “Behind the Label” – illustrates how the lack of transparency in prescription drug pricing and costs – involving opaque price agreements between PBMs, health plans, and pharmaceutical manufacturers – contributes to adverse patient effects such as increased costs and unpredictable price swings for patients, and ultimately adversely affects patients and physicians.

• “Get Involved” – facilitates grassroots advocacy by providing visitors with a customizable message that can be personalized to US Senators and Representatives, calling on legislators to support increased transparency in prescription drug prices. Additionally, visitors have an opportunity to subscribe to future legislative updates and alerts from the AMA.

• “Get Informed” – provides visitors with a myriad of timely articles to help them understand the seemingly arbitrary costs of prescription medication. The articles are categorized according to the following thought-provoking questions:
  o “What influences the price of drugs?”
  o “How does drug pricing affect patients like you?”
  o “What’s being done to help?”

At the time that this report was written, the second stage of TruthinRx.org was scheduled to be launched in fall of 2018 to further mobilize voters around the issue of prescription drug price transparency. TruthinRx.org will include an interactive data visualization that highlights various reasons why drug prices fluctuate. The data visualization will explore the roles of four key themes behind drug price fluctuation: (1) generics – despite the assumption that generic drugs will be affordable, over time, the prices of generic drugs can rise significantly; (2) competition – despite the expectation that competition in the marketplace would lead to lower prices, competitors’ prices can seemingly increase simultaneously; (3) acquisition – the price of drugs produced by a given company can rise significantly after the company is acquired; and (4) supply chain dynamics – PBMs cast themselves as saving money, but with the lack of supply chain transparency, it is unclear how these middlemen negotiate drug prices. The data visualization will lead to a call to action for improved transparency. This interactive subsection of TruthinRx.org can be used both on mobile and desktop devices, and is designed so that it can be shared on social media.

PROGRESS AND IMPACT OF THE TRUTHINRX GRASSROOTS CAMPAIGN

The TruthinRx grassroots campaign has significantly impacted public awareness of, and grassroots action in response to, the opaque process that pharmaceutical companies, PBMs, and health plans engage in when pricing prescription drugs. Between the website’s launch in November 2016 and August 2018, the TruthinRx campaign has achieved the following milestones:

• The TruthinRx campaign generated 827,759 messages sent to Congress demanding price transparency.

• As part of the TruthinRx grassroots campaign, the PAN launched a petition calling for increased prescription drug price and cost transparency, and this petition has been signed by 275,590 individuals.

• TruthinRx.org has been visited 117,474 times, by 95,873 unique internet users.

• The AMA has published 656 posts on Twitter and Facebook focused on the TruthinRx campaign. Combined, these posts were displayed 10,859,853 times (“impressions”). This led to 514,118 people interacting with the posts (“engagements”).

• Evidencing the TruthinRx campaign’s continued impact on public discussion, since July 2017, the hashtag “#TruthinRx” has been mentioned on Twitter and/or Facebook 1,617 times.
AMA POLICY AND ACTIVITY

It is important to recognize that the TruthinRx grassroots campaign is one key component of a much broader, ongoing AMA focus on prescription drug affordability. Recent AMA policy and activity aimed at improving prescription drug price and cost transparency include:

- The AMA developed and disseminated model state legislation entitled, “An Act to Increase Drug Cost Transparency and Protect Patients from Surprise Drug Cost Increases during the Plan Year.”
- The AMA submitted comments in July 2018 in response to the HHS Blueprint to Lower Drug Prices and Reduce Out-of-Pocket Costs. Patient and other stakeholder experiences with affordability and lack of access that were obtained through the TruthinRx campaign were incorporated as vignettes in this comment letter. The AMA has received positive feedback on these vignettes.
- In April 2018, Jack Resneck, Jr., MD, testified at the US House of Representatives Democratic Steering and Policy Committee Briefing on Prescription Medication Pricing and Access Challenges and Solutions. Dr. Resneck’s testimony focused on how the lack of prescription drug pricing transparency impacts his patients.
- In December 2017, Gerald e. Harmon, MD, testified before the Health Subcommittee of the US House of Representatives Committee on Energy and Commerce on the topic of “Examining the Pharmaceutical Supply Chain.” Dr. Harmon’s testimony focused on what the escalating cost and complexity of obtaining medically necessary prescriptions or physician-administered drug treatments mean for patient adherence, timely access, and health outcomes.
- Policy H-110.987, which encourages prescription drug price and cost transparency among pharmaceutical companies, PBMs, and health insurance companies and establishes extensive AMA policy aimed at improving access to affordable prescription drugs, including: promoting legislation that authorizes the Attorney General and/or the Federal Trade Commission (FTC) to take legal action to address price gouging by pharmaceutical manufacturers and increase access to affordable drugs for patients, and encouraging FTC actions to limit anticompetitive behavior by pharmaceutical companies attempting to reduce competition from generic manufacturers.
- Policy H-110.987, also directs the AMA to provide assistance upon request to state medical associations in support of state legislative and regulatory efforts addressing drug price and cost transparency.
- Policy H-125.979, which supports legislation or regulation that secures private health insurance formulary transparency.
- Policy H-110.991, which advocates for greater prescription drug price transparency at the pharmacy point-of-sale.
- Policy H-110.991, also supports physician education regarding drug price and cost transparency and challenges patients may encounter at the pharmacy point-of-sale.

Moreover, the AMA is continuing to develop evolving policy in support of improved prescription drug affordability. Ongoing AMA initiatives include:

- At this Interim Meeting, the Council on Medical Service is presenting Report 1-I-18 that addresses prescription drug importation for personal use.
- At the 2019 Annual Meeting, the Council on Medical Service will present a report that addresses the impact of PBMs on patients.
- At the 2019 Annual Meeting, the Board of Trustees will present a report that addresses three related referred resolutions that address reforming the Orphan Drug Act, legislation related to an optional national prescription drug formulary, and modifications to the Hatch-Waxman Act and Biologics Price Competition and Innovation Act (i.e., Biosimilars Act).
CONCLUSION

In the approximately two years since the TruthinRx grassroots campaign was launched, the initiative has demonstrated significant success in engaging physicians, patients/consumers, and health care policy influencers in discussion of and advocacy to improve prescription drug price and cost transparency. As described above, the TruthinRx campaign is a key component of a broader, ongoing AMA focus on prescription drug affordability, and TruthinRx.org will continue to evolve as relevant AMA policy evolves. The objective metrics outlined above indicate that the TruthinRx grassroots campaign is succeeding in stimulating public discourse, and TruthinRx.org will continue to be updated to capture public attention and mobilize action.