March 3, 2021

Written Testimony of the Caring Ambassadors Program
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Testimony, Public Hearing SB 457

Senate Committee on Health Care

Dear Chair Patterson, Vice-Chair Knopp and committee members,

The Caring Ambassadors Program is a national nonprofit, advocacy organization based in Oregon City, Oregon. Caring Ambassadors has empowered patients to be advocates for their health since 1997. We have worked with the State of Oregon Pharmacy and Therapeutics committee and its predecessors since early 2000. We support SB 457 with Amendment 1, to improve the HERC and P&T committee process.

Increased Community Engagement

"Nothing about us, without us" is a phrase that should be considered by the members of the committees in their decision-making process. Before making decisions, you should first ask two questions; 1) Have you heard directly from patients on this issue? And, 2) What tangible steps has the committee taken to elicit patient feedback?

> From the P & T committee website on public comment rules: "2b. Maximum of 3 minutes per speaker, 10 minutes per agenda item. Information that is most helpful to the Committee is evidence-based, comparative and limited to new information not previously reviewed by the Committee and relating to dossier information or prepared reviews."

Improve public notice and extend the time allowed for testimony based on need. We urge you to invest in outreach to the people most impacted – providers, consumers, and other stakeholders. The public process is best when input is received from the greatest cross-section possible. Where and when is the patient experience taken into consideration? There are times when 10 minutes is not enough for everyone to be heard. I have reached out too many patients who have attended these meetings to testify and share their life experiences. Many have said they leave the meeting feeling unheard and disrespected and feel that their time was wasted.

The HERC and P&T Committee recommendations have broader implications than just access to medications and diagnostics for consumers accessing the Oregon health Plan. The P&T recommendations set the bar from which other states and health insurance providers will measure prescription drug benefits. The meetings are conducted in a way that discourages public participation. The time, location, and materials available to participants are critical to consumers' attendance, engagement, and participation and should be strongly considered and amended to facilitate more public comment and participation.

Stick to the Agenda times. Requiring the P&T Committee to divide their agenda into two separate sections is helpful, but it should also include a statement about adhering to the agenda. Many working advocates follow the distributed agenda and rearrange schedules to attend the event. When their agenda topic is moved, they may be denied their opportunity to be heard before decisions are made.

Ensure that translator services are available. Sound programs are the ones developed with input, inclusion, and engagement from the community members who will be directly served. This facilitates an increase in service utilization, and a decrease in early treatment termination.

Invite public testimony before the group discussion. A typical meeting starts with reading the report developed, a discussion among committee members, and then a few minutes for public input. Why not discuss public input at the top of the meeting? It is very dismissive to be heard after the committee members have made up their mind.

Provide cultural sensitivity training to committee members. To hear a member of the committee, make derogatory remarks about a disease or people living with a condition should never happen.

Caring Ambassadors respects the expertise of the committee members; and, it is impossible to be an expert on all diseases. I have witnessed the P&T committee dismiss expert consultants and expert guideline panels. I have observed when their testimony was not convenient to the committees predetermined course of action they were treated disrespectfully. At a meeting in 2018, one expert was told to be quiet and sit down when he objected to the incorrect and harmful information the committee was discussing.

Have you considered the consequences of ignoring the guidance from expert physicians and guidelines panels that have been dismissed because of misperceived bias due to pharmaceutical funding?

Consultation of at least one expert should be sought, and these experts should be on the panel during the presentation and included in the voting process.

Revisit the Review Process

Trials, if not funded by the federal government, are automatically viewed as biased. Federal funding for all drugs in development is not realistic given NIH's current budget. Clinical trials conducted by pharmaceutical companies should not automatically be deemed as poor. My experience is that pharmaceutical companies do more consultation with patients and advocates than the P & T review process.

Controlled studies are considered by the reviewers as the gold standard but are not always the best option for patients. Some new drugs are so advanced that comparing them to their ineffective predecessor would be harmful to patients.

> ***If controlled trials are the gold standard and the effectiveness of parachutes was in front of the committee, they would find poor evidence of their ability to save lives for those jumping out of planes.***

Four years after being on the market, a drug class review on Direct-Acting Antivirals for Hepatitis C stated, "There is no direct, randomized prospective evidence that treatment with antiviral therapy for chronic hepatitis C leads to improved long-term clinical outcomes in incidence of HCC (liver cancer), liver transplantation, or mortality." The current DAAs' are FDA approved and eliminate the hepatitis C virus in more than 90% of those studied. Today more than 1.5 million people have been cured form the hepatitis C virus using these same drugs and mortality has decreased from 5.01/per 100,000 in 2014 to 3.72 in 2018.[1]

How many Oregonians living with hepatitis C would you recommend getting a placebo or delayed treatment for a few decades to provide this long-term data the committee is requesting?

Remove Barriers to Care

Prior Authorizations are a barrier to care. When the P & T committee has removed prescribing restrictions on a class of drugs then the Prior authorization should automatically sunset as well.

Transparency

Caring Ambassadors is transparent about our fundraising and are open about receiving funds from corporations, pharmaceutical companies, foundations, city and state governments, private donors and the

like. Caring Ambassadors is asked for this transparency to ensure we provide services and advocacy in an informed, unbiased, and legal way. Why then are the committee members not held to the same standard of transparency? Do they participate in PERS which made money on Gilead stock when the new drugs were introduced but denied to Oregonians on OHP? Do they represent a pharmacy or a CCO that may benefit or be hurt by their decision? The only item on the website are members' general title and in the case of the P & T, the city of residence.

We request all committee members state their conflicts of interest, which should be listed on the website, including their place of employment.

For all the reasons above we support SB 457 and Amendment 1 and encourage you to pass this important legislation.

Thank you for your time and consideration. Caring Ambassadors Program greatly appreciates the work you and state agencies are doing to reach the goals of the Oregon Health Authority; improved lifelong health, increased accessibility to quality care and affordable care.

Sincerely,

Caring Ambassadors Program

Executive Director

1. https://www.cdc.gov/hepatitis/policy/NationalProgressReport-HepC-ReduceDeaths.htm