Consumer Outreach Report

Oregon Prescription Drug Affordability Board

June 17, 2026



Oregon Prescription Drug
Affordability Board

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Acknowledgments

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Oregon Prescription Drug Affordability Board

Introduction and purpose

The Oregon Prescription Drug Affordability Board (PDAB) completed a consumer outreach project featuring in-person and online community forums, a board meeting with an extended public comment period, and online feedback forms. From April 28 to May 20, 2026, the board hosted the community forums and outreach efforts to hear from people about the high cost of prescriptions drugs. The feedback helped inform the board's annual drug review process.

Drug review process background

The consumer outreach project was part of the board's 2026 annual drug review process. Each year, the board conducts reviews to identify up to nine prescription drugs it determines may create affordability challenges for the healthcare system or high out-of-pocket costs for patients.

The Oregon PDAB drug review process includes selecting a subset list of prescription drugs, including insulin products, and analyzing data reported by state health plans and data collected by the Oregon All Payer All Claims (APAC) Reporting Program. The board also gathers information from patients, caregivers, advocates, manufacturers, medical experts, clinics, healthcare payers, and other contributors. The board then presents its findings and policy recommendations to the Oregon Legislature in an annual report.

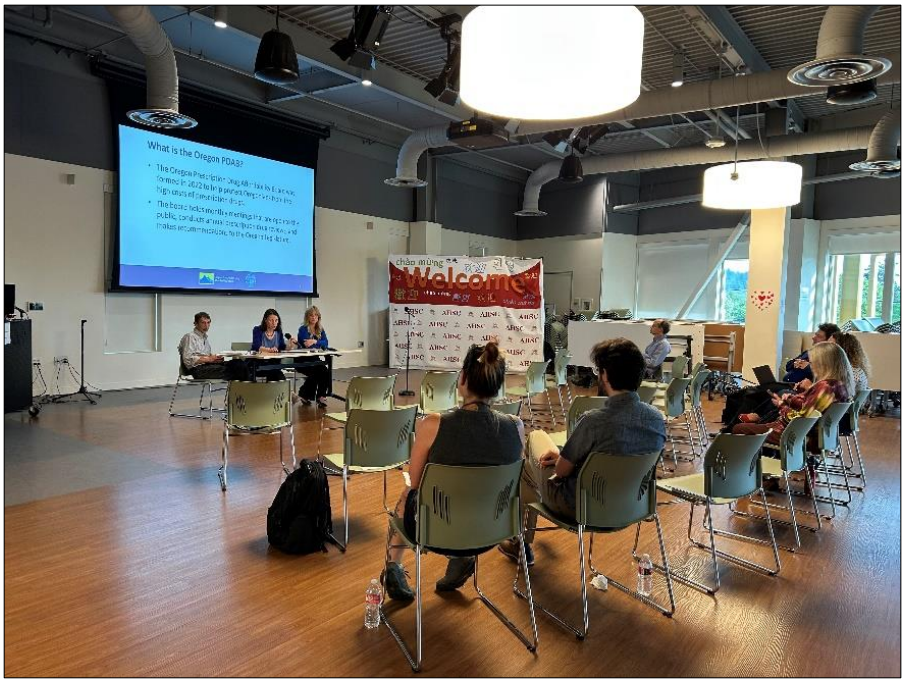
Through the consumer forums, the board also encouraged consumers and patients who were experiencing financial challenges with any prescription drug to share their story at one of the forums or through the board's feedback forms.

Summary of events

Oregon PDAB hosted seven online and in-person community forums and one board meeting in April and May 2026 to hear from patients, caregivers, and others about how medication costs affect their daily lives, finances, and communities. These events were held on the following dates:

- April 28 – 7 p.m., online forum (Spanish interpretation was available)
- May 5 – 5 p.m., in-person forum, Salem Library
- May 6 – 5 p.m., in-person forum, Redmond Library (Spanish interpretation was available)
- May 11 – noon, online forum (Spanish interpretation was available)
- May 12 – 6 p.m., in-person forum, Asian Health & Service Center, Portland (Korean, Vietnamese, and Chinese interpretation was available)
- May 13 – 6:30 p.m., online forum (Spanish interpretation was available)
- May 18 – 5 p.m., in-person forum, Beaverton Library
- May 20 – 8 a.m., online board meeting (Spanish and American Sign Language interpretation was available)

The board provided handouts at the meetings describing the board and its mission, along with a list of the prescription drugs the board is reviewing in 2026. The handouts were translated into four languages: Spanish, Korean, Vietnamese, and two forms of Chinese.



The May 12 PDAB community forum was held at the Asian Health & Service Center, Portland.

The format of the events began with board members introducing themselves. PDAB Executive Director Sarah Young and Consumer Engagement Coordinator Lou Savage then gave a brief presentation about PDAB that included a review of the board's annual legislative report and drug review process, the list of prescription drugs under review for 2026, and the role of the Drug Price Transparency Program in providing data for the board. Maggie Alvarez, Charlie Wente, and Veronica Murray, of the DCBS Division of Financial Regulation (DFR), attended the meetings to provide consumer resources. After the presentation, audience members were invited to speak. Refer to the appendix for a summary of each event.

At the May 20 board meeting, the board provided extended time for each speaker. Eleven people made general comments and one person spoke about Keytruda, which is one of the drugs under board review. Find more details in the May 20 board meeting minutes.

Board member participation

All board members participated in the community forums, with one or two board members attending each event. Patients who spoke were primarily concerned about insurance denials of specific prescriptions or changes in their health insurance policies that limited their prescription drug choices. At each of the in-person and online events, board members engaged with patients who spoke and offered ideas and resources. In Redmond, board member feedback resulted in a patient saving money on a prescription through the Cost Plus Drug Company website, based on follow-up information from the patient. Additionally, members of DFR's outreach team provided resources for contacting DFR consumer advocates for help with specific situations.

PDAB staff members also asked attendees how they heard about the forums. Several attendees responded that they had learned about the forums from the radio. Some said they had attended events where PDAB staff members told them about the forums, while others said they had received a letter and flyer from PDAB or had learned about the forums through a nonprofit organization as a result of PDAB's outreach.

Outreach strategy

In-person meetings with groups

The board reached about 100 people through staff members speaking at community events. The board also made use of social media, paid ads, and public service announcements on Oregon radio stations.



The May 18 PDAB community forum was held at the Beaverton Library and drew participants from as far away as Eugene.

Savage spoke at an event for Korean seniors at the Asian Health & Service Center and invited them to attend the community forums. He also invited the Korean seniors to submit feedback forms about the prescription drugs under board review and let them know the forms were available in Korean, Vietnamese, and Chinese. Two people attended a community forum as a result of hearing Savage speak at this event. PDAB's executive director also spoke with healthcare clinic representatives at a tribal meeting sponsored by Oregon Health and Human Services. She invited them to the community forums and to submit feedback about the medications under review, as well. Savage also spoke at a meeting of Diabetes Support Services. Additionally, PDAB staff members reached out to the Oregon Medical Association, the Hospital Association of Oregon, Health Care for All Oregon, AARP Oregon, Oregon Consumer Justice, and OSPIRG.

Newsletters

PDAB wrote and distributed newsletter articles about the community forums to the Oregon Office of Rural Health, Oregon Health Authority, OSPIRG, Department of Consumer and Business Services,

Oregon Medical Association, Oregon Nurses Association, and state legislators. At least six groups published the articles in their newsletters.

Postal mailings and emails

PDAB mailed letters to 785 Oregon pharmacies, clinics and medical professionals, and advocacy groups. Staff members included a flyer and letter letting recipients know about the community forums and feedback forms and requesting they post the flyer in their pharmacy or clinic for their customers and patients to see. PDAB staff members also sent emails to about 1,000 people and groups who have expressed interest in the board and its work. The emails let people know about the forums and the feedback forms.

Email list

Category	Total
Safety net clinics	47
Patients, caregivers, advocates	223
Scientific/medical professionals	47
Manufacturers	57
Pharmacy benefit managers (PBMs)	129
DCBS-DFR contacts	128
Legislative contacts	51
Pharmacies	660
Total	**1,342**

Postal mailing (letter, flyer)

Category	Total
Safety net clinics	33
Clinics-doctors	61
Pharmacies	657
Advocacy groups	34
Total	**785**

Media outreach

PDAB staff members worked with the DCBS Communications team on a media release posted to the agency's website and sent to specific media outlets in the cities where the community forums would be held. PDAB produced 30- and 60-second radio ads in English and Spanish about the events and sent them to the Oregon Association of Broadcasters for distribution to 150 commercial stations in Oregon to play as public service announcements. PDAB purchased a radio ad with the Spanish station, La

Bronca, in Redmond, received 30 ads on La Patrona Spanish radio station in Klamath Falls as part of a Klamath County grant, and purchased a print display ad in the Portland Observer, an African American owned publication committed to cultural diversity. As a result of the media outreach, KMED radio host Bill Meyer interviewed PDAB's executive director during a live radio broadcast April 23.

Social media

PDAB advertised through Facebook, Instagram, and Linkedin, with ads in English and Spanish.

Legislative outreach

PDAB invited Oregon legislators to attend a community forum and requested they include information in their constituent newsletters. PDAB staff members delivered letters and flyers to the Oregon Capitol and provided digital newsletter articles and flyer images. Several legislators made use of these materials in their constituent newsletters and encouraged people to attend the forums.



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Black Girl LIVE! Returns to Portland Campus

FaithBridge Hosts Events Centered on Care and Community

DO YOUR PRESCRIPTION DRUGS COST TOO MUCH?

Please come to a community forum and share your story about how prescription drug costs have affected you. The board will be reviewing drugs that treat diabetes, autoimmune disease, cancer, MS, psoriasis, and other conditions. dfr.oregon.gov/pdab

In-person forums

Portland – Tuesday, May 12, 6 to 7:30 p.m.
Asian Health & Service Center
9035 SE Foster Road
Portland

Beaverton – Monday, May 18, 5 to 6:30 p.m.
Beaverton City Library
12375 SW Fifth St.
Beaverton

Online forum

Monday, May 11, noon to 1:30 p.m.
Join ZoomGov Meeting
Meeting ID: 160 556 2737

PDAB board meeting

Wednesday, May 20, 8 a.m. to noon
Join ZoomGov Meeting
Meeting ID: 161 233 0328

A display ad about the PDAB community forums was printed in the Portland Observer.

Feedback forms

The board provided feedback forms, with both structured and open-ended response options similar to surveys, about the prescription drugs on the 2026 review list. The forms included a list of medications the board is reviewing and questions about dosage, treatment and effectiveness, length of time on the medication, out-of-pocket costs, insurance coverage, and a place for respondents to share additional feedback. There were forms for six different groups: patients, caregivers, and advocacy groups; individuals with scientific training (medical professionals, pharmacists, researchers, scientists); manufacturers; safety net clinics; pharmacy benefit managers; and insurance companies. The form for patients, caregivers, and advocacy groups was also translated into Spanish, Korean, Vietnamese, and Chinese.

The feedback forms were designed to encourage people to provide voluntary information about the prescription drugs they take, prescribe, manage, or research. This information will inform board members as they conduct their drug reviews. Board members and staff members promoted the

feedback forms during the community forums and the entire consumer outreach project. The forms are posted on the PDAB website and will be open until August 2026. This is the second year PDAB has provided feedback forms about medications on the drug review list.



PDAB's community forum on May 6 was held at the Redmond Library.

As of June 5, the board has received 31 responses from patients, caregivers, and patient advocates about Jardiance, Mounjaro, Ozempic, and Humulin (drugs that treat diabetes), and one response each for Xeljanz and Skyrizi (drugs that treat autoimmune conditions). The following are patient and caregiver comments about these medications, edited for readability, length and to protect patient privacy:

Jardiance

- I ended up not filling my prescription after insurance denied coverage and the out-of-pocket cost is approximately $500/month. My doctor thought this was an important drug for me to try but insurance denial made it unaffordable. Should insurance make these decisions?
- Cost was quoted at $2,000 for a 3-month supply, or $8,000 per year. That isn't affordable for someone on a fixed income from Social Security."
- Very expensive if purchased from U.S. pharmacies. I order from Canada at great cost savings.

Humulin

- Most of our issues with this medication came during a change in insurance coverage. Why does a medication that costs less than $5 to manufacture per 10 ml vial cost over $1,700 for a month's supply of 2-4 packs of pens? The issue is how did we build a system that cares so little about people's health in comparison to the profit margin and yearly bonuses. We need to do better. Hold pharmaceutical companies accountable.

Mounjaro

- I am taking tirzepatide for therapy for Type 1 diabetes as well as heart and kidney disease, and it is an amazing medication. Because it is not approved for Type 1 dm (diabetes mellitus), my doctor did not even try to get it through insurance, so I pay $399 and it lasts about 3 months as

I am microdosing, which works well. It should be approved for treatment of Type 1 dm if one's medical provider assesses that it is an important medication to take. Hopefully this will happen in the near future.

- Currently, the monthly (4 weeks) medication takes 1/2 of my monthly income.
- Mounjaro is for people who are morbidly obese or who have metabolic issues or who have addiction or a lot of other prescribed uses. The cheapest I can get is $500/mo. It's not optional; I have to take it or be too sick to live.
- Medicare doesn't cover this medication for my health issue, and it costs me over $700 per month using a pharmacy coupon.
- The monthly cost of this medication is a major stressor on my limited income. Health insurance covered tirzepatide as a Tier 2 medication on the drug formulary for my diagnosis, even if at this time it's considered off-label use for acquired hypothalamic obesity.
- I had to choose between my prescription of tirzepatide and health insurance. I am retired and not yet Medicare age. Because I no longer qualify for tax break subsidies, I can't afford $800 a month for marketplace insurance and my current prescription that costs $450 a month. I had to cancel my insurance policy and switch to a health share company. If insurance is not going to cover it, it needs to be affordable for all. It is literally saving lives. I have eliminated these comorbidities on the drug: fatty liver disease; prediabetes; obesity; and high blood pressure.
- My dose has been increased, so my cost is going up, and I currently have family helping me pay, but they all have expenses of their own. It might come to the point where I have to stop taking this medication.
- I can't afford to even begin taking this medicine.
- The problem with this drug is access, not so much cost. My doctor gave me a fake diagnosis to get this drug. When we first tried to get my insurance to pay for this drug, insurance denied it. The doctor provided an appeal, and then I was given access to the medication.
- My insurance paid for Mounjaro for a year and then stopped paying for the medication because it was not covered for weight management. I had to switch to the Zepbound version using the manufacturer coupon at $600/month and now Lilly direct at $449/month. I have Acquired Hypothalamic Obesity (AHO), and this medication is the first treatment that works. I've lost 95 pounds and have been able to maintain my weight for over 2 years for the first time in 30 plus years.

Ozempic

- (The) pharmacy employee was not clear on why (my) copay increased $400 for (a) three-month supply. I contacted my insurance company for a better explanation. Advance notice of the copay increase would have been appreciated.
- If I didn't qualify for both the patient assistance program and my insurance company covering the cost of the copay, I would not be able to take this medication.

- I saw Wegovy pills for $25 a month, but Medicare patients have to pay $199 to $399 a month. Add the cost of my Medicare to that, and it is cheaper to get Ozempic outside the USA.
- I need a hip replacement and need to lose weight to get the surgery, and I have been approved through my PCP (primary care provider) for the medicine. OHP (Oregon Health Plan) (said it) will not cover the medication to save my life.
- I can't get on GLP-1 meds because chronic pain isn't a qualifying reason to be prescribed the medication even though clearly 240 pounds with a lumbar fusion is not going to be good for pain. OHP doesn't cover it because I don't have diabetes.
- My doctor has since called in a Wegovy prescription to try to get the weight off due to high blood pressure hypertension and degenerative disc disease, and the insurance still will not approve it, even with cardiac risk.

Skyrizi

- I could not afford this drug without the cap of $2,000 co-pay. Otherwise it would cost $17,000 per year.

Xeljanz

- The only time this medication was hard to access was when the insurance company kept "forgetting" to apply my copay card. They sent a bill saying I owed $5,800. Had I not known better, I would have thought I couldn't afford this drug

Conclusion and recommendations

As outlined in the outreach strategy section of this report, PDAB staff members engaged in extensive outreach efforts to make Oregonians aware of the community forums. These efforts began in early February and continued through April and May. This multipronged strategy included in-person meetings, postal mailings, email notifications, radio and print advertising, social media promotion, and media releases.

Several participants at the forums indicated they heard about the event through PDAB's outreach efforts, including radio announcements, emails, and notification from organizations such as the American Cancer Society. While additional outreach efforts could have been made, the low attendance at the forums was not primarily the result of poor promotion. PDAB should explore a different approach to engaging Oregonians.

The strategy for this year's community forums was to hold the events after the board had determined the list of prescription drugs to be reviewed in 2026. The structure was similar to PDAB's 2024 outreach project, with PDAB both organizing and being the primary presenter at the forums. The forums were held during a five-week period, with the goal of hearing from patients and consumers who were taking the prescription drugs under review to give the board additional input during the review process.

Patients and consumers who were experiencing challenges with drugs not currently under review were also encouraged to share their stories.

In addition to the logistical challenges for staff, the schedule of eight events in five weeks (including the May board meeting) did not achieve the desired results. Input on the drugs under review was slight. Several factors may have contributed to the low turnout at the forums. These could include date and time selection as well as location. However, in speaking with community members as well as state agency and nonprofit outreach staff, expecting significant numbers of consumers and patients to attend a forum with a single focus may be overly optimistic. For these reasons, staff recommend that PDAB use a different strategy for future community outreach efforts. The following five tactics may guide future PDAB outreach efforts.

1. **Provide a limited number of PDAB-sponsored online community forums.**

Giving Oregonians the opportunity to provide the board input at the beginning of the annual drug review should continue to be an important element of the process. This provides the board with timely feedback about the financial challenges patients and consumers are having with the drugs under review. However, as stated above, the seven forums and one online board meeting produced limited input on the drugs under review compared to the staff time and resources needed to host these events.

Recommendation: Sponsor two online forums and dedicate an online board meeting for public input near the beginning of the board's annual drug review.

2. **Partner with community organizations and state and local agencies to identify opportunities to engage Oregonians throughout the year.**

There are numerous opportunities for PDAB to attend existing events and connect with Oregonians about the high cost of prescription drugs. Some of these events are health-related, while others may be focused on specific communities that may have specific health needs.

Recommendation: In coordination with outside organizations and DFR outreach staff members, create an annual calendar to identify existing events where PDAB representatives can be present to engage Oregonians.

3. **Consider the creation of a "speaker's bureau" with the PDAB executive director and board members.**

A positive outcome from this year's forums was the connection with several representatives from patient support groups. In addition, PDAB staff members have been in contact with several hospital systems to learn about their patient support groups. There may be opportunities to be present at meetings of patient support and civic groups. While the availability of board members and the

executive director is limited, attendance at a small number of events throughout the year is another opportunity to increase visibility and feedback.

Recommendation: Advertise the availability of the executive director and board members to discuss PDAB and its work at community events. Develop an internal process for staff members to efficiently respond to speaking requests and provide support to members speaking about PDAB's work.

4. Continue to engage with pharmacists, medical clinics, and advocacy groups.

During the two series of forums that PDAB has hosted (in 2024 and 2026), pharmacists, medical professionals, and advocacy groups have provided valuable feedback to inform the board's work. Pharmacists and medical providers see the effects of the high cost of prescription drugs daily. Advocacy groups communicate with their members regularly. PDAB should make use of these resources in its outreach efforts.

Recommendation: Continue to notify pharmacies, medical clinics, professional organizations, and advocacy groups directly with mailings and emails. Maintain and expand the PDAB email distribution list, currently distributed using the GovDelivery platform. During the drug review period, provide feedback forms in the mailings to make them available for consumers, patients, and members of advocacy organizations.

5. View consumer feedback as a year-round process.

The purpose of the feedback forms has been to inform the board as it conducts annual reviews of specific drugs. While this is a critical element to the review process, giving Oregonians the opportunity to provide both structured and open-ended input year-round can provide the board with additional valuable input. As PDAB changes its outreach strategy beyond its sponsored forums, having accessible feedback platforms and a system to compile and publish results will give patients and consumers additional assurance that their voices will be heard throughout the year.

Recommendation: Make a general feedback form for consumers available at public events and online year-round. The feedback form could combine structured and open-ended responses and be optimized for ease of use with an accessible reading level.

Appendix – Event summaries

The Oregon Prescription Drug Affordability Board (PDAB) hosted online and in-person community forums in April and May 2026 to hear from patients, caregivers, and others about how medication costs affect their daily lives, finances, and communities. At the forums, board members introduced themselves. Executive Director Sarah Young and Consumer Engagement Coordinator Lou Savage also gave a short **presentation** about PDAB, which included who serves on it, its annual legislative report, how it reviews prescription drugs, the prescription drugs under review for 2026, and the role of the Drug Price Transparency Program. Maggie Alvarez, Charlie Wente, and Veronica Murray of the Oregon Department of Consumer and Business Services' Division of Financial Regulation attended the meetings to provide consumer resources. After the presentation, audience members were invited to speak. The following are summaries of the community forums:

Online April 28, 7 p.m.

Guests in attendance: Eric Lohnes, PhRMA; Rebecca McAuliffe, Quinn Thomas Public Affairs; Mark Jackson, Portland pastor; Joe Gardner, Gardner and Gardner, and PhRMA lobbyist; Sara Kofman, Eli Lilly and Company; Jennifer Olson, PeaceHealth; Lee Bliven II, AARP; Lorren Sandt, Caring Ambassadors Program; Matt (no last name given); and three people who called in by telephone but did not identify themselves.

Board members in attendance: Chris Laman, PharmD, MBA; and Lauri Hoagland, NP.

Juan De León, of Professional Interpreters, provided Spanish-language interpretation.

Consumer testimony:

Lee Bliven II, a volunteer with AARP, said he represents older Oregonians. He and his wife, who is medically fragile, take several prescription drugs. According to their recent Medicare Part D statement, his wife's medication cost was $11,000 so far this year. They receive help to pay for prescriptions because his wife is a member of the Cowlitz Indian Tribe. Without the extra help, they would not be able to survive financially. Many older adults choose between paying bills, buying food, paying for housing, or buying medications, he said. The board needs to support the older adult population by managing these outstanding drug prices. He asked the board to please do its best to help regulate "these terrible drug prices."

Mark Jackson serves as a local pastor in the Portland metro area and speaks for the community he serves. He sees within the Black community tremendous and increased concern about prescription drug affordability. He said folks, especially seniors, are making difficult decisions about how to stretch their dollars. He asked what is the board doing to aggressively engage with communities of color to hear their stories; to help the communities learn more

about the board's work; and to affirm and validate the communities' experiences and voices. He said the data shows, when it comes to drug affordability, tremendous disparities in low-income communities and in communities of color. He said what has been very impactful with communities of color, including the African American community, is to come into the community in partnership with trusted entities. Jackson asked if the board has a strategy to partner with Black-led organizations or houses of worship to intentionally and authentically get buy-in from the community. He said community engagement would build trust, elevate community voices around storytelling, and help inform recommendations to the Oregon Legislature.

Sarah Young and **Lou Savage** shared contact information and invited Jackson to reach out and discuss ideas for community engagement.

Lorren Sandt, of the Caring Ambassadors Program, thanked the board for holding the public forums. She said the board should not review cancer drugs, including Keytruda, because people who have cancer are medically fragile. Treatment should be a question between the doctor and patient. She also asked the board not to ignore Keytruda's orphan drug designation because cancer patients don't have a lot of options. She asked the board to think about what may be the outcome of changes to drug access for people living with cancer.

Sandt also shared her personal experience of trying to fill a prescription using her insurance plan but the pharmacy recommended instead using ArrayRx, the Oregon prescription discount program. The drug cost her $28 with ArrayRx versus $450 if filled through insurance. She asked why not make ArrayRx available for all Oregonians as a solution to high prescription drug costs.

Salem Library, May 5, 5 p.m.

Guests in attendance: Rebecca McAuliffe, Quinn Thomas Public Affairs; Matt Markee, Markee & Associates and lobbyist for PhRMA and Bristol Myers Squibb; Joe Gardner, Gardner and Gardner and PhRMA lobbyist; Amber Grant, Pill Box Pharmacy in Silverton; Melanie Zerner, KMUZ community radio; Lorren Sandt, Caring Ambassadors Program; and Rachel Peterson, Pacific Northwest Bleeding Disorders.

Board member in attendance: Michele Koder, PharmD.

Consumer testimony:

Amber Grant, of Pill Box Pharmacy in Silverton, received a letter from PDAB about the community forums. She asked how PDAB's work could bring about prescription drug affordability. PDAB Executive Director **Sarah Young** said the board makes policy recommendations to the Oregon Legislature that can help make prescription drugs more affordable.

Melanie Zerner, with KMUZ community radio, asked about the difference between

PDAB and the Drug Price Transparency (DPT) Program. Young said DPT collects data from manufacturers, insurers, and pharmacy benefit managers, while PDAB members use the data in reviewing prescription drugs each year. Zerner then asked about ArrayRx. Young said the State of Oregon offers discount cards through ArrayRx, but not all medications have discounts in the program.

Lorren Sandt, of the Caring Ambassadors Program, asked how long the feedback form would be open, and Young said it would be open through the end of August.

Redmond Library, May 6, 5 p.m.

Guests in attendance: Rebecca McAuliffe, Quinn Thomas Public Affairs; Erin Daugherty, RN, BSN, and rare disease advocate of Elevate Rare; Kevin Daugherty, Oregon Commission for the Blind; Kevin Russell, St. Charles Medical Center; and Carissa Kemp, Sanofi.

Board member in attendance: Chairperson Shelley Bailey, MBA.

Eusebio Castillo and Martin Conta of TransPerfect were available to provide Spanish interpretation.

Consumer testimony:

Erin Daugherty is a nurse and board member of Elevate Rare, a rare-disease advocacy nonprofit. She is a patient living with a complex, rare disease called Ehlers-Danlos syndrome. She estimates 420,000 Oregonians live with a rare or complex disease. She manages 15 routine and six as-needed medications. She has insurance, but it does not cover all the medication costs. For example, her insurance company won't cover her prescription for 40 mg of Nexium two to three times daily. The company denied coverage because Nexium is available over the counter at 20 mg. She said this creates a pill burden with her taking 120 to 180 pills a month with the over-the-counter medication versus taking 60 to 90 pills with the prescribed medication.

Daugherty also takes Zepbound, which has eliminated episodes of anaphylaxis and emergency room visits for low blood pressure. To afford the $400 monthly cost, she takes half the prescribed dose, which she said is a dangerous but necessary compromise. She is not taking Xolair because of the cost barrier created by insurance denial. She said Xolair is approved by peer-reviewed literature for mast cell disease, yet only Food and Drug Administration-approved for one type (the skin type). Daugherty said Xolair works directly to downregulate mast cells, so this approval should not be considered a wild, off-label use for a biopsy-proven condition. She said the ultimate irony is, if her esophagus worsens, her insurance will cover the surgery to fix it and possibly a high-cost surgical feeding tube and lifelong enteral nutrition. Her insurance company prefers to pay for the catastrophe rather than the prevention, she said.

Oregon law requires medications to be covered if they are an accepted standard of

care, even if off label. Yet the burden of enforcement falls on the consumer. Until there is a route to report these denials that result in immediate fines higher than the cost of the drug being denied, insurers will continue to operate as financial entities rather than healthcare partners. One denial letter should be all the evidence needed for action.

Read the **submitted letter** on the PDAB website.

PDAB Chairperson **Shelley Bailey** shared resources for shopping for better medication prices, including using Cost Plus Drugs.

Veronica Murray, of the Oregon Division of Financial Regulation, said her doctor prescribed a very effective medication for her asthma eight years ago. After a recent medical visit and an added chart note about her asthma being under control, her insurance company refused to pay for the medication. She had to pay $500 out of pocket until her doctor wrote a letter to the insurance company about the reason for the prescription, and coverage was reinstated. She said people can easily get lost in the system.

Kevin Russell, who manages outpatient pharmacies for St. Charles Medical Center in Bend, said people don't have access to the drugs they need, which causes more health problems. "People become lost in the system, and they are not taking their medications; we have a complex, fragmented healthcare system," he said.

Russell gave the example of the manufacturer coupon program for Mounjaro and Ozempic, which ended in 2025. Hundreds of people took these drugs to stabilize their diabetes. With the program ending, these people lost access to Mounjaro and Ozempic because they couldn't afford the medication cost without the manufacturer coupons. St. Charles Medical Center scrambled to help patients, and it leveraged a 340B program. After the hospital completed the administrative work for this program, the manufacturer began offering the coupon again. If manufacturers are going to have patient assistance programs, they shouldn't be able to terminate the program without letting people know, Russell said. "It is incredibly complex; we have doctors trying to provide advocacy so their patients can receive the medications they need," he said.

Online May 11, 12 p.m.

Guests in attendance: Gail Menasco, of central Oregon; Eric Lohnes, PhRMA; Robbie (no last name given); Sage Johnson, Oregon Consumer Justice; Arcadi Kolchak, AbbVie; Katey Tryon, with Rep. Emily McIntire's office; Mychal Amos, director of pharmacy with Sky Lakes Medical Center; Samantha Muir, a pharmacist with Sky Lakes Medical Center; Jonathan DiBello, Manatt, Phelps, and Phillips LLP; Joe Gardner, Gardner and Gardner Attorneys and PhRMA lobbyist; Thomas Cuomo, Oregon lobbyist with Bristol Myers Squibb and PhRMA; Jennifer Olson, Oregon lobbyist with Eli Lilly and Company and PhRMA; Juliana Borrazzo,

Sarepta Therapeutics; and Sara Kofman, Biogen.

Board members in attendance: Chairperson Shelley Bailey, MBA; and Michele Koder, PharmD.

Aida Mendoza and Felipe Dorantes Ramirez of TransPerfect were available to provide Spanish interpretation.

Consumer testimony:

Gail Menasco, of central Oregon, thanked the board for providing this forum to share experiences. She has an individual Affordable Care Act plan through an insurance company. She wanted to raise a patient transparency issue. The week before she gave her testimony, Menasco tried to pick up mefenamic acid when her physician prescribed it after exhausting other options. She had met her out-of-pocket maximum of $7,500 and expected the medication to be covered at $0. Instead, she was told at the pharmacy that insurance denied it because the "formulary wasn't covered," and that it would be $60 per month.

No one told her the next actionable step. The denial did not clearly say that this could be addressed through prior authorization or a formulary exception. She had to call her insurance company, speak to multiple people, and keep pushing before learning her doctor could submit a prior authorization form and that it could potentially be approved within a few days.

Menasco emphasized that her experience is a transparency failure. She said patients should not have to know the magic words or make multiple calls just to find out whether a denial is final, whether a prior authorization is available, what form is needed, or who must submit it.

She encouraged Oregon to consider stronger denial-notice transparency requirements from health plans for prescription drugs. A denial should clearly state: the specific reason for denial; whether prior authorization, step therapy, or a formulary exception is available; what the prescriber must submit; the expected timeline; covered alternatives, if any; and appeal or external review rights. Other states have moved in this direction including California, Colorado, and New York.

"This is a fixable policy issue. A patient should not leave the pharmacy thinking a medication is simply 'not covered' when there is a defined pathway to request coverage," Menasco said.

Read the **submitted letter** on the PDAB website.

Sage Johnson, of Oregon Consumer Justice, asked how PDAB's scope could be changed to have fewer limitations than other states. PDAB Executive Director **Sarah Young** said PDAB is established in state law by the Oregon Legislature and changes in scope and authority would have to be made by the Legislature and governor.

Asian Health & Service Center, Portland, May 12, 6 p.m.

Guests in attendance: Dan Valliere, associate director of Asian Health & Service Center; Charlie Fisher, director of OSPIRG; Eric Lohnes, PhRMA; Lorren Sandt, Caring Ambassadors Program; Sage Johnson, Oregon Consumer Justice; Joe Gardner, Gardner and Gardner and PhRMA lobbyist; and Sara Kofman, Eli Lilly and Company.

Board member in attendance: Chairperson Shelley Bailey, MBA.

Interpreters Stephanie Li, Sunghui Coplon, and Mychi Doan were available for Mandarin, Korean, and Vietnamese languages.

Consumer testimony:

Charlie Fisher, director of OSPIRG, said the advocacy group commissioned a **survey** about healthcare in 2023. The survey showed 3 of 4 Oregonians were concerned about the cost of healthcare. He said many Oregonians pay high premiums, high deductibles, and copays in the hundreds or thousands of dollars for a month's supply. These medications are for conditions such as autoimmune diseases, antidepressants, and cancer, and people are skipping doses. One person cited in the survey said, "I lose sleep when a family member needs a new prescription." It's important for the public to have their voices heard, Fisher said. PDAB needs to shine a light on this problem, and an upper payment limit policy is needed, he said.

Dan Valliere, associate director of the Asian Health & Service Center, asked how the board's review **list of medications** was put together. He also asked what if people would like to comment about another drug that is not on the list. PDAB Executive Director **Sarah Young** and Chairperson **Shelley Bailey** explained the board's drug review process. They said comments about drugs not on the list could shape the board's approach in future drug review processes. They encouraged people to share their stories about any medication with the board. People can share in several ways: write a letter or send a comment to the board; speak at a board meeting or community forum; or fill out a feedback form.

Sage Johnson, of Oregon Consumer Justice, asked about policy recommendations related to the drugs the board determined to be unaffordable and included in the drug review report issued in March 2026. PDAB staff members talked about the board's policy recommendations published in that **drug review report**.

Lorren Sandt, of the Caring Ambassadors Program, asked if the board's recommendation for point-of-sale rebates would be a policy applied to all drugs or only the drugs on the list. Young said the recommendation approved by the board was specific to the drugs the board identified with affordability challenges.

Online May 13, 6:30 p.m.

Guests in attendance: Rep. Emily McIntire, Oregon District 56. (Eric Lohne, PhRMA; and Rebecca McAuliffe, Quinn Thomas Public Affairs, joined briefly but left the meeting soon after it started.)

Board members in attendance: John Murray, RPH. (Lauri Hoagland, NP, left the meeting after five minutes due to a schedule conflict.)

Felipe of TransPerfect Interpreters was available to provide Spanish interpretation.

Discussion

Board member **John Murray** said half the drugs he dispenses in a day at his pharmacy are unaffordable. Murray said he wants to look at what other states are doing with positive results. For example, with Ohio's single-payer Medicaid plan, the state has gone from having a pharmacy access problem to having every pharmacy provide services to people with the greatest needs. Murray said Oregon is ranked number two nationally with the fewest pharmacies per capita.

Rep. Emily McIntire, Oregon District 56, thanked the board for its work and said she would be interested in hearing an update. She said prescriptions, costs, and reimbursements to the pharmacy are all part of the problem. **Cortnee Whitlock**, senior policy analyst for PDAB, said the board is unable to view manufacturer trade secret information confidentially in closed meetings because Oregon's public meetings law allows the media to attend executive sessions. McIntire suggested that the board seek a limited exclusion for once a year or for an emergency. She said not being able to review manufacturer trade secret information confidentially sounds like a missing piece that makes it difficult to determine how much a drug costs.

Beaverton Library, May 18, 5 p.m.

Guests in attendance: Rebecca McAuliffe, Quinn Thomas Public Affairs; Joe Gardner, Gardner and Gardner, PhRMA lobbyist; Sara Kofman, Eli Lilly; Lorren Sandt, Caring Ambassadors Program; Young Ki Park; Young Soon Park; Greg Dardis, Kaleidoscope Fighting Lupus; Kyssandra Myriad, Eugene-Springfield area; and Vicki Schmall, AARP.

Board members in attendance: Vice Chairperson Daniel Hartung, Pharm D; and Daniel Kennedy, RPH.

Consumer testimony:

Kyssandra Myriad, of the Eugene-Springfield area, shared a personal experience of going to the pharmacy on a Friday to pick up a prescription and being told it was unavailable and that she needed a prior authorization. She had been on the medication since 2021 and didn't understand why a prior authorization was needed. The doctor put in a prior authorization on Monday but with the processing time, she went five days without the medication. She said this delay caused a significant health setback. She is concerned

about the many people who are not getting the help they need because of the stress involved in navigating insurance processes.

Board member **Daniel Kennedy** said he was diagnosed with cancer in 2019 and his infusions would have cost $400 every three weeks without health insurance. It would have bankrupted his family. When he worked as a pharmacist, he saw people who had to choose between medications and bankruptcy. He shared information about the Pharmacy Foundation of Oregon, which is working to put pharmacy lockers in remote towns on the coast, in eastern Oregon, and southern Oregon.

Vicki Schmall, representing AARP, said she is thankful for medication that works well. She was diagnosed with multiple sclerosis 40 years ago. For the past 10 years, Schmall has been taking Amantadine, which has been a highly effective treatment for her. She has also worked for 50 years with older adults in Oregon and family caregivers. She has seen older adults struggle to pay for prescription medications, with some taking less medication than prescribed, skipping doses, or delaying refills due to cost. She said affordable prescriptions are very important to the health and well-being of older adults, who are challenged with the cost of medication and putting food on the table. Schmall said AARP recommends these actions: empower PDAB to set fair payment limits on drugs based on prices in other countries or the Medicare-negotiated maximum fair price, ensuring affordability for all payers in Oregon; use buying power across states or agencies to negotiate lower drug prices; save money for consumers by making it easier for pharmacists to substitute less expensive biosimilar drugs for biologic drugs in the same way generic drugs are substituted for brand-name drugs.

Board Vice Chairperson **Daniel Hartung** said his research at Oregon State University involves multiple sclerosis, so he understands the importance of medications.

Lorren Sandt, of the Caring Ambassadors Program, said the state needs an insurance transparency board to look at the other side of the picture.

Young Ki Park said he had been on a medication for five years when his insurance company announced it would no longer pay for it. He also gave the example of having open heart surgery and not paying one penny because of good health insurance coverage, in contrast to this experience with medication.

Greg Dardis, of Kaleidoscope Fighting Lupus, said many of the medications treating lupus are used off label. He discussed partnering with PDAB for future consumer outreach efforts.

Find the community forum handouts on the PDAB website:

- **Slideshow: PDAB community forums 2026**
- **What is Oregon PDAB**
- **Drug review schedule 2026**
- **Consumer resources 2026**