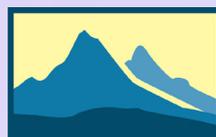


# Consumer Outreach Report

Prescription Drug Affordability Board  
June 17, 2024



Oregon Prescription Drug  
Affordability Board

## **Board members**

Shelley Bailey, chair

Dr. Amy Burns, vice chair

Dr. Dan Hartung

Robert Judge

Dr. Christopher Laman

John Murray

Akil Patterson

## **For more information:**

Prescription Drug Affordability Board

350 Winter St. NE

Salem, OR 97309-0405

971-374-3724

[pdab@dcbs.oregon.gov](mailto:pdab@dcbs.oregon.gov)

[dfr.oregon.gov/pdab](https://dfr.oregon.gov/pdab)

## **Acknowledgments**

This report was prepared by the following Prescription Drug Affordability Board staff:

**Ralph Magrish**, executive director

**Lou Savage**, past director of the Department of Consumer and Business Services and past insurance commissioner of Oregon

**Melissa Stiles**, administrative specialist

**Cortnee Whitlock**, program and policy analyst

**Stephen Kooyman**, project manager

Other contributors of this report:

**Jason Horton**, public information officer, DCBS

**Michael Plett**, communications officer/editor, DCBS

**Jessica Knecht**, lead designer, DCBS

Board participants in the consumer outreach forums:

**Shelley Bailey**, chair

**Dr. Amy Burns**, vice chair

# Table of contents

---

<b>Acknowledgments</b> .....	<b>2</b>
<b>Executive summary</b> .....	<b>4</b>
<b>PDAB mission: seek consumer input</b> .....	<b>6</b>
<b>Community forum structure</b> .....	<b>7</b>
<b>Takeaways and observations</b> .....	<b>9</b>
<b>Recommendations</b> .....	<b>10</b>
<b>Conclusion</b> .....	<b>11</b>
<b>Appendix A – Event summaries</b> .....	<b>12</b>
Portland.....	12
Lincoln City.....	13
Woodburn.....	14
Medford.....	15
Bend.....	16
Online May 8, 2024.....	17
Online May 14, 2024 .....	21
<b>Appendix B – Survey and summary</b> .....	<b>23</b>
<b>Appendix C – Media coverage</b> .....	<b>26</b>
<b>Appendix D – PowerPoint presentation</b> .....	<b>26</b>
<b>Appendix E – Community forum videos</b> .....	<b>26</b>

## Executive summary



The Prescription Drug Affordability Board (PDAB) hosted in-person and online community forums across Oregon to discuss the high cost of prescription drugs and its effect on Oregonians' lives, health, and budgets. The board held events in five cities, along with two online meetings in April and May. About 156 people attended the sessions held in Portland, Lincoln City, Woodburn, Medford, Bend, and online through Zoom. Board and staff members listened to 28 people describe how they skip medications because they cannot afford them, battle insurance companies over prescription coverage, and struggle to find medications that are in short supply.

**Event summaries, survey results, video links, and media coverage are included in Appendices A-E of this report. This report is also posted on the [PDAB website](#).**

Also, the board invited people to take a survey about medication names and costs, along with insurance coverage. Fifteen people completed the survey. PDAB Chairperson Shelley Bailey and Vice

Chairperson Amy Burns attended several events and spoke about the board's goal in wanting to hear from consumers. Bailey and Burns both have pharmacy backgrounds and answered questions and provided resources for consumers throughout the events.

*"We don't have insurance coverage. My husband and myself are both working. He is sick and needs medicine. It is very expensive because we also need to pay for rent and other bills. He needs his medication every three months. We look for the most economical brands so we can buy them. It's hard for us. Most of us work in the fields for very little money. If we need cholesterol medicine or high blood pressure medicine, even with coverage, copays are high."*

*– Patricia M., Woodburn resident*

Some highlights of the consumer stories included a participant in Woodburn, speaking through an interpreter, who talked about her family's \$560 monthly prescription drug costs for her husband's health conditions. The participant said she and her husband both work in the fields for low wages and are unable to afford the medications. Also, a nurse practitioner in Medford and a health care worker in Baker City both described patients skipping unaffordable medications followed by a visit to the emergency room in a health crisis. They said this situation is dangerous for the patient and costly to the health system. A multiple sclerosis patient from Albany said his \$7,000 monthly medication cost puts a tremendous financial strain on his family. A Medford woman said her brother cannot get the diabetes medication that works best for his body due to its high cost.

*"Jardiance is incredibly expensive: \$42 for 30 pills. It is very effective and keeps my blood sugar under control and helped me lose weight. It is also in short supply. Sometimes I must wait two weeks for my medication."*

*– Susan W., Lincoln City resident*

The stories told at the community forums represent what is happening across the state: Medication costs are burdensome for Oregonians. Consumers experience uncertainty about the cost of their prescription drugs and about the ability to access prescriptions. Consumers are confused about how much they will need to pay for their prescription drugs. They also expressed anxiety about the future.

For its next steps, the board will engage with consumers throughout the year, target its outreach to existing community events, and publicize future events well in advance.



## PDAB mission: seek consumer input

---



The Oregon Legislature established PDAB in 2021 through Senate Bill 844. The board's mission is to protect Oregonians and health systems from the high cost of prescription drugs. There are eight members with backgrounds in clinical medicine or health care economics, appointed by the governor and confirmed by the Oregon Senate. One way the board accomplishes its mission is through affordability reviews, which are rigorous studies of the most costly drugs in the state based on criteria in the Oregon Administrative Rules. The Legislature asked the board to narrow the list of costly drugs down to nine, plus at least one insulin product, and present a list each

year. The board's first affordability review process is taking place May through November 2024.

In 2023, the Oregon Legislature expanded the board's mission through Senate Bill 192 to "develop a plan for establishing upper payment limits on drugs sold in this state that are subject to affordability reviews under ORS 646A.694." The Legislature said the plan should include outreach to consumers and others. To fulfill its mandate, the board launched outreach components to hospitals, pharmacies, insurance companies, manufacturers, pharmacy benefit managers, advocacy groups, and consumers.

## Community forum structure

For the community forums, the board selected locations around the state in venues that were centrally located and easily accessible to the public. Here was the schedule:

### In person:

- Portland – Tuesday, April 2, 6-8 p.m., Portland State Office Building
- Lincoln City – Tuesday, April 9, 6-8 p.m., Cultural Center
- Woodburn – Monday, April 15, 5-7 p.m., Woodburn Public Library
- Medford – Thursday, April 25, 6-8 p.m., Rogue Community College Higher Education Center
- Bend – Tuesday, April 30, 6-8 p.m., East Bend Library

### Online:

- Wednesday, May 8, noon to 2 p.m., via Zoom
- Tuesday, May 14, 6-8 p.m., via Zoom

The board provided Spanish interpretation at the Woodburn and online events to encourage more participants from the Spanish-speaking communities. An estimated 9 percent of Oregonians speak Spanish at home, according to the Oregon Office of Economic Analysis.<sup>1</sup> The board also provided American Sign Language interpretation in Medford and at the online meetings to encourage members of the Oregon Deaf community to participate. Three participants at the Medford meeting were from the Deaf community, including one who is a member of the Oregon Disability Commission. There was one participant from the Deaf community at the May 14 online forum.

The board sent a media release providing details

*“Rebif is very expensive. It costs about \$7,000 a month without any kind of help. And the insurance does not cover that much. So that has been a challenge. As we like to say in my household, we’re on a fixed income, and they fixed it good.”*

*– Michael T., Albany resident and multiple sclerosis patient*

about the events to Oregon newspapers, radio stations, and TV newsrooms. In addition, PDAB sent out this information on its social media platforms. In response, the Rogue Valley Times posted an article about the Medford event, and KDRV-TV featured an interview with the PDAB vice chairperson. The Bend Bulletin included the Bend event and the online meetings in its community calendar. See Appendix B.



**Come share your story in April and May about how medication costs have affected you**

[dfr.oregon.gov/pdab](https://dfr.oregon.gov/pdab)



<sup>1</sup> Hispanic Heritage Month 2019: A Profile of Hispanic Population in Oregon. Oregon Office of Economic Analysis and the U.S. Census Bureau, 2019. [https://www.oregon.gov/das/oea/documents/hispanic\\_heritage\\_month\\_2019\\_oregon.pdf](https://www.oregon.gov/das/oea/documents/hispanic_heritage_month_2019_oregon.pdf). Accessed May 17, 2024.

*"I think those prescription drug prices are very hard. It makes a difference in what I can afford and what I cannot. I just think there should be a better way."*

*– Jim H., 77, Portland*

For the meeting format, moderator Lou Savage, a past director of the Department of Consumer and Business Services and a former Oregon insurance commissioner, started the meeting with an overview and PowerPoint presentation. Savage talked about the board's mission and accomplishments, including the board's recommendation to the Legislature that resulted in a \$35 monthly cap on insulin medication. He explained that an upper payment limit is a limit on what purchasers in Oregon would pay for specific drugs. He emphasized the board does not have the authority to create upper payment limits, but the board is studying the option at the direction of the Legislature. He also discussed some of the opinions about why prescription drug costs are high, such as co-pay coupons, patents, and pharmacy benefit manager practices.

The PDAB chairperson spoke at the meetings in Portland, Woodburn, and online, telling guests about her work as a co-owner of a Portland pharmacy. She also shared her passion for serving on the board and finding ways to make prescriptions affordable. She encouraged guests to share their stories. The PDAB vice chairperson, a pharmacist in Grants Pass, welcomed participants at the Medford meeting and encouraged people to speak, knowing their stories will likely resonate with others in the room. At the conclusion of the overview, Savage invited participants to share their stories, with the suggestion they consider these three questions:

- How has the cost of your prescription drugs affected you or your household?

- Do you feel you can follow your medical treatment plan for your condition with the cost of your prescription drug(s)?
- Do you, or have you had to, switch your Rx due to insurance coverage?

A total of 28 people shared their stories during the seven events. Their stories are summarized in Appendix A of this report. At each forum, the board chairperson, vice chairperson or staff members provided feedback and ways to help solve immediate needs. For example, the board chairperson provided a local clinic name to a Woodburn family struggling to pay for blood pressure, cholesterol, and diabetes medications. The board vice chairperson encouraged a Medford patient who was having trouble getting the right inhaler to talk to her provider about the prescription.

The meetings ended with Savage sharing a list of prescription drugs the board will be reviewing this year with the participants and inviting them to attend board meetings and submit public comment. The comment can be about the cost of any prescription drugs that are creating financial challenges for people, not just the drugs on the board review list, he said. He also invited people to take the community forum survey about medications and costs.



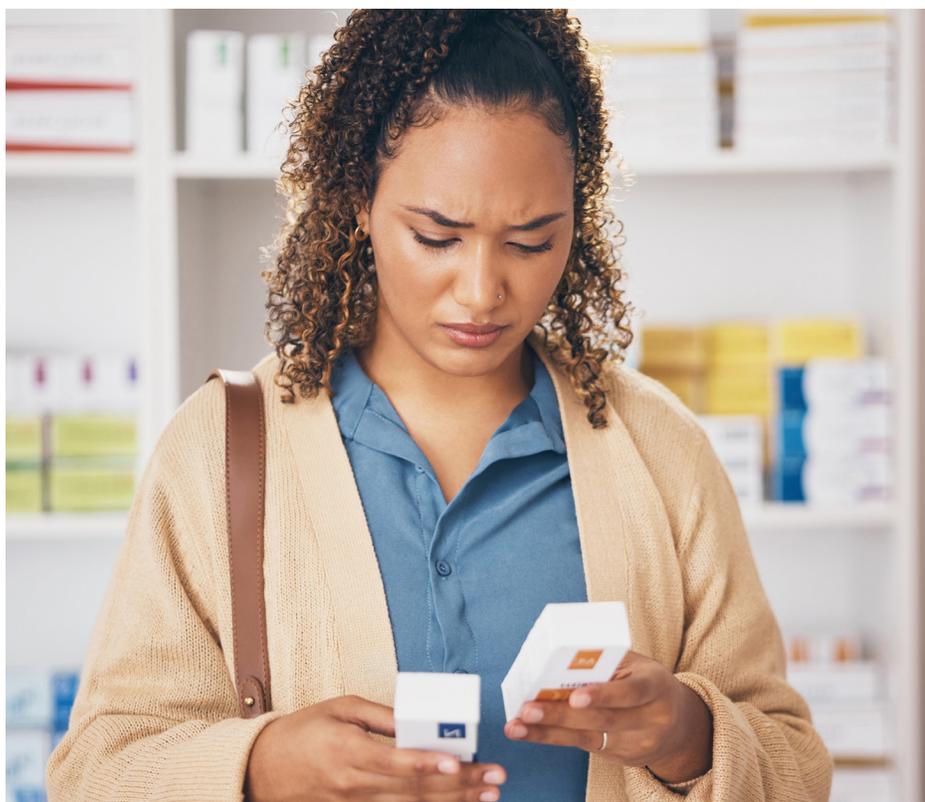
## Takeaways and observations

The consumers and advocates who shared their stories at the forums about their challenges with the cost of prescription drugs had a wide range of experiences; however, some common themes came through. Consumers are experiencing uncertainty, confusion, and anxiety about being able to afford and have access to the prescription drugs needed to maintain their health.

**Consumers experience uncertainty with the cost of their prescription drugs.** Consumers expressed concern that insurance coverage for certain drugs can change. When the out-of-pocket cost changes, it can have a significant effect. Consumers also expressed uncertainty about what financial assistance programs are available for high-cost drugs.

**Uncertainty about the ability to access prescriptions was frequently expressed.**

Consumers experienced uncertainty about whether their insurance would cover a specific drug that was prescribed by their care provider, as well as the



*"We were working with a patient who took insulin but couldn't afford it. She quit taking it, and she didn't say anything. She ended up in dialysis with kidney failure. ... The health effects are detrimental or even deadly to them at that point."*

*– Jana Parker, community health worker, Baker City*

availability of the prescribed drug. Access concerns include delays, because waiting for a prescription can create serious, sometimes life-threatening, health issues.

**Consumers expressed confusion about how much they will need to pay for their prescription drugs.** Insurance coverage is not clear, both in terms of cost and what specific drugs will be paid for. It is unclear when a brand-name drug will be approved, or only a generic drug. Confusion (or lack of knowledge) about financial assistance programs was also expressed. Several consumers had no knowledge of these programs or were confused about how they worked.

**Consumers expressed anxiety about the future.** Several consumers have anxiety about being able to continue to afford the drugs prescribed to them. Advocates have identified consumers missing meals to be able to afford their prescription drugs. Anxiety was also expressed about ongoing access to their prescription drugs, either from changes in their insurance coverage, availability, or both.

## Recommendations

The attendance at the five in-person and two online forums totaled 156. This turnout was less than hoped for. There are several factors that may have accounted for this.

Due to concerns about completing the consumer forums on a timeline that would meet the initial deadline set for a report to the Legislature, the board and staff thought it was necessary to schedule the forums in April and May. This presented some logistical challenges, particularly for the in-person forums. More time for outreach and publicity could have improved attendance.

While it was important for all Oregonians to be aware of the forums, the board was particularly interested in hearing from consumers who are having challenges with the cost of their prescription drugs. Care providers, medical clinics, and hospitals may be in the best position to provide guidance on how to reach these populations.

Communities of color and marginalized communities were not well represented at the forums. Staff members did outreach to several organizations to encourage participation, and four of the forums had Spanish language and sign language translation available. These efforts were not sufficient. Planning for future consumer engagement should include planning with organizations representing

*“As a nurse practitioner, I can see the cost of treatment is too high. Patients can’t afford medications, don’t pick it up at the pharmacy and end up in the emergency room where the cost of the care is tremendous.”*

– Laurie H., La Clinica, Medford



communities of color and marginalized populations. More resources for publicity in the media serving these communities would also be useful. This would include, but not be limited to, newspapers serving the Hispanic, Black, Asian, and Russian communities.

There is also a significant question as to whether in-person forums are the best vehicle for consumer engagement. It may be more effective to reach people at existing events with high attendance, such as a county fair or a grower’s market.

One advantage of in-person forums has been the ability to collect contact information from consumers. The board could send follow-up emails to consumers who attended the in-person forums, inviting them to board meetings and updating them about the board’s work.

## Conclusion

The board laid a foundation for future public input when it hosted seven community forums around the state in April and May 2024. The board can build on this foundation by engaging with the consumers throughout the year, inviting them to board meetings and informing them of the board's work. The board can also target its outreach to existing community events with high attendance. The board can plan and publicize future events well in advance and hopefully draw more people to come and share their stories about burdensome high-cost medications.

Refer to Appendices A-E for meeting and survey summaries, video links, meeting presentations, and media coverage.

*"My brother is a diabetic, and they switched him to a generic medication. It didn't work for his body, causing problems for his feet. How can he stay on the medication that helps him and not pay so much for that insulin?"*

*– Joanna Wilson, Medford resident and member of the Oregon Disability Commission*



## Appendix A – Event summaries

---

Here are written summaries of the community forums in each city and also online. The online forums were recorded and posted on the PDAB website: <https://dfr.oregon.gov/pdab>.

### Portland

#### **Prescription Drug Affordability Board (PDAB) Portland Community Forum**

**Location:** Portland State Office Building, Portland

**Date:** April 2, 2024

#### **Guests in attendance:**

Jerry W., Robert N., Michael T., Mark S., Julie L., Mary L., Eric Lohnes of PhRMA, Sara Kofman, of Biogen, Lorren Sandt of Caring Ambassadors, Rebecca McAuliffe of Quinn Thomas, John Mullin of OCAP, and OSPIRG campaign associate Luke Winkler.

#### **Board, staff and legislators in attendance:**

PDAB Chairperson Shelley Bailey, Rep. Rob Nosse, Former Department of Consumer and Business Services Director and former Oregon Insurance Commissioner Lou Savage, External Affairs Director Mary Jaeger, Maggie Alvarez of Division of Financial Regulation Outreach, and PDAB Administrative Assistant Melissa Stiles.

#### **Consumer testimony:**

**Mark S., Portland:** Mark said his testimony today is very personal and a matter of life and death. He supports adequate funding for research and development for cure. During the pandemic, routine tests were hard to obtain because beds were used for COVID-19 patients. He missed four years of annual tests. Two years ago he took the routine test and was diagnosed with liver cancer that had spread to other organs and was untreatable and terminal. The doctors said most people at this stage survive six months to a year. He has lasted past the year and, in some ways, feels better than when he was diagnosed. He said his slim chance at life depends on an innovation. Without it, he will eventually deteriorate and die.

He said he benefited from an innovation over a decade ago, which probably allowed him to live another 10-plus years. His annual physical kept coming up with a low platelet count and it finally reached the point where they had to hand count the platelets. He took Interferon and Ribovarin, which had low success rates. Then Harvoni was developed. It was 95 percent effective with few side effects, one pill a day for 12 weeks. After taking Harvoni, he had no more virus and a virtually healthy, normal liver. His medication was paid for by the government. He said medicine needs to advance. Curtailing the innovative process by not adequately funding it serves no one. The government routinely subsidizes these new drugs, so cost is negated on them. He would rather have a cure.

**Robert N., Multnomah County:** As a result of taking psychiatric drugs for 20 years, Robert developed tardive dyskinesia, which causes involuntary neck movements. He takes Ingrezza once per day. The retail cost is \$75,000 for a three-month supply, though his Kaiser Permanente health insurance covers most of the cost. However, it requires a pre-authorization, which is difficult for the doctors. The Ingrezza is slowly helping the tardive dyskinesia symptoms to go away. He recommends anyone with tardive dyskinesia get a case manager to work on securing and paying for the necessary medications to control symptoms, especially to get help with prior authorizations.

**Luke Winkler, campaign associate, OSPIRG, of Portland:** He thanked PDAB for its work on high medication costs. He said he talks to people who struggle with costly medications. He talked to a person suffering with arthritis because she can't afford the medications to treat it. He knows people living with migraines because they can't afford to treat them.

**Lorren Sandt, executive director, Caring Ambassadors:** Lorren represents patients who

have lung cancer and hepatitis C. She appreciates what the board is doing and wants to help the board find solutions. She is a proponent of patient engagement, which is different than public comments, where people speak to the board during a meeting. Public engagement is sitting down and talking to patients, finding out the cost drivers. She wants to work with the board to make this happen. Colorado has a patient engagement board and she hopes Oregon will have one too. She wants to make sure cost savings are for the patient and not just the state. If a patient is on a drug paid for by the pharmaceutical company, that helps the patient's medication costs. It helps the patient afford the medication. She hopes the board will have advisory boards to look at the drugs. Her organization works with groups like the Cascade AIDS project and hemophilia groups. Sandt said she is happy Bailey is the chairperson of the PDAB board because she is a patient advocate. When she was a pharmacist and the state said no, Bailey got people cures.

**John Mullin, Oregon Coalition for Affordable Prescriptions (OCAP):** The stories heard this evening are magnified 1,000 times over, John Mullin said. He thanked DCBS for sponsoring these meetings. He said OCAP supports industry transparency and drug affordability for consumers, but is also cognizant that consumers are paying higher costs. He thanked Rep. Nosse for being present and said Rep. Nosse is a champion in helping form the PDAB. He thanked Bailey for her leadership. He is also a proponent of having an advisory board, though it would probably require legislation. Everyone needs to learn more by hearing from other voices, he said.

## Lincoln City

### Prescription Drug Affordability Board (PDAB) Community Forum

**Location:** Lincoln City Cultural Center, Lincoln City

**Date:** April 9, 2024

#### Guests in attendance:

John A., Gleneden Beach; Judy H.; Susan W., Lincoln City; Robert C.; Madonna McGuire Smith, executive

director of Pacific Northwest Bleeding Disorders; and Lohnes.

#### Board, legislators, public officials and staff in attendance:

Rep. David Gomberg, Sen. Dick Anderson, County Commissioner Claire Hall, PDAB Executive Director Ralph Magrish, Equity Officer Veronica Murray, Shannon Romero of Division of Financial Regulation Outreach, Savage, and Stiles.

#### Consumer testimony:

**Judy H., Lincoln City:** Her husband had osteoporosis and found great relief by taking Forteo (Teriparatide) nightly at a cost of \$800 to \$1,500 per month. They filled out a form, sent in their tax returns, and got the medication for free through a coupon program. She said it makes no sense why they could get it for free when others couldn't. Her husband also had a heart condition. The cardiologist told them to go to Canada to get the medicines because they were unaffordable in this country. Additionally, her doctor prescribed a medication that cost \$113 to treat a skin condition. Her pharmacist found a coupon from GoodRx to bring the price down to \$9. She asked these questions: Why is there so much disparity in the price of medications? Wouldn't it be better to have a fair price for everyone instead of having these extremes? Why in Canada do these medications cost half the price? Why are drug companies making such a profit?

#### **Madonna McGuire Smith, executive director of the Pacific Northwest Bleeding Disorders**

**Benton County:** Her 16-year-old son, two other sons, and husband have rare bleeding disorders. The treatment involves drugs that cost \$1 million per year. Pharmacy benefit managers (PBMs) and insurance companies have formularies that determine which drugs will be covered. Her son went through a pharmacokinetics (PK) process to determine the best hemophilia therapy for him. As a result, the doctor prescribed a specific medication, but the insurance company wouldn't

cover it. Why would doctors go through detailed analysis if the best treatment will not be covered? Additionally, she had thyroid cancer and went through treatments. She takes medicine every day to stay alive. She was prescribed a generic because it was most effective. But the insurance company sent her the brand-name. Every month she fought with them and asked why. They told her they get a great rate, a kick back from the brand-name product.

Her son is a hemophilia patient and treatments cost \$50,000 per month for two shots. OHSU said she had to sign on to SaveOnSP, which allows OHSU to collect all the coupons. Her son was in the hospital and nearly died. They were not allowed to leave the hospital because they wouldn't sign up for SaveOnSP. The hospital collected \$30,000 in coupons. It is frustrating that the middleman, insurance companies, and others contribute to the problem of the patient's ability to get medicines they need. She said her family is not alone in the struggle to pay for costly medicines for rare diseases.

**Susan W.:** She takes Jardiance and it frustrates her to see drug advertisements on TV because she realizes consumers are paying for the ads. She said Jardiance is incredibly expensive, \$42 for 30 pills, yet it is very effective and keeps her blood sugar under control and helps with weight loss. It is also in short supply. Sometimes, she must wait two weeks for her medication to become available. The insurance company called and asked why she was not taking it every day. She told them sometimes it is because the medication is cost prohibitive and she can't afford it. Other times the medication is unavailable at the pharmacy.

**Sen. Dick Anderson, of Lincoln City:** He asked about House Bill 4149, the pharmacy benefit manager bill that the Legislature passed in the 2024 session. Magrish said DCBS is beginning the rulemaking process this spring and summer. He said the PBM reporting will include rebates, how much is returned to insurance companies, how much kept in profit, and how much returned to the consumer. Sen. Anderson said that should help with transparency.

## Woodburn

### Prescription Drug Affordability Board (PDAB) Community Forum

**Location:** Woodburn Public Library, Woodburn

**Date:** April 15, 2024

#### Guests in attendance:

Patricia M. and her three children, Woodburn; Stephanie H., Woodburn; Ramiro R., Woodburn; Lorren Sandt of Caring Ambassadors; Joe Steirer of GSK; and Luke Winkler, OSPIRG, of Portland.

#### Board and staff in attendance:

Bailey, Savage, Jaeger, Alvarez, Murray, Multicultural Communications Program Manager Ruth Kemmy, Drug Price Transparency Policy Team Assistant Sally Sylvester, and Stiles. Jorge Guzman and Cesar Guzman of Vive Northwest provided Spanish interpretation for the event.

#### Consumer testimony:

**Patricia M., Woodburn:** (speaking through interpreter Cesar Guzman). They don't have insurance coverage. She and her husband both work in the fields for very little money. He is sick and needs medicine every three months, which is very expensive. They also need to pay for rent and other bills. It's hard for them but she knows other people are in the same situation. She looks for the most economical brands to buy. If they need cholesterol medicine or high blood pressure medicine, even with coverage, co-pays are high. Many people need this benefit.

**Bailey** thanked Patricia for telling her story. She said GoodRx.com and Mark Cuban's CostPlus Drug Company provide discount cards that might help. Federally qualified health centers receive drugs at discounted prices and are supposed to pass on the savings to the public. Going to these clinics is a short-term answer to broader solutions. She said she would speak privately with Patricia after this meeting to brainstorm about solutions. **Joe Steirer of GSK** said the federally qualified health

centers in Woodburn that would provide lower-cost prescriptions are Salud Medical Center and Pacific Pediatrics, sponsored by the Yakima Valley Farm Workers Clinic.

**Luke Winkler, OSPIRG, of Portland:** He thanked PDAB for its work to make medications more affordable for Oregonians. Lowering the cost of prescription drugs is an important part of lowering health care costs.

## Medford

### Prescription Drug Affordability Board (PDAB) Community Forum

**Location:** Rogue Community College HEC, Medford

**Date:** April 25, 2024

#### Guests in attendance:

Ingri L.; J.R. C.; Janice V.; Joelle M.; Lauri H., nurse practitioner, Medford; Joanne Wilson, Oregon Disability Commission member; and Luke Winkler, campaign associate, OSPIRG, of Portland.

#### Board and staff in attendance:

PDAB Vice Chairperson Amy Burns, Savage, Karla Martinez of Division of Financial Regulation Outreach, and Stiles. Eric Crook and Belle Tower provided American Sign Language interpretation.

#### Consumer testimony:

**Laurie H., Medford:** Laurie is a patient with psoriasis and a nurse practitioner with a federally qualified health center. She has excellent coverage for the medication that treats psoriasis. She had to be on methotrexate for a long time before she was able to get on a biologic. Some of the less expensive treatments for the step requirements were not as effective for a chronic condition and insurance won't cover it. It induces anxiety for the patient. Each biologic works differently and patients don't know how it will impact the condition.

As a nurse practitioner, she can see treatment costs are too high. Patients can't afford medications, don't pick it up at the pharmacy and end up in the

emergency room where the cost of the care is tremendous.

Also, as a nurse practitioner, she wishes providers had a way of knowing when a medication is unavailable when prescribing for the patient. Sometimes practitioners can substitute and sometimes they can't. Inhalers are an example of a medication that is very expensive and doesn't work the same for everyone. Dermatology with Medicare is also very high, for example, Metrogel and other antibiotic gels.

**Savage** echoed Laurie's point about people not taking their medicines, which increases costs for the health system.

**Jim C., Medford:** He uses two generics, Carvedilol and Atorvastatin, covered by Medicare with a nominal monthly cost. He has had glaucoma most of his life and can no longer drive. He has had several surgeries and used eye drops that cost \$400 per month, covered by his insurance through employment. But he has had insurance gaps and been in indigent health care as well, chasing eye drops every month. He takes four different types, twice daily. His sight loss has accumulated over the years, reducing his quality of life. Getting the drops has been a challenge at times, caused by both cost and supply issues. When he had trouble getting Xalatan, for example, he stopped by his ophthalmologist's office and they gave him free pharmacy samples.

**Janice V., Medford** (speaking through American Sign Language interpreters). She has health insurance through her employer. She has been taking Flovent, 250 milligrams for a co-pay of \$35 per month. This year the total changed, and they said Flovent was not available. They gave her a generic that cost only \$5 per month. She asked if the quality of the generic was as good as the name brand.

**Burns** said generics are considered interchangeable. They have to be equivalent.

It doesn't mean a patient responds the same to a generic. She recommended talking to the provider about the medication. The laws for Oregon pharmacies require them to switch to a generic for any medication that has one. Brands have higher out-of-pocket costs than generics for patients.

**Wilson**, a member of the Oregon Disability Commission, said her brother is diabetic and they switched him to a generic medication. It didn't work for his body, causing problems for his feet. How can he stay on the medication that helps him and not pay so much for that insulin? **Burns** said the cost of insulin is impairing the ability for consumers to afford the medication they need to stay alive. That was one of the first recommendations PDAB made to the Legislature, to institute a cap on insulin of \$35. The board is interested in looking at the cost of insulin for Oregonians.

**Laurie H.** said she works in a school-based health center and sees patients who are having trouble getting medications for ADHD, including Adderall and Vyvanse. Kids don't take their medication because they can't get it. **Burns** said there is a national shortage of methylphenidate. Multiple manufacturers have quality concerns that need to be addressed before they can continue manufacturing. There is an increase in use and demand and a decrease in supply. When there was a shortage of .5 milligrams, people switched to 10 milligrams and now there is a shortage of 10 milligrams. Looking at the system as a whole, how much change can the board afford with its recommendations is challenging. Looking at national issues, it gets harder. She is aware of these shortages affecting kids and adults by switching meds and sometimes it's not in the same therapeutic class. There are also shortages in insulin. She said more regulation or federal support is needed to ensure a sufficient supply.

**Laurie H.** said there is a shortage of vaccine support in the pharmacy industry. It is preventative care versus life saving care. **Burns** said many pharmacies don't have sufficient staff to provide vaccines. The board has had conversations about how high-cost

drugs impact pharmacies. The compensation they receive when buying medication is not sufficient to cover costs. We have had talks about how to increase transparency. There is a correlation between registering the pharmacy benefit managers (PBMs) and additional transparency for downstream users, she said. The board recommended more PBM transparency.

**Savage** said the margins are thin for pharmacies. If a small pharmacy shuts its doors in rural Oregon, there may not be another option for 100 miles.

**Burns** said Bi-Mart pharmacy served more people in rural areas and when it closed, people living in Grants Pass felt it acutely. More recently Rite Aid filed for bankruptcy. From a state and federal perspective, there needs to be scrutiny, making sure patients have these medications and access to the services, she said.

**Laurie H.** asked if the board had jurisdiction over mail order drugs. **Burns** said forums like this help give board members ideas for future topics and that could be a future topic. **Savage** said there are a lot of questions about the mail-order business in Oregon as it relates to interstate commerce law.

**Wilson** said her friend almost died from not understanding the medication directions. She asked if American Sign Language could be provided at pharmacy counters. She said American Sign Language is a language that reading and writing do not replace.

**Luke Winkler, campaign associate, OSPIRG, of Portland:** He said OSPIRG as a public interest group, talks to people who have seen an 18-fold price increase in medications in Portland. He knows a patient in Sweet Home who could afford only one meal a day because of high drug costs.

## **Bend**

### **Prescription Drug Affordability Board (PDAB) Community Forum**

**Location:** East Bend Library, Bend

**Date:** April 30, 2024

### Guests in attendance:

Joseph Gardner, lobbyist and policy analyst with Gardner & Gardner in Portland; Mary Griffin of Bend, Oregon AARP driver safety and deputy state coordinator community outreach programs; Evelyn Cook of Bend, AARP; Dianne Danowski Smith of Publix Northwest PR in Portland; Bill Robie, state government relations director, National Bleeding Disorders Foundation; and Winkler.

### Staff in attendance:

Savage, Karla Martinez, and Stiles.

### Consumer testimony:

**Mary G. of Bend:** She said she pays an annual premium and a co-pay. She learned that people who have the Oregon Health Plan get all prescriptions free. For example, the weight-loss drugs for diabetes, many people can't afford to get them, including those who are obese and doing the healthy things. If the Oregon Health Plan provides prescriptions for free, why do others have to pay so much? **Savage** asked if she has seen the prices of medications go up in the last few years. **Mary** said yes, and she did stop taking one medication because the price went up. She took the opportunity to evaluate her health. She said sometimes doctors prescribe a medication and never take people off of it; many people are overmedicating themselves.

**Winkler** thanked PDAB for its work. He has heard from a person in Portland who has arthritis that is progressing because she can't afford to take her medicine. It shouldn't have to be this way, he said.

**Karla M.** of Salem said recently her whole family was sick and they were prescribed Albuterol inhalers. Her daughter went to the pharmacy to pick it up and the cost was \$50. They were very shocked at the price. She said it included an Albuterol pump, which they didn't need. She wondered if there was a generic that could have been provided instead of the brand name.

**Bill Robie, state government relations director, National Bleeding Disorders Foundation:** He

represents a patient group whose medications cost \$50,000 to \$70,000 per month. If patients don't take their medications, they will die. In Oregon, most people with bleeding disorders are treated at OHSU. He asked about the board's affordability review process. He wants to make sure his organization is engaged, and people are telling their stories to the board. He said there are three gene therapies on the market to treat bleeding disorders.

**Diane Smith** of Portland asked Winkler about his sense of patients wanting to be involved in the board process. She said there are hundreds of patients impacted by these decisions. **Winkler** said a lot of people feel strongly about this and want to be involved. **Smith** said there needs to be a role for patients and patient advocates. **Savage** said they plan to record the online meetings and post them on the website so board members can view them. The consumer forums were meant to be listening session and not formal board meetings. **Robie** recommended doing one in-person board meeting a year. He likes to see people face to face. He thinks people would be willing to drive to Salem.

## **Online May 8, 2024**

**Guests in attendance:** Artia Solutions; Joe Gardner, Arielle & Leif; John Mullin of OPAC; Jana, CHW, of St. Luke's Clinic; Alex Johnson II, mayor of Albany; Mei K.; Richard M.; Jim H.; Michael Q.; Legislative Advocates; Shauna W.; Lorren Sandt of Caring Ambassadors; Tiffany Westrich-Robertson of AiArthritis; Luke Winkler of OSPIRG; Suzanne of Allies for Healthier Oregon/We Can Do Better; Alison G. of Myers and Stauffer; Brian DuVal of AiArthritis; Rebecca McAuliffe of Quinn Thomas; Tim Layton; Kristen O.; Margo P.; Paula W.; Rebecca; Leah Hueser; Katie Chandra; Scott Bertani, director of advocacy at Health HIV; Andy V.; Daniel O.; Alison T.; Trish McDaid-O'Neill of Astra Zeneca; Meaghan C.; Kelsey H.; Sophia G.; Arielle G.; Mike E.; Traci M.; Chloe G.; Laura B.; Elin S.; and Joe Steirer of GSK.

**Board and staff in attendance:** Megan Wai of Sen. Patterson's office, Bailey, Savage, Jaeger, PDAB Project Manager Stephen Kooyman, and Stiles. Eizaak Jordan, Jorge Guzman, and Cesar Guzman of Vive Northwest provided Spanish interpretation. Bethany Kocmich and Damon Thayer of Willamette Sign Language provided American Sign Language interpretation.

**Jim H.**, 77, has been on Medicare 12 years, has COPD, and takes two inhalers. He also has Atrial fibrillation and takes three medications with high copays. For Xarelto, a blood thinner, his co-pay is \$398 for a three-month supply. He is considering going back to a cheaper but inferior medication, Warfarin. If he gets Spiriva at the grocery store pharmacy, he pays \$606 for a three-month supply or he pays \$333 from Canada. His inhaler Budesonide cost \$479 for a three-month supply at the grocery store pharmacy but \$369 from Canada. He is considering changing supplemental insurance companies. He said: "I think those prices are very hard. It makes a difference in what I can afford and what I cannot. I just think there should be a better way."

Listen to the testimony at [00:01:13 in the May 8 community forum video](#) on the PDAB website.

**Michael Q., Albany:** Michael has been diagnosed and living with multiple sclerosis for 20 years. Multiple sclerosis is an unpredictable disease of the central nervous system, including the brain, spinal cord, and optic nerves. It disrupts the flow of information with the brain and between the brain and body. People have different symptoms and flow of the course of their disease. His symptoms include severe foot drop, which impacts his ability to walk, eyesight problems, problems with temperature control, and fatigue. He went on disability retirement from his job at a community college about two years ago and had to change insurance. He went with the Oregon Insurance Marketplace, which added tens of thousands of dollars per year for prescription drugs costs. He takes a disease-modifying therapy called Rebif for multiple sclerosis. Insurers in the Oregon marketplace will provide coverage regardless of

pre-existing conditions but they don't cover medication for those pre-existing conditions. Rebif is very expensive. It costs about \$7,000 a month without any kind of help. And the insurance does not cover that much. It has been a challenge on a fixed income.

One cost that is perhaps not seen quite as frequently is the cost of time required and the fact that changing insurances may require a delay in treatments because of paperwork needed, needing to schedule with different physicians and neurologists, and going through the system to get approval for the medications needed. Sometimes, it's not the cost that slows down the medical treatment plan but the time to get approvals and work through pharmacy systems. Oregonians, especially those dealing with a disability, the elderly, veterans or those in under representative communities, need reasonably-timed access to reasonably-priced medications. **Bailey** thanked Michael for sharing his story and perspective, especially the comment related to the opportunity cost of time. She said it becomes a job and takes away from other work that could be done.

Listen to the testimony at [00:20:11 in the May 8 community forum video](#) on the PDAB website.

**Alex Johnson II, mayor of Albany.** For the past 15 years, he has been a broker of insurance for Medicare, helping clients that take expensive medications, such as Eliquis. So many medications are ridiculously overpriced, he said. He tries to help patients get exceptions to the insurance formularies or work with their doctor to find more affordable medications. His concern is that the Eliquis patent expired but the manufacturer got a five-year extension from the U.S. Food and Drug Administration (FDA), delaying the generic drug, Apixaban. Pharmaceutical companies should not be able to extend patents to delay generics, he said. Congress and the FDA need to help with these extremely high drug costs. It's hurting people. He is concerned that doctors prescribe medications that are counterproductive

to medications patients are already taking. One drug may counteract the effects of the other one or reduce its efficacy. There is no communication about prescriptions between doctors. The system needs a check and balance. He said, "I often sit with someone who is in tears because they can't afford their medications."

Listen to the testimony at [00:25:45 in the May 8 community forum video](#) on the PDAB website.

**Arielle Goranson**, Portland, has worked in primary care transformation for the past decade, focusing on health equity data. She said it is well documented that people of color have worse health outcomes and higher rates of certain conditions that need medication. She read a paper recently about health disparities and outcomes involving medication access and high drug costs being a driver of the inability to access medications, disproportionately affecting communities of color. Those who disproportionately face medication access issues might also benefit by new drugs, and new treatments. She urged the board and decision makers to try to curb health care costs for medication and mitigate any unintended consequences that could further disenfranchise these systematically-disadvantaged, underserved communities. She encouraged the board to engage with diverse stakeholders to ensure they are not advancing one thing at the cost of communities that have been disadvantaged in the past. She provided these links:

- [2023 AHRQ National Healthcare Quality and Disparities Report](#)
- [Racial Disparities in Medication Use](#)
- [Racial and Ethnic Disparities in Access to Medical Advancements and Technologies](#)

Listen to the testimony at [00:30:01 in the May 8 community forum video](#) on the PDAB website.

**Suzanne, Allies for Healthier Oregon/We Can Do Better:** She asked how can insurance brokers, such as Alex Johnson, be of service to Oregon consumers in helping find affordable medications.

Listen to the testimony at [00:35:00 in the May 8 community forum video](#) on the PDAB website.

**Winkler** He thanked PDAB for its work on lowering prescription drug prices. Prescription drug prices are far too high and that hurts everyday Oregonians, he said. OSPIRG hears horror stories from people who have to miss work and deal with migraines because they can't afford the prescriptions that their neurologist prescribes, or people who have to let their arthritis progress because they can't afford treatment. It's saddening and heartbreaking. The board can't fix all of the issues but their work is needed and an appreciated part of improving Oregon's health care.

Listen to the testimony at [00:36:10 in the May 8 community forum video](#) on the PDAB website.

**Jana P., CHW, community health worker at St. Luke's in Baker City:** She shared stories from her experience working at a clinic and pharmacy with patients who can't afford costly insulin. One of the pharmacy patients couldn't afford their insulin prescription, quit taking it without telling the pharmacy staff, and ended up in dialysis with kidney failure. Elderly patients especially are afraid to speak up or they don't know who to tell and so they just go without, she said. The health effects are detrimental or even deadly. She also works with patients who need Eliquis, which is horribly expensive, even with Medicare or private insurance. She helps patients find financial assistance through manufacturer programs. However, many patients with Medicare or Medicaid don't qualify. She asked if there is a way to help the Medicare population qualify for financial assistance for expensive drugs. Even patients who can afford Eliquis for three to six months of the year will run out of money and the ability to keep taking the medication. **Savage** thanked her and said her comment was echoed in Medford. If someone ends up in the emergency room or urgent care because they haven't been taking their prescription, it impacts their health and it's costing the system as well.

Listen to the testimony at [00:38:21 in the May 8 community forum video](#) on the PDAB website.

**Scott Bertani, director of advocacy at Health HIV:** He currently works with the Cascade AIDS Project (CAP) that has a 340B program within the HIV ecosystem. He applauded PDAB for having conversations with its partners in Oregon about any upper payment limit considerations and how that will play out for patients. Upper payment limits may impact patients who are taking Biktarvy, for example, if they are forced to switch to a multi-tab regimen. There could also be some additional cost to the systems. He advocates that patients with high acuity should be given special consideration during that switch period, such as more direct and intensive case management involvement to ensure continuity of care. He is glad PDAB is having the conversation with CAP but hopes that conversation gets played out for the rest of the community because there are more HIV individuals than those with Ryan White clinics. There are a lot of people on Medicare and Medicaid. CAP does an amazing job, as do other Oregon community based organizations. Please sure to think about some of those medication pickup logistics and switch needs. Listen to the testimony at [00:41:54 in the May 8 community forum video](#) on the PDAB website.

**Tiffany Westrich-Robertson, chief executive officer, AiArthritis:** She thanked the board for providing this opportunity for patients and caregivers. She represents people in Oregon. She is also a patient with arthritis and uses biologics. She can afford her medication because of the co-pay assistance plans. She knows there are a lot of patients in Oregon who struggle to pay for their prescriptions. She thanked the board for asking the important question: “What is the name of the drug you are having trouble affording?” That question has been missing in some of the PDAB conversations around the country. Boards need to find out what is expensive before picking drugs that may be expensive for the state, but co-pay assistance programs for patients.

Many patients are struggling with Medicare and unaffordable prescriptions. In most states with PDABs, Medicare isn’t something that can be reviewed or talked about in the PDAB. The second component to think about in asking these questions about expensive drugs is the “why.” If the reason is Medicare and it can’t be addressed, maybe that is a recommendation the board can pass on the Legislature.

Listen to the testimony at [00:44:18 in the May 8 community forum video](#) on the PDAB website.

**Lorren Sandt, Caring Ambassadors Program:** She thanked the board for having the forum. She said this conversation brought up a question to add into the survey: “What tier is the drug on the patient’s insurance plan?” That makes a big difference whether a drug is affordable or not. **Savage** asked her to explain what is meant by tier. **Sandt** said every insurance plan has different levels of paying for the drugs based on a tier of 1 through 5, for example. The most expensive drugs are generally on a tier 5. The co-pay depends on the drug’s tier. For instance, she uses a very expensive cream. On Blue Cross Blue Shield, it was a tier 2 and on UnitedHealthcare, it’s a tier 5. She now has a 50 percent co-pay for the cream. It makes a big difference to know what tier a drug is on, helps to understand what’s covered, and would give PDAB more information about affordability. The person who spoke earlier with multiple sclerosis, his drug is on a high tier and so it was very unaffordable for him. Not all drugs are covered equally.

Listen to the testimony at [00:46:25 in the May 8 community forum video](#) on the PDAB website.

**Bailey:** To follow up on the conversation about Eliquis, Bailey asked Jana if she is aware of Array RX, which offers drug discounts through a consortium of states, including Oregon.

**John Mullin, board president of the Oregon Coalition for Affordable Prescriptions:** The chart in the PowerPoint that looks like the back of a television screen shows the complexity of the situation that we're in as a country as it affects providers and consumers. The Oregon Coalition for Affordable Prescriptions works on industry transparency and affordability for purchasers consumers. He encouraged people to visit the OCAP website or Facebook page to learn about their work. He said they don't receive any funds from the pharmaceutical industry and they are not advocating for particular drugs. They are interested in making it better for people who struggle to afford the price of their prescriptions.

He said even though thousands of Oregonians struggle with affordability, the task of getting people to show up and tell their stories is difficult because of time and personal vulnerability people put forward in telling their stories. He appreciates the board chairperson being present here because PDAB doesn't often hear from consumers. The board is doing really important technical work.

Listen to the testimony at [00:50:47 in the May 8 community forum video](#) on the PDAB website.

## Online May 14, 2024

### Guests in attendance:

Joe Gardner and Lynda Gardner of Gardner & Gardner lobbyists; Rebecca McAuliffe of Quinn Thomas; Bandana Shrestha of AARP; Avi Bakshani of WilmerHale law firm; John Mullin; Frances P.; Jason T.; Arielle Goranson, MPH; Bridge Budbill of Oregon Law Center; Lucy Laube of National Psoriasis Foundation; Sandt; Joanna Wilson of Oregon Disability Commission, and Kay B.

### Legislators, board, and staff in attendance:

Rep. Cyrus Javadi, Bailey, Savage, Jaeger, and Stiles. Eizaak Jordan, Jorge Guzman, and Cesar Guzman of Vive Northwest provided Spanish interpretation. Eric Crook and Belle Tower provided American Sign Language interpretation.

**Rep. Javadi:** He represents House District 32 on the North Oregon Coast and also serves on the Health Care Committee. He just finished his first term. He is looking forward to the comments and feedback tonight. At the capitol, legislators are very concerned about the cost and affordability of health care and that includes prescription drugs. Legislators spent a lot of time last session talking about everything, from insulin to medications for cancer, as well as high blood pressure and all sorts of different conditions; the role the pharmacy benefit managers play, as well as insurance companies; and the immense pressure on Oregonians to continue to meet those needs. Thanks for providing this opportunity and forum.

Listen to the testimony at [00:05:00 in the May 14 community forum video](#) on the PDAB website.

**Frances P.:** Frances thanked the board for having this forum. Frances moved from North Carolina to Oregon 15 years ago, studied public health in college, finished a business degree, and has been employed at various restaurants. Frances serves on the Zinger Farm board and is very interested in health equity. Frances is recently in between jobs, lost private insurance, and now has access to the Oregon Health Plan. Frances recently learned that prescriptions are tied to providers. Only one of Frances' regular doctors takes OHP, so there is a need to re-establish care. Frances recently learned the pharmacy would not fill the prescriptions because the prescribing provider did not take OHP. Frances had enough money saved to pay out of pocket while job seeking and finding an OHP provider. As someone who is a queer person, trust is really important, Frances said. Health disparities are different for LGBTQ folks, especially LGBTQ folks of color. Frances said this was a learning opportunity to share with the board. **Bailey** wanted to confirm that **Frances** had a valid prescription with refills and simply because that medical provider was not in network for fee-for-service or Medicaid, that prescription did not process properly on the insurance. Frances

confirmed that was the case and that this situation could impact other Oregonians. **Bailey** said this was a new feedback and thanked Frances for sharing. Frances said it is important to think about continuity of care issues that intersect with prescription drug costs. Bailey suggested looking into Array Rx, a state discount card for prescription drugs.

Listen to the testimony at [00:24:00 in the May 14 community forum video](#) on the PDAB website.

**Joanna Wilson, member of the Oregon Disability Commission:** (speaking through ASL interpreter)

Joanna said her son has a chronic illness and it is getting worse. She wondered about his medication for chronic pain. He needs medication that's stronger. She asked if there a law about prescription limitations for people who are low income on the Oregon Health Plan. If the doctor knows the patient is low income, does the doctor prescribe the lower cost medication? Would people with higher incomes be prescribed something different? **Bailey** said what Joanna referenced is part of a discussion related to plan design and how insurers in Oregon and PBMs build formularies of the drugs they cover and drugs they don't cover. She said there are laws that protect access for people on Medicaid versus those who have commercial plans. Formularies are not built off someone's ability to pay. It's a broader plan design discussion between insurers, PBMs and payors. Certain economic groups are not targeted or limited in access. She thanked Joanna for sharing about this challenge and said the PDAB board wants to hear from consumers as it continues its work and provides recommendations to the Legislature. On a personal level, she said she is sorry about the health issues Joanna's family is experiencing. She appreciates her sharing today.

Listen to the testimony at [00:32:11 in the May 14 community forum video](#) on the PDAB website.

**John Mullin, board president of the Oregon Coalition for Affordable Prescriptions (OCAP):** He thanked Bailey for the good work PDAB is continuing to do. For consumers who have not shared their

story, please visit the OCAP website or Facebook page, he said. When consumers tell their stories, it has a real impact. He is pleased that Bailey has been at the presentations because the board has a lot of technical work to do. Unless they hear from consumers, they are really not getting the flavor of what's happen around the state. He thanked DCBS for sponsoring the forums and looks forward to the summary report. For those consumers who spoke, they were speaking on behalf of thousands of Oregonians struggling with paying for their prescription drugs.

Listen to the testimony at [00:41:48 in the May 14 community forum video](#) on the PDAB website.

**Wilson** (speaking through an interpreter) said she has heard of people stockpiling medication, taking it as little as possible, or taking half a dose because of the cost. Is it dangerous?

**Savage** thanked Wilson for bringing that up. At the Medford meeting, a nurse practitioner spoke about folks who cut back on medication end up in the emergency room or urgent care center. It does have an impact. It severely impacts their health. And for the cost to the health care system, if someone goes to ER or urgent care, it increases cost of care. It has impact on individual and health care system.

Listen to the testimony at [00:45:04 in the May 14 community forum video](#) on the PDAB website.

# Appendix B – Survey and summary

---

## Survey

### Age range:

- 18 – 30
- 31 – 46
- 47 – 61
- 62 – 75
- 76 and over
- Prefer not to answer

## Annual income

- \$0-\$9,999
- \$10,000-\$24,999
- \$25,000-\$49,999
- \$50,000-\$74,999
- \$75,000-\$99,999
- \$100,000-\$149,999
- \$150,000+
- Prefer not to answer

## County:

\_\_\_\_\_

## Medical conditions

1. \_\_\_\_\_ 2. \_\_\_\_\_ 3. \_\_\_\_\_

## Prescription drug(s) taken to treat the above medical condition(s):

1. \_\_\_\_\_ 2. \_\_\_\_\_ 3. \_\_\_\_\_

## How often:

1. \_\_\_\_\_ 2. \_\_\_\_\_ 3. \_\_\_\_\_

## Monthly costs:

1. \_\_\_\_\_ 2. \_\_\_\_\_ 3. \_\_\_\_\_

## Please circle which applies to you:

Private health insurance

Medicare

Medicaid

## Survey results April-May 2024

**Age:** 62-75

**Income:** \$50,000 - \$74,999

**County:** Deschutes

**Medical condition:**

**Prescriptions:**

**How often:**

**Monthly costs:**

**Insurance type:** Medicare

---

**Age:** 62-75

**Income:** \$10,000 - \$24,999

**County:** Jackson

**Medical conditions:** Glaucoma with 95 percent vision loss; living with it for 35 years, AFIB

**Prescriptions and how often:** Carvedilol 12.5 mg 2x/day, Atorvastatin 10 mg/day

**Monthly cost:** Painless copay of about \$20/month

**Insurance:** Medicare with BCBS Advantage

---

**Age:** 62-75

**Income:** \$50,000 - \$74,999

**County:** Jackson

**Medical condition:** Psoriasis

**Medications and how often:** Stelara, quarterly

**Monthly costs:** None, but worry annually that it won't be covered

**Insurance:** Medicare

---

**Age:** 76

**County:** Jackson

**Medical conditions:** Heart failure

**Prescriptions and how often:** Xarelto, 1 daily

**Insurance:** Medicare

---

**Age:** 31-46

**Income:** \$25,000 - \$49,999

**County:** Marion

**Medical conditions:** High blood pressure and cholesterol, diabetes

**Medications and how often:** 3 medications but don't recall the names. 2x/month, 3 tablets daily, 3 tablets daily

**Monthly cost:** \$180, \$80, and \$260

**Insurance:** Private health insurance

---

**Age:** 47-61

**Income:** \$25,000 - \$49,999

**County:** Multnomah

**Medical condition:** Tardive dyskinesia

**Medication and how often:** Ingrezza, once per day

**Monthly costs:** Retails for \$75,000 for 3 months supply

**Insurance:** Private health insurance

**Note:** got a prior authorization and Tx failure exception

---

**Age:** 62-75

**Income:** \$10,000 - \$24,999

**County:** Lincoln

**Medical conditions:** High blood pressure, diabetes, high cholesterol

**Medications and how often:** Metformin 2x daily, Jardiance once daily, Verapamil once daily, Pravastatin once daily

**Monthly costs:** Metformin varies, little; Jardiance varies, expensive; Verapamil varies, medium cost; Pravastatin reasonable

**Insurance:** Medicare

---

**Age:** 47-61

**Income:** \$75,000 - \$99,999

**County:** Benton

**Medical conditions:** Hemophilia, Von willebrand disease (VWD), other rare bleeding disorders

**Medications and how often:** Factor products for HEMA weekly, blood products for VWD as needed on demand

**Monthly cost:** \$75,000+

**Insurance:** Private health insurance

---

**Age:** 31-46

**Income:** \$0 - \$9999

**Medical condition:** Chronic complex post-traumatic stress disorder (CPTSD), premenstrual dysphoric disorder (PMDD), Anxiety

**Medications and how often:** Venlafaxine daily, Propranolol daily, Lorazepam, as needed

**Monthly costs:** \$50, \$35, and \$35

**Insurance:** Medicaid

---

**Age:** 62-75  
**Income:** \$50,000 - \$74,999  
**County:** Marion  
**Medical conditions:** Idiopathic distal symmetric polyneuropathy, sleep apnea, chronic pain  
**Medications and how often:** Cyclosporine ophthalmic 2x/day, Belsomra 1x/night, Gabapentin 1x/night  
**Month cost:** \$20, \$20, and \$3.72  
**Insurance:** Private health insurance and Medicare

---

**Age:** 62-75  
**Income:** \$25,000 - \$49,999  
**County:** Washington  
**Medical conditions:** Depression, social anxiety  
**Medications and how often:** Effexor XR 1x/day, Lexapro 1x/day  
**Monthly cost:** \$100 co-pay  
**Insurance:** Medicare  
**Note:** I am waiting approval for assistance for both medications otherwise the cost is \$1,000

---

**Age:** 31-46  
**Income:** \$100,000 - \$149,999  
**County:** Washington  
**Medical conditions:** ADHD, Anaphylaxis, Asthma  
**Medications and how often:** Epinephrine daily, Strattera, twice daily  
**Monthly costs:** \$150, \$190, and \$22  
**Insurance:** Private health insurance

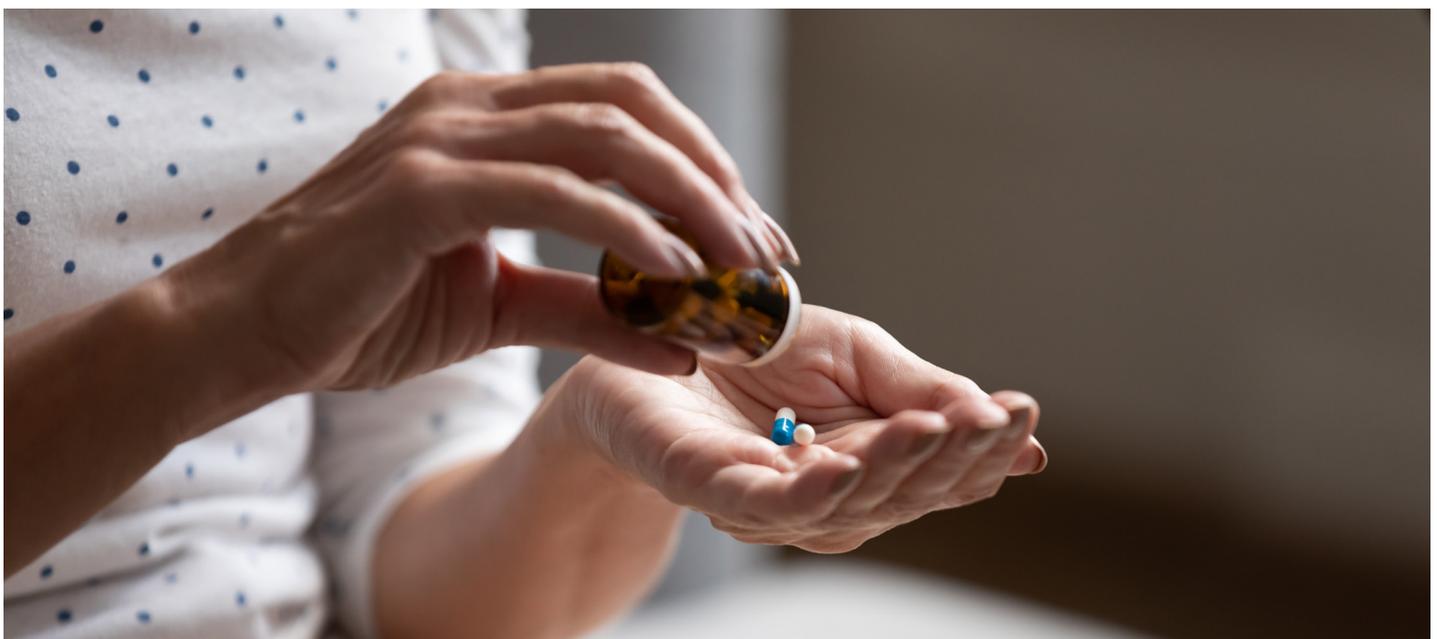
**Age:** 62-75  
**Income:** \$25,000 - \$49,999  
**County:** Douglas  
**Medical conditions:** Heart failure, tumor, back disc issues  
**Medications and how often:** Eliquis 2x day, Bystolic 2x day, Telmisartan, 1x day  
**Monthly cost:** \$700, \$200, and \$100  
**Insurance:** Medicare

---

**Age:** 76 and over  
**Income:** \$25,000 - \$49,999  
**County:** Lane  
**Medical conditions:** AFIB, congestive heart failure, osteoporosis  
**Medications and how often:** Eliquis 2x/day, Cartia 2x/day, Atorvastatin, once a day  
**Monthly costs:** \$450, \$250, and \$40  
**Insurance:** Private health insurance, Medicare

---

**Age:** 47-61  
**Income:** \$100,000 - \$149,000  
**County:** Lincoln  
**Medical condition:** Diabetes  
**Medications and how often:** Metformin twice daily, Glipizide once daily, Atorvastatin once daily  
**Monthly costs:** \$15, \$5, and \$5  
**Insurance:** Private health insurance



## Appendix C – Media coverage

Staff sent press releases to Oregon media outlets and also advertised the event on social media. Here are two examples of media coverage about the community forums.

### Rogue Valley Times

View the article at this link: [Medford forum on rising prescription drug costs set for RCC Higher Ed Center | Local&State | rv-times.com](https://www.rv-times.com/story/news/2024/03/28/medford-forum-on-rising-prescription-drug-costs-set-for-rcc-higher-ed-center-local-state/7544444002/)

### KDRV TV station in Southern Oregon

View the video at this link: [Oregon Prescription Drug Affordability Board hosting public forum Thursday in Medford | Top Stories | kdrv.com](https://www.kdrv.com/story/news/2024/03/28/oregon-prescription-drug-affordability-board-hosting-public-forum-thursday-in-medford/7544444002/)

## Appendix D – PowerPoint presentation

The PowerPoint presentation shown at the community events is posted on the PDAB website: <https://dfr.oregon.gov/pdab/>.

Here is the direct link:

- [April-May Community forum PowerPoint presentation](#)

## Appendix E – Community forum videos

- The online community forums were recorded with participants' permission. The videos are posted on the PDAB website: <https://dfr.oregon.gov/pdab/>.

Here are the direct video links:

- [May 8, 2024 Community forum about prescription drug costs](#)
- [May 14, 2024 Community forum about prescription drug costs](#)

