RDA
rare disease alliance

Dear Oregon PDAB Team,

My name is **Carolina Sommer**. I'm here today as a rare disease parent and Co-Founder of the Rare Disease Alliance. Thank you for the opportunity to speak as you continue your important work at the Oregon Prescription Drug Affordability Board.

Rare disease families do not live typical lives. Our medical journeys are complex, our evidence is limited, and our timelines are very different from more common conditions.

Today, about **1 in 10 people live with a rare disease**, yet **95% of rare diseases still have no FDA-approved treatment**. When a therapy does become available, it often represents years of research, enormous risk, and sometimes the only treatment option a patient will ever have.

I recognize the difficult responsibility this board carries in balancing affordability with maintaining access to needed therapies, and I appreciate the thoughtfulness of that work.

As you know, your policies set reimbursement limits within the healthcare system, which can influence how providers are able to deliver care.

Hospitals and pharmacies must purchase, store, and administer these medicines, all of which carry real costs. If reimbursement is set below those costs, providers may experience financial losses when delivering care.

In those situations, smaller community hospitals, specialty pharmacies, or clinics operating on tight margins may find it difficult to continue offering the therapy.

Even when a policy does not change what a patient pays, it can influence whether treatment is available locally. For rare disease patients, that access can be life-changing.

Oregon law thoughtfully included protections for rare disease therapies, recognizing that these treatments often serve very small patient populations and may be the only available option.

Families like mine already spend years searching for diagnoses, coordinating care, and supporting breakthrough research that leads to new treatments. For our community, the arrival of a therapy is an extraordinary milestone.

Rare disease families are not asking for special treatment. We simply hope that as this board continues its work, the protections already in Oregon law are implemented in a way that ensures patients with the fewest options can maintain access to the therapies they depend on.

Thank you for your time and for considering the perspective of rare disease patients and families.

Sincerely,
Rare Disease Alliance Team