

Chairwoman Schmidt, Vice Chair Deeter, Ranking Member Somani, and Members of the Committee:

My name is **Lauren Wilson**, and I am the mother of **Freya Wilson**, who will turn four years old this coming Sunday.

When Freya was born, she was immediately taken to the NICU and later transferred to **Cincinnati Children's Hospital** due to low blood sugar. During her stay, the genetics team conducted testing and informed us that Freya was the **only known person in the world** with her specific combination of conditions. Freya has:

- Chromosome 9p deletion
- Chromosome 7 duplication
- Hypoglycemia and hyperinsulinism
- Epilepsy
- Von Willebrand disease
- Low muscle tone
- A floppy upper airway prone to frequent infections

Just four months ago, we learned of a 2008 article in the *India Journal* that described four other children with the same genetic abnormalities. Despite this new information, the outlook remains uncertain. We were told early on that Freya would be **developmentally delayed** and unlikely to reach any of the typical childhood milestones.

Because of Freya's complex medical needs, my husband and I faced a significant challenge in finding a **daycare facility** equipped to provide the level of care she requires. Before finding **Easterseals Redwood**, we were turned away by multiple facilities.

Easterseals Redwood changed everything for our family.

The team at Easterseals Redwood made it possible for my husband and I to continue working—something we must do, as we cannot afford to live on a single income. When Freya enrolled, the nursing team brought on an additional nurse specifically to help care for her and other children with medical needs.

The nursing team provides **vital, daily care**, including:

- Administering medications (including emergency rescue meds)
- Monitoring blood sugar and oxygen saturation
- Performing airway clearance

Because of this specialized care, we can go to work each day, **with peace of mind**, knowing Freya is safe and supported.

In addition to medical support, Freya receives weekly, on site, **physical, occupational, and speech therapy**. Thanks to these therapies, she has made tremendous progress. She can now:

- Sit up on her own
- Frog-hop crawl
- Pull herself to stand
- Take steps using a gait trainer and walker

Without the support of Easterseals Redwood, my daughter would likely be **confined to a hospital bed** and reliant on machines—rather than the **joyful, playful toddler** she is today.

Every morning when we drop her off, we're greeted by her peers shouting, "**Freya's here!**" Her friends and teachers ensure she's included in everything—from the mini-gym to arts and crafts.

Above all, Easterseals Redwood's diverse environment, dedicated medical staff and compassionate teachers, provides us with what we value most as parents: **peace of mind** that our medically complex child is not only safe, but **thriving**.

Thank you for your time and attention.