Finding the Flowers in the Dirt: Six Years from Diagnosis to Advocacy

My story with Luella did not begin with a diagnosis.
It began with silence.

When I was pregnant, I remember feeling something wasn't quite right. I didn't feel her move the way other mothers described. I carried that quiet worry in my chest, but every appointment reassured me that everything looked "fine." I trusted the system. I trusted that if something were wrong, someone would see it.

But after she was born, the pieces didn't fit.

Her low muscle tone was there from the beginning. She was fragile in ways I couldn't fully explain. Feeding was hard. Holding her felt different. The questions started to multiply, but answers did not come easily. Doctors were kind, but many were unfamiliar. No one immediately recognized what we were facing.

For six months, we lived in a fog of uncertainty.

It wasn't until Luella was six months old that we finally heard the words: Prader-Willi Syndrome.

By then, we were already exhausted — emotionally, physically, spiritually.

Those early months were some of the darkest of my life. Postpartum depression wrapped itself around me quietly at first, then tightly. I leaned into isolation. I pushed friends and family away, not because they didn't care, but because I didn't know how to explain what I was feeling. It was easier to retreat than to try to articulate the fear.

We were holding an uncertain future in our hands — and it felt fragile.

The diagnosis brought answers, but it also brought a new weight. Prader-Willi Syndrome. A lifelong condition. A rare genetic disorder. Feeding challenges. Developmental delays. Behavioral complexities. Endless unknowns.

The future felt like a black pit I was staring into.

But even in that darkness, something was slowly taking root.

I began to learn. I began to research. I began to ask better questions. I began to show up to appointments differently. I began to understand therapies, supports, and educational rights. I learned how to sit at IEP tables with preparation instead of intimidation. I learned that my voice mattered in rooms where decisions were being made about my daughter's life.

And somewhere along the way, I realized something profound:

Advocacy is love with action behind it.

Every appointment attended.
Every therapy scheduled.
Every late-night research session.
Every time I pushed for clarity or resources.

It was love.

Luella will never walk this journey alone — not through medical appointments, not through therapy sessions, not through moments of frustration when things feel harder for her.

What began as survival slowly became purpose.

I became a Parent Mentor with PWSA USA, walking beside families who were just receiving the diagnosis that once shattered me. I became a Peer Supporter with Parent to Parent of Pennsylvania, offering empathy rooted in lived experience — because I remember how isolating those early months felt.

I found my footing within the Pennsylvania Rare Disease Advisory Council (PARDAC), stepping into statewide conversations about rare disease policy and support. What began in hospital rooms expanded into leadership spaces. What started as protecting one little girl grew into advocating for many.

And through it all, Luella has humbled me in ways I never expected and molded our family in ways only God could orchestrate.

She has softened my pride, strengthened my faith, and reordered what truly matters. Through her, I have learned that love does not need words to be powerful.

She did not just change our plans — she refined our hearts.

Six years ago, I felt buried in the dirt — overwhelmed by postpartum depression, fear, and uncertainty.

Today, I understand something I couldn't see then:

Roots grow in the dark.

The dirt was real.
The depression was real.

The isolation was real.
The fear was real.

But so was the growth happening underneath.

That growth led me to formally establish A Parent’s Promise LLC — an extension of the promise I made in those earliest days: that I would turn pain into purpose, isolation into connection, and uncertainty into advocacy.

Luella’s diagnosis did not end our story.

It reshaped it.

It refined me.
It strengthened me.
It called me forward.

And now, six years later, I can say this with conviction:

The flowers did grow.

Not despite the dirt —
but because of it. 🌸

--Momma to a PWS Warrior

Kayla Day