

16p11.2 GENETIC FOUNDATION



Bringing Hope for the 16p11.2 Community



MEET THE 16P11.2 DUPLICATION LEADER



*Brooklynne Semeniuk -
Duplication Leader of
16p11.2 Genetic Foundation*

From Diagnosis to Leadership: A Mother's Journey of Advocacy & Hope

Behind every movement is a story, and behind the growing awareness of **16p11.2 Duplication** is a mother whose journey began with uncertainty, resilience, and an unwavering commitment to her child.

A full-time working mother of two from Alberta, Canada, Brooklynne balances family life alongside her partner, Michael, while also pursuing a full-time online university education. Her path into advocacy was not planned, it was shaped through lived experience. It began with the early challenges of raising her first child at a young age. Those early lessons in patience and perseverance would later become essential as she navigated a far more complex journey with her youngest daughter, Briah.

A Long Road to Answers

In July 2024, after months of alarming symptoms and a prolonged hospital stay, Briah was diagnosed with 16p11.2 Duplication. From just six weeks old, signs began to emerge – missed developmental milestones, feeding difficulties, and ongoing health concerns that escalated into seizures, elevated blood pressure, and failure to thrive.

Doctors searched tirelessly for answers, conducting extensive testing with little clarity. Genetic testing, which was considered a last resort, finally revealed the cause: a duplication in the 16p region of Briah's DNA. While the diagnosis brought relief in finally having answers, it also came with the difficult reality of a condition with no cure.

The journey took an unexpected turn when further testing revealed that Brooklynne also carries the same duplication, unknowingly passing it on to Briah.



A Diagnosis That Rewrote the Past

At first, the focus remained solely on Briah's care. But over time, the diagnosis began to illuminate a lifetime of unanswered questions. Childhood struggles with learning, difficulty forming social connections, and recurring health issues such as severe headaches and migraines suddenly made sense. What once felt like isolated challenges became part of a shared genetic story between mother and daughter.



Celebrating Milestones That Matter

Despite the obstacles, Briah's journey has been marked by powerful moments of triumph. From taking her first independent steps to proudly saying her own name, each milestone carries profound meaning. These victories, small to some, represent resilience, determination, and hope. They are daily reminders of her strength and the joy she brings to those around her.

Finding Community and Building One

Like many families facing rare conditions, the search for information initially led to frustration. Resources for 16p11.2 Duplication are scarce. That changed with a connection to the 16p11.2 Genetic Foundation. What began as support quickly evolved into purpose. Recognizing the lack of representation for duplication families, Brooklynne felt called to help build something that didn't yet exist. In October 2025, she took a courageous step by sharing her family's story on stage at the 16p11.2 Deletion Conference. That moment became a turning point, sparking deeper involvement and the beginning of her leadership journey.

Leading with Purpose

Now serving as Duplication Chapter Leader, she has played a pivotal role in shaping a growing community. In just one year, her efforts have helped:

- Launch the first duplication-focused awareness campaign: Double the Love
- Contribute to conference programming and breakout sessions
- Support research initiatives and survey development
- Expand global connections through online platforms
- Strengthen community support for families navigating similar journeys

Looking Ahead: A Vision for the Future

Her advocacy is driven by one central mission: ensuring that no family feels alone in their journey.

Looking toward 2026 and beyond, Brooklynne's goals include:

- Advancing research through the addition of a scientific advisor
- Strengthening community pillars of advocacy, education, and support
- Organizing the first joint Duplication and Deletion Conference in 2027
- Building a more inclusive and connected global network by 2030

Brooklynne's Message to the Community

At the heart of this work is a deeply personal commitment to transform fear into action, uncertainty into knowledge, and isolation into connection. Her message: **families navigating 16p11.2 Duplication are no longer alone.** They are part of a growing, compassionate community led by individuals who truly understand the journey – parents, advocates, and professionals working together to create meaningful change. And at the center of it all is a mother who turned her daughter's diagnosis into a movement, one built on resilience, advocacy, and hope.

YOUR VOICE MATTERS:

HELP SHAPE THE FUTURE OF THE 16P COMMUNITY

16P11.2 COMMUNITY SURVEY

In rare disease communities like ours, every voice carries weight, and every story has the power to shape the future.

For families navigating 16p11.2 conditions, the journey can often feel isolating: limited information, gaps in care, and uncertainty about what lies ahead. While these experiences are deeply personal, they also reveal important patterns, and that's where community surveys become essential.

Surveys transform individual experiences into a collective insight. When families take a few minutes to share their realities, it creates a clearer, more complete picture of what life with 16p11.2 truly looks like. This data becomes one of the most powerful tools we have to drive change.

TURNING EXPERIENCES INTO ACTION

The information gathered from community surveys directly influences:

- Research priorities, ensuring studies focus on the issues that matter most to 16p11.2 families
- Clinical care improvements, helping providers better understand patient needs
- Development of resources for both our families and healthcare professionals

With family input, the 16p11.2 Genetic Foundation can advocate with clarity, confidence, and purpose for our community.

BUILDING A STRONGER FUTURE TOGETHER

Change doesn't happen overnight, but it starts with understanding. Surveys are one of the simplest and most impactful ways to contribute to that understanding.

As a thank-you, each completed survey will be entered into a drawing to win one of two one-hour consultations with Dr. Faranak Herrera, DO, MPH, Founder of the 16p11.2 Genetic Foundation. As both a physician and a 16p parent, Dr. Herrera brings a uniquely personal and professional perspective to the community making this a truly special opportunity.



SURVEY





HELP US TELL OUR STORY: WE NEED YOUR PHOTOS

As we continue to design of our new foundation website, we have a powerful opportunity to better reflect who we truly are as a community. The goal is to ensure that every family who visits our site sees real faces, real stories, and real lives that mirror their own.

WHY YOUR PHOTOS MATTER

For too long, rare diseases have been represented by stock images and generic visuals that fail to capture the heart of their experience. But 16p11.2 is not generic, and neither are the incredible individuals and families who live with it every day.

Your photos tell a story that words alone cannot:

- The strength in your child's smile
- The resilience behind every milestone
- The love that defines your family's journey

BUILDING A WEBSITE THAT REFLECTS US

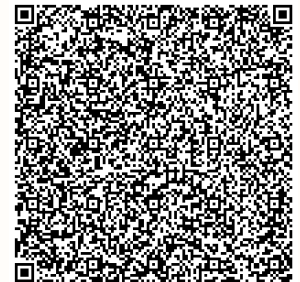
Every visitor to our new website should feel seen, supported, and less alone from the moment they arrive.

By sharing your photos, you are helping:

- Replace generic imagery with authentic representation
- Highlight the diversity and beauty of our 16p11.2 community
- Create a space that truly belongs to all of us

For families who are newly diagnosed, finding our website may be one of their first steps into this journey. Imagine the comfort they will feel seeing children who look like theirs, families who understand, and moments that reflect hope not isolation. Your contribution could be the reason another parent feels reassured, understood, and empowered.

This is more than a website update. It's a chance to redefine how our community is represented. We are calling on all families to share photos of your children, your moments, your journeys. Whether it's a candid smile, a milestone celebration, or a quiet everyday moment, it all matters. Together, we can create something that truly reflects the heart of 16p11.2. Let's show the world who we are.



SUBMIT

