16p11.2 GENETIC FOUNDATION

16p11.2 Genetic Foundation

FOR EVERY 16p11.2 FAMILY

Connection. Care. Hope.

Different journeys. Shared support.

16p11.2 deletion and duplication variants can affect speech and language, learning, development, and health. They may be associated with autism, ADHD, anxiety, and seizures, but each person's strengths and support needs are different.

BP4-BP5 deletions can increase the risk of obesity; BP4-BP5 duplications can be associated with low weight. Neither affects everyone.

Welcoming individuals and families with variants at every breakpoint.
BP2-BP3 variants bring their own patterns, including early weight gain and metabolic differences.

1. **Connect**
   Bring families together for education, support, and community.
2. **Advance research**
   Connect families, scientists, and research opportunities to move discovery forward.
3. **Drive better care**
   Advance coordinated care, clinical guidance, and clinician education.
4. **Advocate for policy**
   Promote understanding and improve access to care and education.

Find your community. Start your roadmap.

Join our Facebook community

Start here.

The Family Roadmap: a step-by-step guide for 16p11.2 families.

16pfoundation.org

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Welcome to our community.

Dear 16p11.2 family,

If you are reading this, your family has just received a 16p11.2 diagnosis, and I know the ground feels unsteady beneath you. I have stood exactly where you are standing.

My name is Faranak Herrera, and most people call me Franki. I am a physician, and I am also the mom of a son with a 16p11.2 deletion. When we got his diagnosis, I did what every parent does: I searched for answers, for a roadmap, for someone who had walked this road before us. What I found was very little. No clear path. No community waiting with open arms. Just questions.

That grief and that emptiness became the reason this foundation exists. I turned the hardest news of my life into the work of my life: building the 16p11.2 Genetic Foundation so no family has to start from nothing the way we did. Today we are a community of deletion and duplication families, at every breakpoint, funding research, writing family resources, and showing up for each other.

I will not tell you this road is easy. I will tell you that you do not have to walk it alone. And one day, when you are ready, your story may become someone else's lifeline, the way other families' stories became mine.

For today, just this: welcome. We are so glad you found us, even if you wish you never needed to.

With love and solidarity,

Faranak "Franki" Herrera, DO, MPH
Founder and CEO, 16p11.2 Genetic Foundation

What your support makes possible

Your gift directly powers the work families ask us for most:

- **A dedicated ICD-10 code for 16p11.2**
  Generic codes hide our numbers and block coverage and research. A dedicated code makes 16p visible.
- **16p CARE at Boston Children's**
  Specialist, coordinated 16p care at a world-class children's hospital.
- **Clinical trials**
  Moving 16p science from the lab to real treatments.
- **A parent support app**
  Community, resources, and answers in every family's pocket from diagnosis day.
- **Family conferences**
  Where families meet each other and the researchers. Next: Boston, July 2027.

Every gift, large or small, moves this work forward.

You can't undo a diagnosis.
But you can change what comes next.

Share 16pfoundation.org with the next 16p family, or fuel this work with a gift.
No family should start from nothing.

Scan to give

The 16p11.2 Genetic Foundation is a 501(c)(3) nonprofit organization.