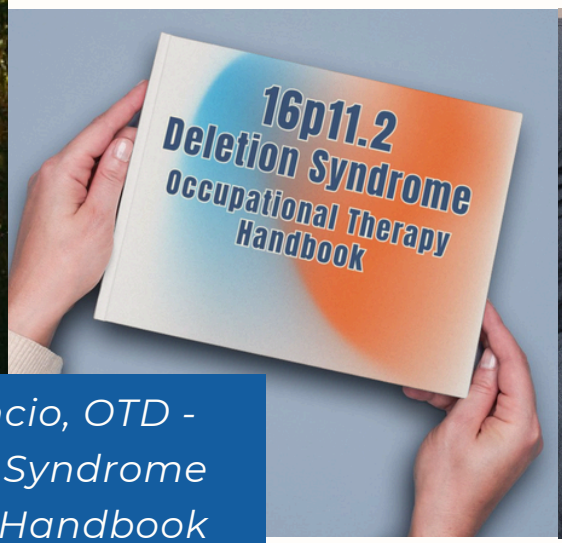
JUNE 2026 | ISSUE NO. 3

16p11.2 GENETIC FOUNDATION

Bringing Hope for the 16p11.2 Community

Nancy Ascencio, OTD - Author of 16p11.2 Deletion Syndrome Occupational Therapy Handbook

MEET NANCY ASCENCIO: A GIFT TO THE 16P11.2 COMMUNITY



A Graduate Student's Gift to the 16p11.2 Community

Every meaningful resource has a story behind it, and the story behind the 16p11.2 Deletion Syndrome Occupational Therapy Handbook begins with a young woman who has always been passionate about helping others.

Nancy Ascencio was born in Jalisco, Mexico, and raised in Southern California as the youngest of four siblings. Her parents, both graduates of the University of Guadalajara, instilled in their children the value of education, perseverance, and giving back to others. From an early age, Nancy knew she wanted a career that would allow her to help people, particularly those who are underserved and underrepresented.

She pursued that calling at the University of California, Irvine, where she double majored in Psychology and Social Behavior and Social Ecology while earning a minor in Sociology. Along the way, she volunteered, worked as a caregiver, supported students with disabilities, and explored different helping professions before discovering occupational therapy, a field she immediately knew was the right fit

One experience, however, would shape her future in a way she never expected.

Nancy worked as a nanny for a family whose son has 16p11.2 deletion syndrome. Through that role, she witnessed firsthand the challenges families face when navigating a rare genetic diagnosis. She saw the endless appointments, the constant advocacy, the struggle to find knowledgeable professionals, and the sacrifices families make to ensure their children receive the support they deserve. She also saw the remarkable progress that occupational therapy could help achieve.

When Nancy entered the Occupational Therapy Doctorate Program at California State University, Dominguez Hills in 2023, she carried those experiences with her. As she learned about evidence-based practice, family-centered care, and pediatric therapy, she realized there was a significant gap in resources available specifically for families affected by 16p11.2 deletion syndrome.

Rather than simply identifying the problem, Nancy decided to become part of the solution.

For her doctoral capstone project, she committed herself to creating a resource unlike anything that had previously existed for the 16p11.2 community. What began as a graduate school project grew into a monumental undertaking. Nancy dedicated hundreds of hours to researching scientific literature, analyzing occupational therapy interventions, organizing information, and translating complex clinical concepts into practical guidance that families could use.

JUNE 2026 | ISSUE NO. 3

The result is 300+ pages of rigorously researched guidance – the 16p11.2 Deletion Syndrome Occupational Therapy Handbook.

16p11.2 GENETIC FOUNDATION

This comprehensive handbook explores the impact of 16p11.2 deletion syndrome across the lifespan and examines how occupational therapy can support individuals and families at every stage of development. It includes practical strategies for daily challenges, evidence-based intervention recommendations, guidance for caregivers, and information designed to empower families as they navigate therapies, school systems, and everyday life.

Creating a resource of this magnitude required an exceptional level of dedication. While balancing the demands of doctoral coursework, fieldwork placements, and preparation for professional licensure, Nancy poured her time, expertise, and heart into producing a handbook that would serve families she might never meet. Her work transformed academic research into a meaningful and accessible resource for our community.

The impact has already been felt around the world. The handbook has reached families in 39 countries, providing education, support, and hope to caregivers seeking answers and practical tools to help their loved ones thrive.

At the 16p11.2 Genetic Foundation, we are profoundly grateful for Nancy's contribution. Her project demonstrates the incredible value that graduate students can bring to rare disease communities. One student, one project, and one vision created a resource that will continue supporting families for years to come.

READ THE GUIDE:

16p11.2 Deletion Syndrome Occupational Therapy Handbook

JUNE 2026 | ISSUE NO. 3

COULD YOU HELP BUILD THE NEXT RESOURCE?

Nancy's work has inspired us to think bigger about what is possible when students, universities, and rare disease communities collaborate.

We are actively seeking graduate students, doctoral candidates, faculty mentors, and academic programs interested in developing projects that benefit individuals with 16p11.2 deletion and duplication syndromes.

We would especially welcome partnerships in:

- Speech-Language Pathology
- Physical Therapy
- Psychology and Behavioral Health
- Social Work
- Transition to Adulthood and Adult Services

Imagine the impact of a comprehensive speech and language handbook, a physical therapy guide, a mental health resource, or a transition-to-adulthood toolkit created specifically for the 16p11.2 community. These projects could provide families with life-changing information while helping students gain meaningful experience serving a rare disease population.

Nancy showed us what is possible when passion, education, and service come together. We hope her work will inspire the next generation of graduate students to partner with the 16p11.2 Genetic Foundation and help build the resources our families need and deserve.

Thank you, Nancy, for your remarkable gift to our community. Your dedication has left a lasting legacy that will continue to support families around the world for years to come.

Contact Us

16p11.2 GENETIC FOUNDATION

JUNE 2026 | ISSUE NO. 3

BRIDGING THE GAPS: NEW WEBINAR SERIES COMING TO THE 16P11.2 COMMUNITY

The 16p11.2 Genetic Foundation is excited to announce a major initiative designed to strengthen our community, improve access to information, and support the future development of the 16p11.2 Center of Excellence coming to Boston in 2027.

In June 2026, we will launch the **16p Webinar Series: Bridging the Gaps**, a twice-monthly educational and community-focused webinar program. This series will serve as the foundation for a broader educational curriculum being developed for 2026 and beyond.

Together, these initiatives will help educate families, prepare individuals for specialized care, increase research participation, and strengthen connections across the global 16p11.2 community.

WEBINAR SERIES LAUNCHES JUNE 25

Join Dr. Faranak Herrera on June 25, 2026, for our inaugural webinar, "You're Not Alone: Understanding 16p11.2 and the Role of the Foundation."

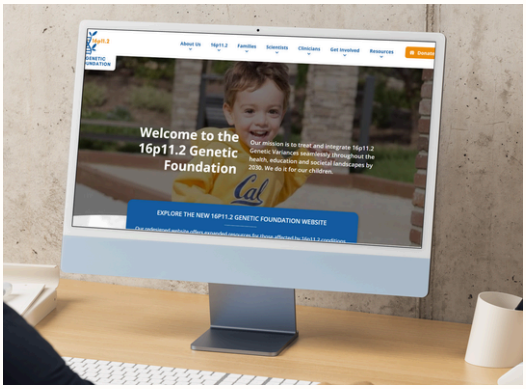
This free webinar will introduce families to 16p11.2, highlight Foundation initiatives, and share opportunities to get involved in research, advocacy, and community support.

Watch for registration details and future webinar announcements!

CONNECTING EDUCATION, CARE, AND RESEARCH

Education empowers families to advocate for their loved ones, participate in research, and access specialized care. Through the Webinar Series and future curriculum, families will gain valuable knowledge while helping build a stronger, more connected 16p11.2 community.

JUNE 2026 | ISSUE NO. 3



WELCOME TO OUR REDESIGNED WEBSITE: A NEW HOME FOR THE 16P11.2 COMMUNITY

We are excited to officially welcome you to our new online home:

HTTPS://16PFOUNDATION.ORG

This launch is more than a website update. It reflects how far our community has come and where we are headed together.

As our Foundation has grown, so has our understanding of the needs across the full spectrum of 16p11.2 genetic variances. **What began with serving a smaller portion of the community has evolved into a broader commitment to support individuals and families affected by proximal and distal deletions and duplications across 16p11.2.** That growth inspired a new, more inclusive digital home and identity.

Our new website was built with one goal in mind: making it easier for families, caregivers, clinicians, researchers, donors, and supporters to find trusted information, meaningful connection, and opportunities to take action.

WHAT YOU'LL FIND ON THE NEW WEBSITE

- Expanded educational resources to help families better understand 16p11.2 genetic variances and navigate next steps after diagnosis
- Improved navigation and organization so information is easier to find and explore
- Research and clinical updates designed to connect families with advances in care and scientific discovery
- Community opportunities including events, newsletters, and ways to stay connected
- Greater transparency and impact reporting so supporters can see how the Foundation is growing and advancing its mission

You'll also find content that reflects the Foundation's four pillars of impact: connecting our community, advancing research, improving care through Centers of Excellence, and advocating for broader recognition and support for individuals living with 16p11.2 genetic variances.

16p11.2 GENETIC FOUNDATION

JUNE 2026 | ISSUE NO. 3

ALL ROADS LEAD TO BOSTON

Exciting things are happening in the 16p11.2 community, and all roads are leading to Boston.

The 16p11.2 Genetic Foundation is thrilled to announce plans for the 16p11.2 Conference in July 2027, bringing together families, clinicians, researchers, advocates, and community leaders for both duplication and deletion. The conference will provide opportunities to learn about the latest research, connect with other families, and help shape the future of care for individuals living with 16p11.2 conditions.

One of the highlights of the conference will be the participation of Dr. Wendy Chung, whose pioneering work in genetics and neurodevelopmental disorders has helped advance understanding of 16p11.2 and improve outcomes for countless families. Her dedication to research and patient care continues to inspire our community and drive progress toward better treatments and support.

The conference comes at a pivotal moment for the Foundation. **At the same time, efforts are underway to establish the first 16p11.2 Center of Excellence in Boston, creating a dedicated hub for specialized clinical care, research, education, and family support.** This Center of Excellence represents an important step toward ensuring that individuals with 16p11.2 deletion and duplication syndromes have access to coordinated, expert care tailored to their unique needs.

Together, the 2027 Conference and the development of the Boston Center of Excellence reflect the Foundation's commitment to connecting families with leading experts, accelerating research, and building a stronger future for the entire 16p11.2 community.

Over the coming months, we will share additional details about conference registration, speakers, educational sessions, family activities, and opportunities to get involved.

Together we are building the future of 16p11.2 care, research, and community.

16p11.2
GENETIC FOUNDATION

JUNE 2026 | ISSUE NO. 3

HELP TELL THE STORY OF 16P11.2

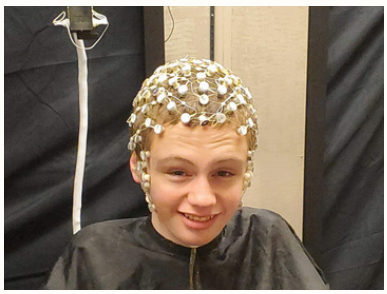
Send Photos

One of our biggest goals as we continue to grow is to ensure that our Foundation reflects the people we serve.

We are actively seeking photos of individuals with 16p11.2 to feature not only on our website, but also across Foundation materials including newsletters, educational resources, presentations, awareness campaigns, printed materials, social media, and future community initiatives.

We want our community to be represented by real people, real families, and real stories, not stock images.

Whether it's a candid family moment, therapy photo, favorite activity, milestone celebration, conference memory, or everyday life, your photos help show the strength, diversity, and experiences within the 16p11.2 community.



BUILDING A STRONGER FUTURE TOGETHER

The 16p11.2 Genetic Foundation is growing, and we are looking for volunteers to help expand our impact. Whether you have experience in fundraising, social media, family support, events, design, advocacy, administration, research, or simply a passion for helping others, there is a place for you.

Every project, connection, and milestone happens because members of our community step forward to help. No matter how much time you can give, your talents can make a difference for all those affected by 16p11.2.

Interested in getting involved?
Reach out to learn more about current volunteer opportunities.

16p11.2 GENETIC FOUNDATION

JUNE 2026 | ISSUE NO. 3

CURIOUS KID SERIES CONTINUES TO INSPIRE LEARNING AND WELL-BEING

The 16p11.2 Genetic Foundation's *Curious Kid Series* provides engaging, age-appropriate learning opportunities for children and families while exploring genetics, individuality, and emotional wellness in fun and accessible ways. These books are available for purchase on Amazon, and a portion of proceeds from every sale goes to the Foundation to support individuals affected by 16p11.2 genetic conditions.

WHAT ARE MY GENES?

Learn the basics of genetics, including what genes are, where they come from, and how they help make each of us unique. Through interactive activities and discussion, children gain a better understanding of the building blocks that contribute to who we are.

WHAT IS VARIATION?

Celebrate the differences that make every person special and explore how genetic variation contributes to diversity in appearance, abilities, interests, and personalities. The book encourages curiosity, acceptance, and appreciation for the many ways people can be different.

JUST BREATHE

Focusing on emotional wellness, this book introduces simple breathing and mindfulness techniques to help children manage stress, anxiety, and big emotions. Participants practice calming strategies they can use at home, school, and in everyday life.

The *Curious Kid Series* is designed to help children build knowledge, confidence, and resilience while connecting with others in the 16p11.2 community.

Click the titles above to purchase.

16p11.2 GENETIC FOUNDATION