



February 2026

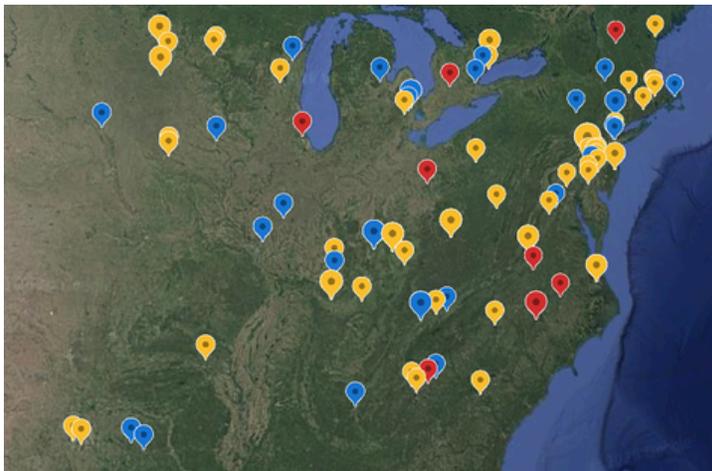
ASXL NHS NEWSLETTER

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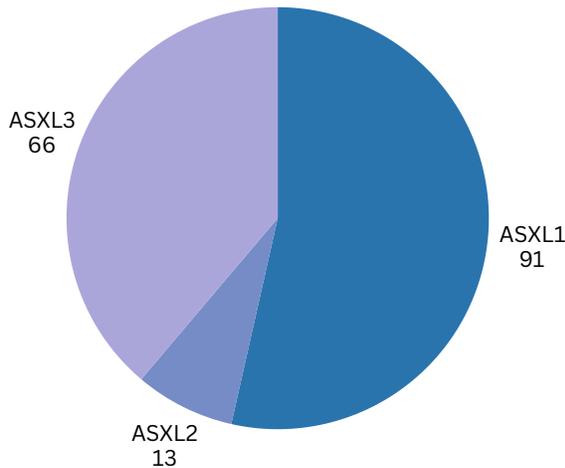
Our Worldwide Community

ASXL1 ASXL2 ASXL3

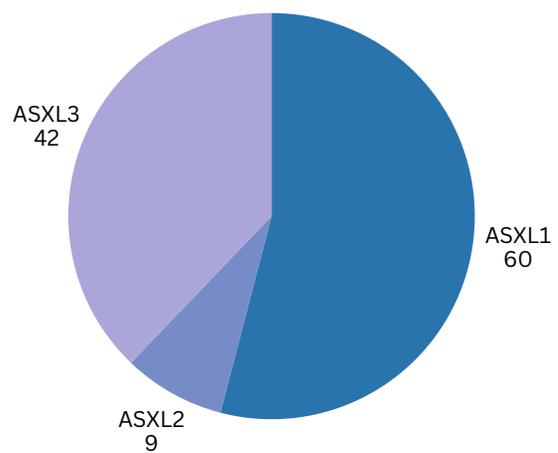


170 families have enrolled in the NHS study and 111 ASXL individuals donated blood to our REACH Biobank. Countries not included in the map: Australia, New Zealand, Canada, Colombia, Brazil, Chile and Argentina.

ASXL NHS Enrollment



ASXL Biobank Enrollment



We're actively enrolling participants in the study and collecting blood samples for the REACH Biobank!



Want to check your enrollment status or learn how to participate?
Email us at ASXL-CHROMATIN-REGISTRY@mednet.ucla.edu — we're happy to help.

ASXL NHS & ALPS UPDATES

Study Spotlight: ASXL Behavioral Phenotyping Study (ALPS)

Led by Dr. Natasha Ludwig at the Kennedy Krieger Institute



• About the Study:

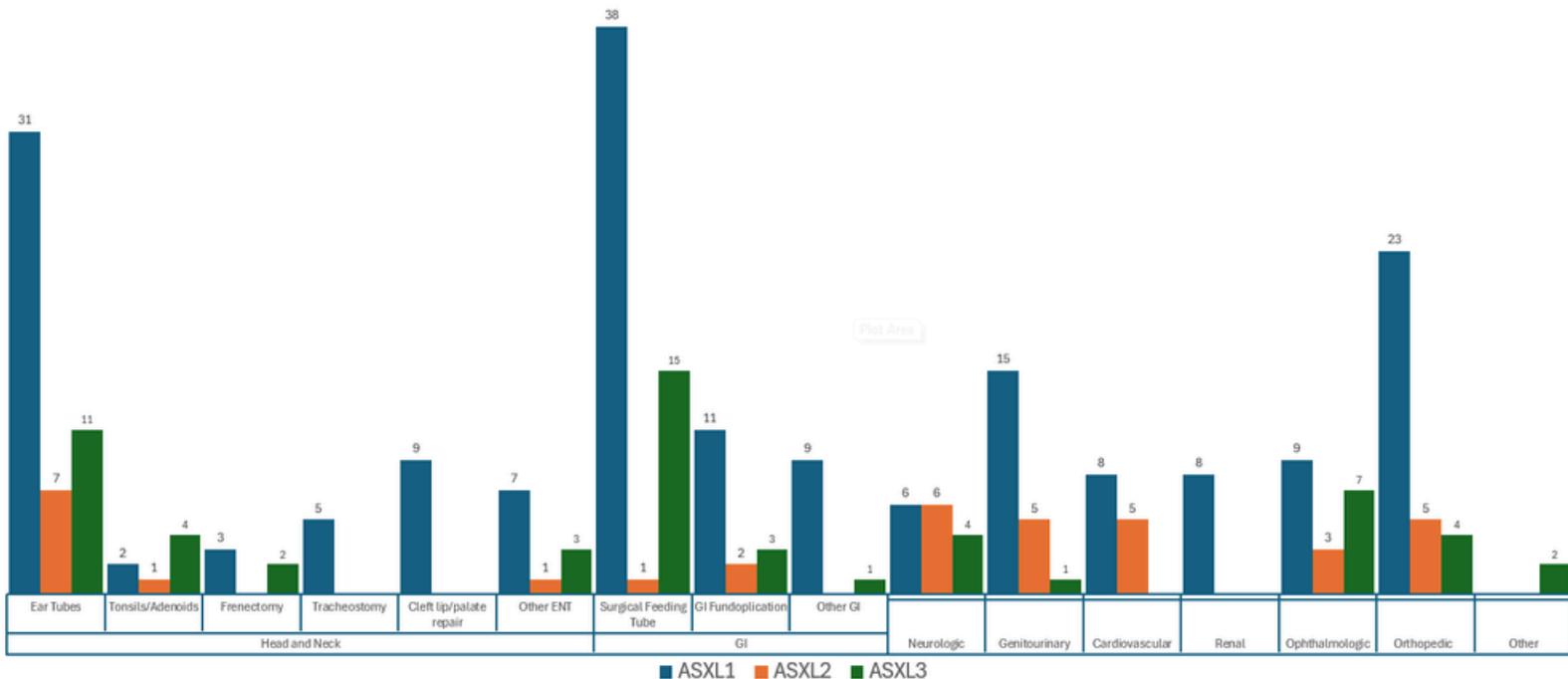
- The ALPS Study is part of the ASXL NHS and aims to better understand the cognitive, social, and behavioral profiles of individuals with ASXL-related disorders and identify the most effective assessment tools for future research and clinical trials.

• Participation:

- In-Person Component
 - This was successfully conducted during the 2024 Family Conference and will return again at the 2026 Family conference.
 - Remote Component (Recent Launch)
 - This option makes it easier for families who are unable to travel to participate in the study.
 - It includes: 2 Telehealth interviews and Online surveys which can be completed at home
- In just the last three months, we welcomed **11 new ASXL1 and ASXL2 families** into the remote study! This growth reflects the incredible commitment of families helping move ASXL research forward.

NHS Survey Data

Surgical Procedures in the ASXL-Related Disorders



This chart highlights the distribution of surgical procedures across participants with ASXL1, ASXL2, and ASXL3 variants. Surgeries related to the head and neck as well as the gastrointestinal system were the most frequent surgeries but surgeries have been reported in many different organ systems.

COMING SOON!

JUNE 2026 ASXL Research Symposium & Family Conference



Connect with us at the 2026 ASXL Research Symposium and Family Conference!

Conference will have opportunities to participate in:

- ✓ Sample collection to support future research
- ✓ Neurodevelopmental testing and behavioral assessments
- ✓ Direct engagement with leading ASXL researchers and clinicians

- Save the date: **June 25th - June 28th 2026**
- Location: Ann Harbor, Michigan, United States
- For more information visit the [ARRE Foundation website](https://www.arrefoundation.org)

ASXL Legacy Study

We are preparing to launch the ASXL Legacy Study, a new initiative within the Natural History Study designed to learn from families who have lost a loved one due to ASXL-related disorders.



Part of the ASXL-Related Disorders Natural History Study

By understanding medical histories and clinical experiences, this work will help improve care, guide future research, and will also serve as a compassionate space for families to contribute to advancing research while preserving their loved ones' legacies.

We will be sharing more information soon 

Achievements from the ASXL NHS Study and REACH Biobank

Title: Initial use of the physical abilities and mobility scale (PAMS) in ASXL-related disorders

Authors: McLean, H., Northrup, R., Wong, S., Sloan, J., Russell, B.E., Wilson, R., Ludwig, N.N.

Conference: American Academy of Cerebral Palsy and Developmental Medicine Annual Conference, New Orleans, Louisiana, United States. October 15-18, 2025.

Title: Considerations for enhancing conference-based data collection for rare neurogenetic conditions through multi-interest holder collaboration

Authors: Northrup, R.A., Russell, B.E., Wilson, R.B., Johnson, A., Adams, L., Sloan, J., Wong, S., Capps, I., Franklin, J., Hommer, R., & Ludwig, N. N.

Conference: ASXL Research Symposium, Boston, Massachusetts, United States. October 19-20, 2025. Poster Award Winner.

Title: Initial Investigation of Cortical Visual Impairment in ASXL-Related Disorders.

Authors: Magallanes, A., Hommer, R., Albert, P., Wilson, R., Russell, B.E., Ludwig N.N.

Conference: ASXL Research Symposium, Boston, Massachusetts, United States. October 19-20, 2025. Poster Award Winner.