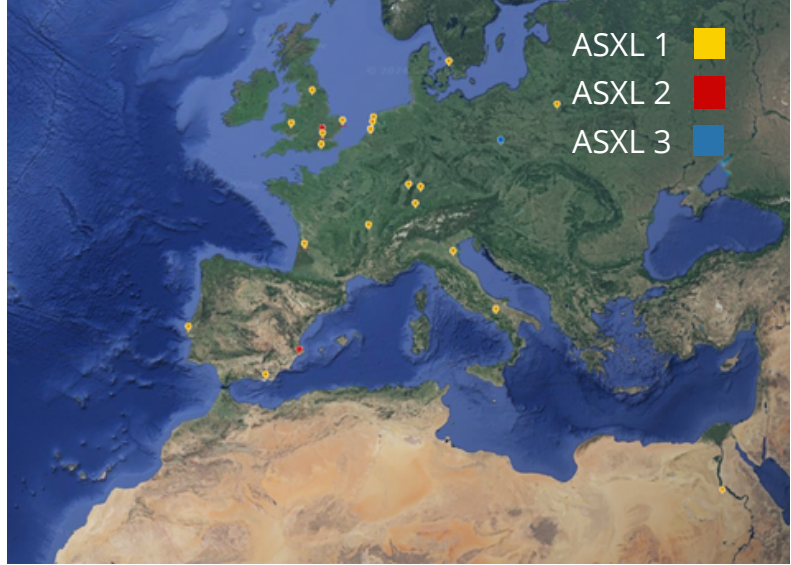
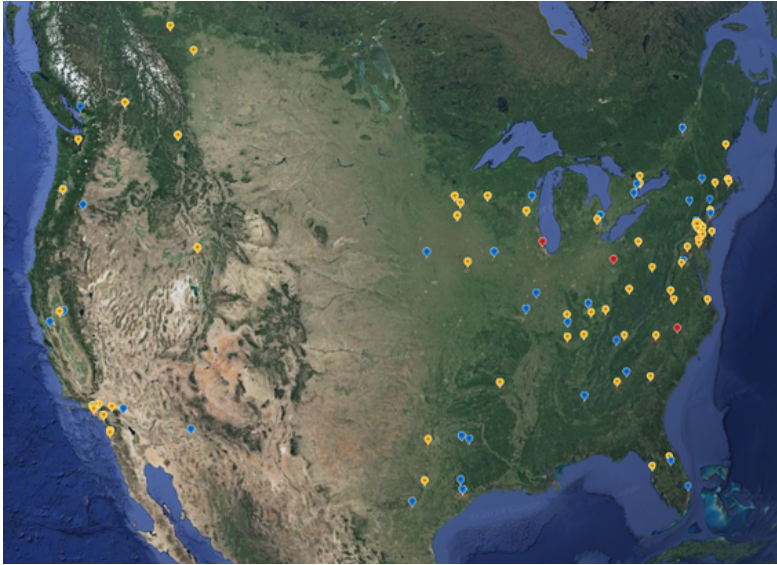


# ASXL NEWSLETTER

BIANCA RUSSELL, MD  
WEN HANN-TAN, MD

LOREN PENA, MD PHD  
VANDANA SHASHI, MBBS MD

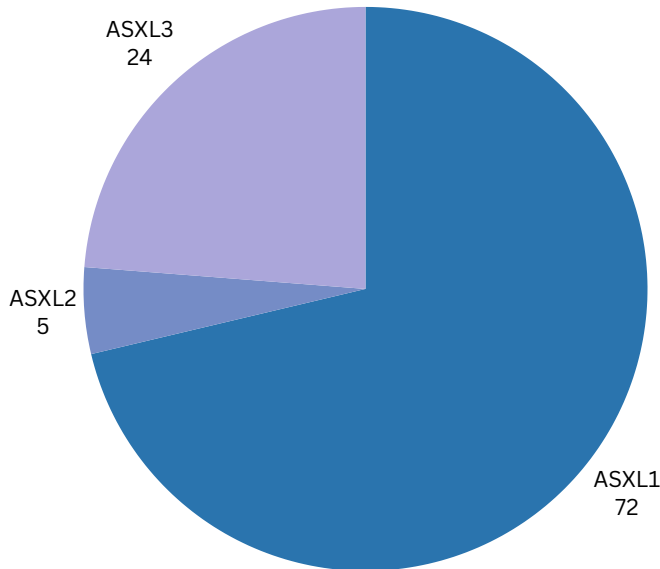
JENNIFER COHEN MD  
NATASHA LUDWIG, PHD



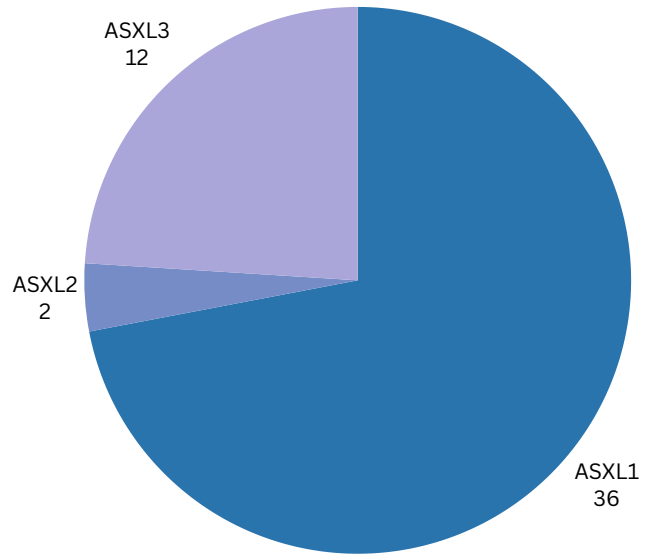
## Registry Around the Globe

137 families are enrolled in our Registry or are in the process of enrolling. Not pictured countries include: Australia, New Zealand, Brazil, Colombia, Chile, China, and Egypt.

### ASXL Registry Enrollment (completed)



### ASXL Biobank Enrollment (completed)



Email [ASXL-CHROMATIN-REGISTRY@mednet.ucla.edu](mailto:ASXL-CHROMATIN-REGISTRY@mednet.ucla.edu) to check your registry enrollment status or if you are interested in participating in the Biobank

# ASXL Family Conference

*Save the date for 2024!*

## ASXL Research Symposium and Family Conference

July 18-21, 2024 | Baltimore, Maryland, U.S.A.

**ARRE**  
ASXL RARE RESEARCH ENDOWMENT



Our UCLA Registry and Biobank team will be present at the family conference to collect data with more information to come! We look forward to seeing everyone there.

## New Registry Site



We are excited to announce that Kennedy Krieger Institute has been added as a site to the UCLA Registry. The site PI is Natasha Ludwig, PhD. Dr. Ludwig is in the process of helping our team roll out standardized neurodevelopmental assessments to increase clinical trial readiness.

[REACH-BIOBANK.ORG](https://REACH-BIOBANK.ORG)

# REACH Biobank

Rare Epigenetic And Chromatin Disorders

In collaboration with Dr. Valerie Arboleda and Isabella Lin, we have launched a REACH website for the ASXL Registry and Biobank. This website will serve as the location of our data dictionary and data request forms.

**ARRE**  
ASXL RARE RESEARCH ENDOWMENT

Thank you to the  
ARRE Foundation  
and the BOS  
Foundation for their  
continued financial  
support!

