

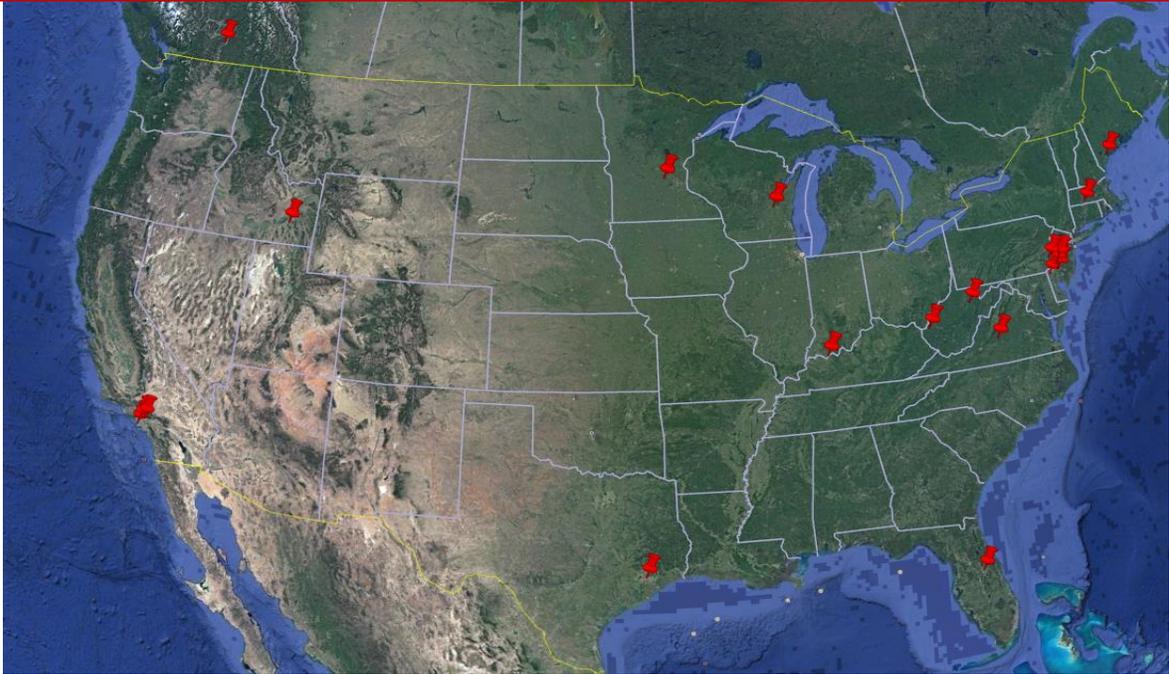


ASXL Registry Newsletter

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**Pictured Left:
Enrolled ASXL1
Families in the US and
Canada**

Registry Tidbit:
Average Age of
Participants is
6.5 years.

We will continue to
update these maps in
our newsletters and
plan to add ASXL2 and
ASXL3 families as
more families enroll.

**Pictured Right:
Enrolled ASXL1
Families in Europe**



SAVE THE DATE
July 27-28, 2018
Los Angeles, CA
ASXL Research
Meeting and
BOS Family Meet-Up
Sponsored by:

UCLA **MATTEL** Childrens Hospital

**Bohring Opitz
Syndrome
Foundation, Inc.**

AARE

Enrollment Numbers

Total Completed Enrollment: **33**

- ASXL1: **29**
- ASXL2: **1**
- ASXL3: **3**

ASXL1 Surveys Completed: **15**

We have an additional **40 families** who have not yet completed the enrollment and consent process. Our goal is to enroll **50 families** within the first year.

Easy Enrollment:

Step 1: Email ASXLRegistry@cchmc.org

Step 2: 15-30 minute phone call to review the consent form and answer questions

Step 3: Sign consent form and send it back.

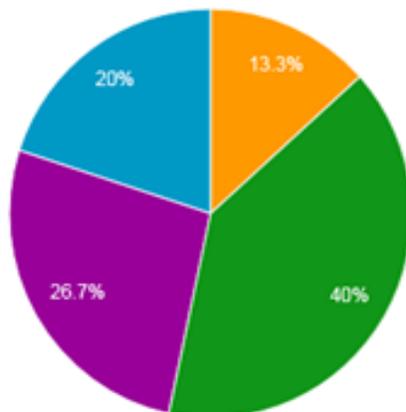
Why Enroll?

While we have been able to gather some data, it is incomplete. We encourage families to enroll and complete the surveys. This will allow us to obtain accurate information that can be used to help determine treatments, management plans and expectations for the future. For the Registry to be a continued success, we need your support. We will continue to work on developing new surveys that should take less than 20 minutes to complete in order to keep your time commitment to a minimum. Please, continue the enrollment process and complete the survey. And if you have already completed your survey, thank you for your time.

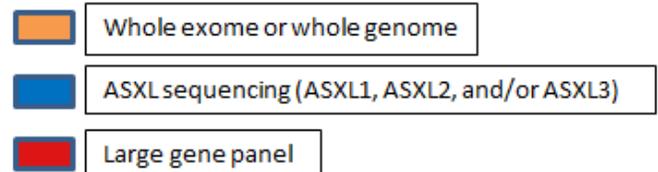
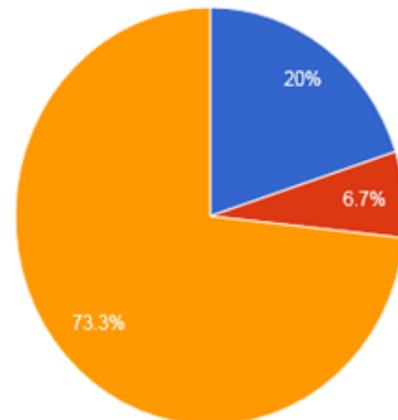
We welcome your feedback and suggestions.

Preliminary Survey Data:

Age of Diagnosis Based on Genetic Testing



Identification of ASXL Change in Participants



Next Steps

Our next goals are to begin creating surveys for the ASXL2 and ASXL3 families. We are hoping to be in contact with these families in the future to ensure the Registry continues to serve the needs of all ASXL-Families.

We have begun collecting additional neurologic data (EEGs and MRIs) from the enrolled ASXL1 families with the plan to analyze and publish data focusing on the neurologic issues in BOS.