

## 2024 ASXL Family Conference - Family Financial Scholarship Application

### Introduction and background

Thank you for your interest in attending the ASXL Family Conference with the support of a family financial scholarship!

### Understand the scholarship program

We strongly encourage you to [watch the informational video](#) (7 minutes 30 seconds) and/or review the program information found at [www.asxlconference.org/family-scholarships](http://www.asxlconference.org/family-scholarships) prior to starting the application. **These resources explain the intent of the scholarship program and describes the priority criteria for applicant selection.**

### Completing the application

This application will take approximately 15 minutes to complete. You will not be able to come back to this application once it is in progress.

**Before you begin this survey, please ensure you have the following information available:**

- **Genetic testing reports for each affected individual in your family** (document upload)
- **A brief written statement of why a scholarship would benefit your family (max: 150 words)**
- Your estimated arrival/departure dates
- Who in your family is planning to attend the conference
- Your interest in participating in research activities at the ASXL Family Conference
- If you have a Clinical Research ID (number is not required for the application)

### Definitions of terms used in this application

- **Applicant:** The person completing this application
- **ASXL-related disorder:** A neurodevelopmental disorder caused by a variant in the ASXL1, ASXL2, or ASXL3 gene; also known as Bohring-Opitz Syndrome (ASXL1), Shashi-Pena Syndrome (ASXL2), and Bainbridge-Ropers Syndrome (ASXL3)
- **Parent/primary caregiver:** A parent or guardian who is responsible for the care of an individual with an ASXL-related disorder
- **Affected individual(s):** Individual(s) in your household with an ASXL-related disorder

\* 1. Are you (the applicant) a parent/primary caregiver of an individual with ASXL-related disorder OR are you an individual with an ASXL-related disorder?

Yes

No

## 2024 ASXL Family Conference - Family Financial Scholarship Application

### About you and your family

\* 2. Applicant name

**First name**

**Last name  
(surname)**

\* 3. Applicant email address

**Email address**

\* 4. Applicant address

**Street address**

**Street address line 2**

**City**

**State/province**

**Zip code/postal code**

**Country**

\* 5. May we add your contact information to our database so you can receive future communications from the ARRE Foundation?

- Yes - I opt in to receive or continue receiving communications from the ARRE Foundation
- No - I opt out of receiving communications from the ARRE Foundation

\* 6. Which ASXL-related disorder affects your family?

- ASXL1/Bohring-Opitz Syndrome
- ASXL2/Shashi-Pena Syndrome
- ASXL3/Bainbridge-Ropers Syndrome
- Not sure

\* 7. How many people in your family have a confirmed diagnosis of an ASXL-related disorder?

- 1
- 2
- 3
- 4 or more

## 2024 ASXL Family Conference - Family Financial Scholarship Application

### Information about the affected individual (1)

Please answer the following questions about the first affected individual in your family. *If you indicated that more than one person in your family has an ASXL-related disorder, you will be prompted to complete this information for each individual.*

#### \* 8. About the affected individual

First name

Last name

Year of birth

Year of ASXL diagnosis

\* 9. What type of ASXL variant does the affected individual have? *This information can be found on the individual's genetic testing report.*

- Pathogenic variant
- Variant of uncertain significance
- Likely pathogenic
- Unknown/not sure
- Has a clinical diagnosis (has not had genetic testing)
- Other (please specify)

Genetic testing reports will be reviewed by the clinical genetics team at UCLA as part of the eligibility screening process. If you are not comfortable sharing your genetic report here, please email it directly to the UCLA team at [asxl-chromatin-registry@mednet.ucla.edu](mailto:asxl-chromatin-registry@mednet.ucla.edu) and note in your email that you are providing the report for the scholarship eligibility screening process.

10. Please upload the genetic testing report here.

Choose File

Choose File

No file chosen

A Clinical Research ID (CRID) is a unique identifier that can be used to share your research data between studies. If you are interested in participating in an ASXL research study at the conference, the study may require a CRID. Signing up for a CRID takes 2-3 minutes at [thecrid.org](http://thecrid.org).

\* 11. Does this affected individual have a Clinical Research ID (CRID)?

- Yes
- No
- Unsure

\* 12. Other than the person described above, is there another individual in your family who has an ASXL-related disorder?

Yes

No

## 2024 ASXL Family Conference - Family Financial Scholarship Application

### Information about the affected individual (2)

Please answer the following questions about the second affected individual in your family. *If you indicated that more than two people in your family has an ASXL-related disorder, you will be prompted to complete this information for each individual.*

#### \* 13. About the second affected individual

First name

Last name

Year of birth

Year of ASXL diagnosis

\* 14. What type of ASXL variant does this affected individual have? *This information can be found on the individual's genetic testing report.*

- Pathogenic variant
- Variant of uncertain significance
- Likely pathogenic
- Unknown/not sure
- Has a clinical diagnosis (has not had genetic testing)
- Other (please specify)

Genetic testing reports will be reviewed by the clinical genetics team at UCLA as part of the eligibility screening process. If you are not comfortable sharing your genetic report here, please email it directly to the UCLA team at [asxl-chromatin-registry@mednet.ucla.edu](mailto:asxl-chromatin-registry@mednet.ucla.edu) and note in your email that you are providing the report for the scholarship eligibility screening process.

15. Please upload the genetic testing report here.

Choose File

Choose File

No file chosen

A Clinical Research ID (CRID) is a unique identifier that can be used to share your research data between studies. If you are interested in participating in an ASXL research study at the conference, the study may require a CRID. Signing up for a CRID takes 2-3 minutes at [thecrid.org](http://thecrid.org).

\* 16. Does this affected individual have a Clinical Research ID (CRID)?

- Yes
- No
- Unsure

\* 17. Other than the person described above and previously, is there another individual in your family who has an ASXL-related disorder?

Yes

No

## 2024 ASXL Family Conference - Family Financial Scholarship Application

### Information about the affected individual (3)

Please answer the following questions about the third affected individual in your family. *If you indicated that more than three people in your family has an ASXL-related disorder, you will be prompted to complete this information for each individual.*

#### \* 18. About the third affected individual

First name

Last name

Year of birth

Year of ASXL diagnosis

\* 19. What type of ASXL variant does this affected individual have? *This information can be found on the individual's genetic testing report.*

- Pathogenic variant
- Variant of uncertain significance
- Likely pathogenic
- Unknown/not sure
- Has a clinical diagnosis (has not had genetic testing)
- Other (please specify)

Genetic testing reports will be reviewed by the clinical genetics team at UCLA as part of the eligibility screening process. If you are not comfortable sharing your genetic report here, please email it directly to the UCLA team at [asxl-chromatin-registry@mednet.ucla.edu](mailto:asxl-chromatin-registry@mednet.ucla.edu) and note in your email that you are providing the report for the scholarship eligibility screening process.

20. Please upload the genetic testing report here.

Choose File

Choose File

No file chosen

A Clinical Research ID (CRID) is a unique identifier that can be used to share your research data between studies. If you are interested in participating in an ASXL research study at the conference, the study may require a CRID. Signing up for a CRID takes 2-3 minutes at [thecrid.org](http://thecrid.org).

\* 21. Does this affected individual have a Clinical Research ID (CRID)?

- Yes
- No
- Unsure

\* 22. Other than the person described above and previously, are there additional individuals in your family who has/have an ASXL-related disorder? *If yes, the ARRE Foundation will follow up with you to collect information about the additional affected individual(s).*

Yes

No



## 2024 ASXL Family Conference - Family Financial Scholarship Application

### Anticipated attendance details for your family

**Please answer the following questions to help us understand who in your family may attend the ASXL Family Conference and when you will be there.**

23. Approximately how many people in your family are planning to attend the ASXL Family Conference?

Adults

Children (age 18 and younger)

24. Is the affected individual(s) planning to attend the ASXL Family Conference?

Yes

No

Unsure

25. Where are you traveling from to reach Baltimore? (City and state/province)

26. What are your current *estimated* arrival and departure dates?

Estimated arrival date

Estimated departure date

\* 27. Are you interested in learning more about opportunities to participate in ASXL research studies at the conference? *If yes, someone from the ARRE Foundation will follow up with you to provide additional information.*

Yes

No

## 2024 ASXL Family Conference - Family Financial Scholarship Application

### Family financial need and background

**The following questions will help us understand your family's background and financial need. This information will only be used during the scholarship awarding process; it may also be reported as a summary to funders who require this information (you will never be identified in a summary report).**

\* 28. How would this scholarship help your family attend the 2024 ASXL Family Conference?  
*Please limit your response to approximately 150 words.*

\* 29. Does any member of your household have any of the following experiences? Please check all that apply.

- Identify with a minority racial or ethnic group
- Identify with the LGBTQ+ community
- Have a physical or intellectual disability
- Have been or currently are homeless
- Have been or currently are in the foster care system
- Have been or is currently receiving free or reduced school lunch (U.S. only)
- Have or had no parents or legal guardians who completed a bachelor's degree (4 year university/collegiate degree)
- Receive or received government support for food or housing
- Grew up in a rural area or urban inner-city environment
- None of the above

\* 30. Is your household currently receiving government support to help you pay for food or housing?

- Yes
- No

## 2024 ASXL Family Conference - Family Financial Scholarship Application

### Acknowledgments

The following is important information to understand about the scholarship program:

**Travel stipends:** Family financial scholarships are intended to subsidize the cost of attendance at the ASXL Family Conference. The amount per scholarship is anticipated to be approximately \$750 USD per family. Families are responsible for additional costs not covered by the scholarship.

**Focus group participation on July 20:** At least one primary caregiver in the scholarship recipient's household must participate in the three discussion-based focus groups on Saturday, July 20. These focus groups are part of the ASXL Family Conference programming. The focus groups will gather additional family input on the topics of gastrointestinal-related concerns, neurodevelopment (cognition/intellectual disability and communication), and behavioral dysregulation (aggressive behavior, self-injury, and other unwanted behaviors). Participation in other in-person research activities at the ASXL Family Conference is strongly encouraged of all family attendees.

**Participation in an orientation session by April 30:** All accepted scholarship recipients must participate in a 30-minute orientation session with ARRE Foundation staff to be scheduled at a time that works for you before April 30. This is to ensure you understand all the program requirements and to answer any questions you might have about attending the ASXL Family Conference.

**Acceptance of award by April 30:** All accepted scholarship recipients must formally accept their award by Tuesday, April 30. Failure to formally accept will result in forfeiture of your scholarship, which will then be awarded to a waitlisted family.

\* 31. Please acknowledge your understanding of the following program details by checking each box.

If accepted, I understand that:

- The scholarship may not cover all of my family's travel costs and I am responsible for additional costs related to travel and participation in the conference.
- A primary caregiver from my household is required to participate in the focus group discussion sessions the afternoon of Saturday, July 20.
- I am responsible for making my family's own travel plans, including arranging ground transportation to and from the airport (if applicable).
- I must schedule and participate in a 30-minute orientation call with ARRE Foundation staff by April 30.
- I must formally accept my financial scholarship award by April 30 and if I fail to do so by the deadline, my scholarship will be given to a waitlisted family.
- My scholarship funds will be paid to me/my family after the conference unless arranged otherwise (US recipients by check and non-US recipients via wire transfer).