



Recently Diagnosed with DDX3X?

Hello and welcome to the DDX3X tribe! If your child has just been diagnosed with DDX3X syndrome, please know you have landed in a place of people who understand. If you want to get involved, here are a few steps to get started:

- Join the “Gene DDX3X” Facebook group**
Find support, resources, child updates, and parent questions from other members of the DDX3X community when you join our DDX3X Facebook group.
- Like the “DDX3X Foundation Research” Facebook page**
Get more information about research, the patient registry, and other specific DDX3X Foundation updates when you like our Research Facebook group.
- See what we currently know about DDX3X Syndrome**
Read articles summarizing what DDX3X is and what we’ve learned about it so far on the “Resources for Families” page of our website.
- Join the Patient Registry**
Filling out this form will help researchers learn about and understand the DDX3X gene mutations that affect our children. You can find the form under the “Registry” page on our website.
- Bookmark DDX3X.org**
Stay updated on new information about DDX3X Syndrome by saving our website to your browser.
- Follow DDX3X on Instagram**
Follow us on Instagram to join our community! Email us at beth@ddx3x.org with your child’s first name, date of birth, and picture if you want their story to be featured.
- Participate in our next Family Day event**
Our annual Family Day event allows you to meet others in the community, hear presentations from researchers, and more! Visit our “Family Conference” page to learn more.
- Enroll in Sherr’s Brain Development Research Study**
Dr. Elliott Sherr is leading the way with DDX3X research. Find more information about the study and complete a form to enroll your child on the “Recently Diagnosed” page of our website.
- Enroll in the Mount Sinai Study**
Join this study to accelerate rare disease research and track the natural history of the five single-gene causes of autism, including DDX3X. For more details, visit our “DDX3X Research” page.
- Arrange for a Skin Biopsy**
One parent and your child can have a skin biopsy performed to support current DDX3X research. Learn more about this process on our “DDX3X Research” page.
- Shop on Amazon Smile**
Please consider shopping using Amazon Smile, where all proceeds will support the DDX3X Foundation and our research.
- Fundraise for the DDX3X Foundation**
Please considering supporting Dr. Sherr’s current research to find a drug treatment for girls with the DDX3X mutation. You can show your support by visiting the “Donate” page on our website.

To Learn More About Resources For DDX3X Families, Please visit <https://ddx3x.org/>