

# DDX3X Foundation Fundraising Toolkit



In 2021 the DDX3X Foundation is raising money to develop Centers of Excellence for DDX3X Syndrome to ensure all DDX3X patients have access to facilities with clinicians and staff who specifically understand the diagnostic criteria of the disorder and are dedicated to identifying and meeting the various needs of those diagnosed.

## WHAT IS DDX3X SYNDROME?

- DDX3X Syndrome is a rare disease caused by a spontaneous mutation within a DDX3X gene at conception or can be inherited.
- The syndrome was discovered in the United States in 2014.
- It primarily affects girls due to its location on the X-chromosome, though there are some boys it has affected as well.

## ABOUT THE DDX3X FOUNDATION

- The DDX3X Foundation is an international nonprofit organization founded in 2015 by parents of children with DDX3X Syndrome.
- The foundation funds research, education, and treatment programs focused on DDX3X Syndrome.
- The foundation has three primary functions: support research, connect families, and raise awareness.





# HOW TO RAISE MONEY FOR THE DDX3X FOUNDATION

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- **Support the DDX3X Foundation on AmazonSmile.**  
For eligible purchases, the AmazonSmile Foundation will donate 0.5% of the purchase price to the DDX3X Foundation.
- **Fundraising on the following days is especially important** and will help the foundation to raise both money and awareness for DDX3X Syndrome.
  - **International DDX3X Day** – June 12, 2021
  - **Giving Tuesday** – November 30, 2021
  - **Rare Disease Day** – February 28, 2022
- **Double your impact by finding out if your employer matches charitable donations made by employees.**  
Thousands of companies match employee contributions to 501c3 organizations. Make sure to submit any necessary paperwork if your employer offers corporate matching.
- **Shop the DDX3X Foundation store.** All proceeds from sales go directly toward funding research for DDX3X.  
Place your order at <https://store.ddx3x.org/collections/all>.
- **Host a fundraiser of your own.** We have lots of ideas to help you get started at the end of this document.
- **Plan a regional fundraiser.** Connect with others in your area to host a group event.



# SAMPLE SOCIAL MEDIA POSTS

- As many of you know, my [child], [name], has a rare disease called DDX3X syndrome. I am asking our friends and family to consider making a donation to the DDX3X Foundation to support research for this disease. All contributions go directly toward our continuing efforts to find a cure. <http://ddx3x.org/donate>
- Please consider helping me raise money for the DDX3X Foundation by [insert information about activity i.e. visiting our lemonade stand, purchasing a raffle ticket, etc.] All proceeds will go toward funding research to better understand DDX3X Syndrome. Thank you so much for your support!
- Supporting research on DDX3X mutations is a cause that is close to my heart. This [insert day/month/event] I am raising money for the DDX3X Foundation to fund research for DDX3X Syndrome. Please consider making a donation at <http://ddx3x.org/donate> Thank you!
- Did you know I am raising money for the DDX3X Foundation? All contributions go directly toward funding research for DDX3X Syndrome. Please consider donating today to help me reach my goal of \$XX.  
<http://ddx3x.org/donate>



# SAMPLE EMAIL

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Dear Friends and Family,

As many of you know, our [daughter/son/grandchild], [name], has a rare genetic mutation called DDX3X Syndrome. It is a randomly occurring genetic mutation on the X chromosome that manifests itself in motor, speech, and cognitive disabilities on a fairly broad range, with some children being affected in more severe ways than others.

I am raising money to support the DDX3X Foundation, an international nonprofit organization founded in 2015 by parents of children with DDX3X Syndrome to fund research. I am proud to be part of this community and would be so appreciative of your support.

Thanks to donors like you, doctors and scientists are actively studying the syndrome, and working on treatments and a cure. Today, we invite you to invest in the future of our children through a donation to the DDX3X Foundation.

We are extremely humbled by your generosity and are truly blessed to have so many kind and loving people in our corner. There is no dollar amount that is too small, ALL contributions make an impact. Please make your donation at <http://ddx3x.org/donate>.

Thank you so much for your support!

# DOWNLOADABLE IMAGES AND LOGOS

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# FUNDRAISER IDEAS

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**Be sure to post about your fundraising activities in the Facebook group. It is a great way to connect, have others cheer you on, and inspire your DDX3X community!**

- Host a birthday fundraiser. A great way to raise money for a cause you care about is to ask for donations in lieu of gifts.
- Consider a challenge grant. Ask friends and family to join you in supporting the DDX3X Foundation by promising to match all donations up to a certain dollar amount.
- What's something you're really good at? Calligraphy? Making jewelry? Use your talents to raise money for DDX3X Syndrome.
- Get your family and friends together to host a car wash. Tip: ask for donations instead of setting a price.
- Have a bake sale. This is a great option for an in-person event or use social media to share your offerings and schedule contactless delivery.
- Set up a lemonade stand. Lemonade stands are a great way to get your kids involved in the fun.
- Run a 5k – or a marathon! Ask your friends and family to support your run by donating to the foundation.
- Sell your stuff. Have a yard sale or consign your gently-worn items.
- Ask a local business to support the foundation by donating a portion of sales from a certain day or item. In exchange you will encourage your friends and family to patronize the business – it's a win-win!
- Hold a 50/50 raffle at a local sporting event.