



YWHAG RESEARCH FOUNDATION FUNDRAISING TOOLKIT

How to Host a Fundraiser

for the benefit of the YWHAG Patient Community

WWW.YWHAGFOUNDATION.ORG



FUNDRAISING TOOLKIT

HOW TO HOST A FUNDRAISER

Welcome!

Thank you for choosing to support YWHAG Research Foundation, a nonprofit dedicated to discovering a cure for YWHAG genetic mutation.

Whether you're honoring a loved one or raising awareness in your community, your decision to host a fundraiser brings us one step closer to answers, treatment, and healing for families affected by the YWHAG genetic mutation.

**This toolkit is here to guide you—step by step—
with tips, resources, and ideas to help you
fundraise with confidence and heart.**



ABOUT YWHAG RESEARCH FOUNDATION

YWHAG-related neurodevelopmental disorders are ultra-rare genetic conditions that affect brain development, behavior, and function. *As of now, we've identified approximately 50 individuals worldwide who have been diagnosed with YWHAG-related disorders.*

At YWHAG RESEARCH FOUNDATION, we:

- Support families through education, resources, and connection
- Advance research by funding collaborative, cutting-edge science
- Raise awareness across the medical and scientific community
- Advocate for better outcomes for our children and loved ones

YWHAG WIP (WORK IN PROGRESS):

OUR ACTIVE PROJECTS THAT YOUR FUNDRAISER WILL SUPPORT

100% OF DONATIONS GO DIRECTY TOWARDS RESEARCH

Czech Centre for Phenogenomics Institute of Molecular Genetics of the Czech Academy of Sciences

Characterizing and Phenotyping of disease models

Hugh Kaul Precision Medicine Institute University of Alabama at Birmingham

Studying iPSCs and conducting drug screening to accelerate a therapeutic approach to target the disease and rapidly transition to a clinical setting.

Transcripta Bio (previously Rarebase)

Drug repurposing project supporting therapeutic strategy development.

The Jackson Laboratory (JAX)

YWHAG variant project and disease models.

Simons Searchlight

Host of the YWHAG Biorepository contributing to advancing research and cross-disorder data harmonization.

YWHAG Research Foundation Scientific Advisory Board

A partnering international network of researchers and clinicians advancing YWHAG science.

Rare-X

Data collection platform hosting an international patient registry.



FUNDRAISING IDEAS

You don't have to do it all— just do what feels right for you. Here are some go-to options:

CELEBRATE A MILESTONE

- Birthday, graduation, or anniversary
- Ask for donations instead of gifts

GATHER YOUR COMMUNITY

- Potlucks, trivia nights, craft fairs, or bake sales
- Partner with local schools, businesses, or teams

GET ACTIVE

- Host a walk, run, bike ride, or yoga class
- Ask friends and family to sponsor you

ONLINE CAMPAIGN

- Use Facebook, Instagram, or GoFundMe to launch a digital campaign
- Share your story with a personal fundraising page

HOW TO GET STARTED

1. CHOOSE YOUR FUNDRAISER

Pick the type of event or campaign that works best for you.

2. CONTACT US

Reach out to us at info@ywhagfoundation.org so we can assist.

3. SET A GOAL

Be realistic and optimistic! Every donation counts.

4. SPREAD THE WORD

Share your personal connection to YWHAG. Use email, social media, or word-of-mouth.

5. COLLECT DONATIONS

Direct donors to our nonprofit, www.ywhagfoundation.org/donate or use a platform like GoFundMe.

6. EXPRESS GRATITUDE

Appreciation goes a long way. Share updates and celebrate milestones with your supporters.



HOW TO EXPLAIN YWHAG GENETIC MUTATION TO FRIENDS AND FAMILY

Imagine your body is like a complex machine with many tiny parts that work together to keep you alive and healthy. Inside your cells, there are tiny instructions called genes that tell your body how to grow and work properly.

The YWHAG gene is like a special instruction manual that tells your body how to make a protein called 14-3-3 γ . This protein is like a tiny helper that makes sure your brain cells work correctly and talk to each other properly. Sometimes, because of a mistake in the genetic code, the YWHAG gene can get altered or "mutated". This is like a typo in the instruction manual. When this happens, the 14-3-3 γ protein might not work correctly, or might not be made at all.

This can cause problems in the brain, especially during development. It's like the brain cells are trying to follow the instructions, but they're not quite right. This can lead to difficulties with brain function, behavior, and development.

The YWHAG mutation can cause a range of problems, including epilepsy (where the brain has abnormal electrical activity), intellectual disability (where the brain has trouble learning and processing information), and Autism Spectrum Disorder (where the brain has trouble with social interactions and communication).

The YWHAG Foundation is working to understand how this mutation affects the brain and how they can help people with YWHAG-related disorders. We want to find ways to help the brain cells follow the correct instructions, so people can live healthy and happy lives.



WHERE TO SEND DONATIONS

ONLINE

www.ywhagfoundation.org/donate

CHECKS

Payable to Rare Village Foundation (our partnering Nonprofit)

MAIL TO

RARE VILLAGE FOUNDATION
6808 OLD GLORY COURT
MCKINNEY, TEXAS 75071

*Please note YHWAG Research Foundation in MEMO

YOU'RE NOT ALONE

HAVE QUESTIONS? NEED GRAPHICS, LANGUAGE, OR BRAINSTORMING SUPPORT?

Email us at info@ywhagfoundation.org

We're here to walk with you—every step of the way. Your fundraiser makes a difference. Every dollar raised helps us:

- Fund scientific studies and clinical research
- Expand our global family support network
- Create educational resources for newly diagnosed families
- Engage clinicians and geneticists to improve care
- Host webinars, conferences, and community events

YOU'RE NOT JUST RAISING MONEY—YOU'RE HELPING REWRITE WHAT'S POSSIBLE.



THANK YOU, THANK YOU

YOU ARE HELPING US BUILD A STRONGER FUTURE—NOT JUST FOR ONE CHILD OR FAMILY—BUT FOR AN ENTIRE GLOBAL COMMUNITY AFFECTED BY THIS RARE CONDITION. THANK YOU FOR YOUR PASSION, CREATIVITY, AND SUPPORT.

TOGETHER, WE ARE YWHAG STRONG.



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