



Dear parent,

Welcome to the ZC4H2 Associated Rare Disorders (ZARD) Community. We are so thankful you decided to take the first step to reach out. Together, we have the potential to make a real difference in the lives of our loved ones with ZARD!

The ZC4H2 Research Foundation has a mission to advocate for the community through **research, awareness, and support**:

❖ RESEARCH

Currently the Foundation has 5 ongoing research projects, and all are listed on the Foundation website, www.ZC4H2foundation.com. We have a partnership with the Orphan Disease Center, from the University of Pennsylvania, who, along with our scientific and medical committee, help us determine the most relevant research projects to accomplish our goal of developing viable treatments.

GET INVOLVED

Sharing information about your child is KEY to help us reach our mission. We strive to support medical and scientific research as well as developing and sharing the best practices for care among our ZARD community. But that is not possible without patient information... please help us by sharing your information. If you have any questions or concerns, we will be happy to address them. Please email us at info@zc4h2foundation.com.

❖ AWARENESS

The Foundation strives to increase the awareness about our condition, not only within the medical and scientific communities, but also among the general public. We do that through updates on genetic/ medical websites including NORD, OMIM, and GeneReviews. Most doctors looking for information on rare diseases look to these three websites for key information. Currently the information is lacking so we are striving to fix this. As of May 2022, the NORD website, rarediseases.org, has been updated on ZC4H2. Hopefully this will prevent the wrong information being shared with newly diagnosed patients.

We are also improving awareness to the general public by adding content to the Foundation website along with an active Instagram @ ZC4H2_Foundation, the ZC4H2 Foundation Facebook page, and local community events/fundraisers.

GET INVOLVED

You can download the attached documents which you can share with your doctors, therapists, care givers, or anyone involved in the care of your child. Additional documents including "Statements" may be helpful and can be downloaded from the website.

For the community, please share the website and follow us on social media. Like and comment to help us improve overall engagement with the public. If you have a photo to share for social media or the website, you can email us along with your written permission for use.



❖ SUPPORT

As a Foundation our main way to support the community is through information. If you remember for a moment how you felt when you first got the diagnosis: confusion, sadness, relief, concern, and more. All these feelings are a normal reaction to a new diagnosis; however, when you don't have information, these emotions can be intensified by a feeling of isolation. We really don't want another family to have that experience. Through support we can really help other families by providing hope through science. Our support groups include the Facebook parent group (exclusively for parents) and the Facebook community group (open to anyone who has a loved one, patient, or student impacted by ZARD).

GET INVOLVED

Please join the support groups and share with friends who want to learn more. Cathy and Megan are the admins for the parent group and Jasmine is the admin for the community group. We are eager to connect with you and support you on this journey. We really are here to help in any way possible.

Parents of Children with ZARD (ZC4H2 Associated Rare Disorders) Facebook group
ZC4H2 (ZARD) Community Facebook group



PLEASE JOIN OUR EFFORTS

Last but not least, do you have extra time to share with the Foundation? Maybe you have experience with fundraising, research, accounting, or marketing? Please reach out to us and let us know you are interested in helping with the day-to-day activities of the Foundation. We will connect you with a subcommittee that aligns with your preferences.

We look forward to hearing more about your loved one with ZARD!

Sincerely,

Cathy Paul-Fijten, Megan Grieves, Jasmine Castro-Torres, and Carly Russell

Attached:

1. *Informative document- ZARD for distribution to medical professionals*
2. *Frints et al 2019- ZARD research publication for distribution to medical professionals*
3. *Scientific Meeting Summary on ZARD*
4. *Questions and Answers on ZARD*