



RARE DISEASE DAY
FEBRUARY 28, 2018
TOOLKIT



RAREDISEASEDAY.ORG



WHAT IS RARE DISEASE DAY?

Rare Disease Day is a global day of awareness that takes place the last day of February each year. The day is designed to educate the general public about rare diseases and their impact on patients' lives. It also seeks to reach policy makers, public authorities, industry representatives, healthcare professionals, and others. A different theme is attached to Rare Disease Day each year. The Theme for 2018 is *Research*.

WHY RESEARCH?

95% of rare diseases have no approved treatment. For those living with XLH, the standard of care has focused on managing the complications of the illness as opposed to addressing the underlying cause. With a potential new treatment coming to market, the XLH community knows the importance of research in developing treatments and cures. Additionally, patients are the voice of rare disease. By mobilizing and sharing that voice, significant impact can be made. [Consider these important roles that patients play in research.](#)

ABOUT RARE DISEASES

In the United States, a disease is classified as rare when it affects fewer than 200,000 people. Collectively, however, there are more than 7,000 rare diseases affecting 30 million people, or one out of every ten. 80% of rare diseases are genetic in nature, making them lifelong diseases. In addition, approximately 50% of those afflicted with a rare disease are children. XLH affects about 1 in 20,000 or approximately 16,000 in the United States. These numbers are staggering. [Here are some additional facts about rare disease.](#)

WHY GET INVOLVED WITH RARE DISEASE DAY?

Building awareness of XLH is important in educating the public, policy makers, and others about the impact XLH has on our lives. Participating in Rare Disease Day is a great way to join a global movement that brings awareness across the world.

As someone living with or impacted by XLH, you are our most important voice in helping others understand XLH, how The Network serves those living with it, what our key goals and objectives are and how others can support our mission.

WHAT YOU CAN DO

There are multiple ways you can get involved in rare disease day and spread awareness of XLH. We have provided several suggestions as well as tools that can help you make a difference.

1. Share your story

The biggest impact you can make is by sharing your story. Putting a face to XLH and helping others to understand its effect is our most valuable tool in helping us to advance effective

policies, raise funds, and continue medical advances. You can share your story in a number of ways!

- Social Media

- Consider filming a short video and sharing it to your social media. Tell your followers how you're affected by XLH, the impact it has had on your family and why The Network is important to you.

- Tag The Network in your postings! You must be following our social media in order to do this! We utilize [Facebook](#), [Twitter](#), and [Instagram](#).

- Be sure and use the hashtags #rarediseaseday, #xlhnetwork, and #shareyourrare so that your postings appear with others spreading awareness of rare disease day and XLH.

- [Download RareDiseaseDay.org social media resources](#). When you post, please be sure to include your connection to XLH.

- Consider participating in [Handprints Across America](#). Take a photo of yourself and post it with the Handprints Across America poster and write XLH on the poster! Also use the hashtags #HandprintsAcrossAmerica, #xlhnetwork, #rarediseaseday.

- Also make sure you follow and share on all of the rare disease social media sites:

- <https://www.facebook.com/RareDiseaseDay.US/?ref=hl>
 - <https://twitter.com/RareDayUS>
 - <https://www.instagram.com/rarediseasedayus/?ref=badge>
 - <https://www.facebook.com/rarediseaseday>
 - <https://twitter.com/rarediseaseday>
 - <https://www.facebook.com/NationalOrganizationforRareDisorders/>
 - <https://twitter.com/RareDiseases>
 - <https://www.youtube.com/user/raredisorders>

- Reach out in the Community

- Consider contacting your local community centers, libraries, hospitals and other gathering places and ask if you can have an informational table for rare disease day. The Network has brochures and fact sheets that you can distribute! Email info@xlhnetwork.org for more information.

- If you or someone you know belongs to a civic organization such as Kiwanis, Elks or another service group, ask if you can speak during an upcoming meeting about rare disease and XLH. These organizations are always looking for speakers, and if you have a connection, chances are that just for asking, you'll be invited to speak. The Network will provide you with talking points and informational sheets, so don't be shy! Even if you don't have an opportunity to make a formal presentation, time is often allotted at meetings for members to share news. You can use this as an opportunity to information about rare disease, XLH, and your connection.

-Ask your church, synagogue or other religious institution to recognize rare disease day during that weekly service and lend your voice by saying how you are impacted by XLH. If there is a bulletin that is issued each week, this is also an opportunity to share information.

-If your child has XLH, speak to your school and ask if you can help facilitate a classroom discussion. Make it fun and interactive and involve your child in the presentation. Suggest an essay writing assignment. [Here are some additional activities that you can utilize!](#)

-Display posters throughout the community. Libraries, coffee houses, community centers, and town halls all typically offer public community boards. [Utilize an official Rare Disease Day poster](#) and include The Network's website to direct people to learn more about XLH.

- Reach out to the Media

-Consider writing a letter to the Editor announcing Rare Disease Day, XLH, why research is important, and how it has impacted your family. (See sample under the resources section)

-You can also send a press release to local papers, television and radio stations. (See sample under the resources section)

-Consider following up with your local media to see if they would be interested in doing a story on rare disease day and XLH. The Network will provide talking points, so please share with us if you have an interview opportunity!

- Reach out to your Elected Officials

-Follow your legislators on social media and tag them on Facebook and Twitter announcing Rare Disease Day and XLH. Make your message simple:

@lawmaker, today is #RareDiseaseDay. I am a patient with/I have a child/family member with #XLH. Help spread awareness and learn more at www.xlhnetwork.org

-Ask your Governor or State representatives to issue a proclamation recognizing Rare Disease Day. (See sample language under resources section)

-Schedule an appointment with your elected officials and put a face to rare disease and XLH. Let them know how important funding for research is in treating rare diseases. (See the resources section of this booklet for fact sheets and other information that you can take with you)

- Host a Local Event

-Consider hosting a local meet and greet or similar event to try and connect with others from the XLH Community in your region. It doesn't have to be anything extensive. It can

be as simple as a gathering at a local coffee house! The Network can help with ideas and can also help publicize your event! Email info@xlhnetwork.org or call 518-527-6236 for assistance. Local events can also be listed on the [Rare Disease Day website](#).

- Raise Money to Support The Network and Help Others Living with XLH

Cause awareness days offer a great opportunity to raise funds for things that personally affect you. Here are some ways you can raise funds during Rare Disease Day.

-Online through Network for Good. Creating an online fundraising page allows you to reach those near and far to encourage them to support something that is meaningful to you and your family. It takes only a couple of minutes to create a page and you can then share it with everyone you know through social media or email. Want to make a bigger impact? Consider asking your friends and family members to do the same! Visit www.xlhnetwork.org or email info@xlhnetwork.org for more information. We will even help you set it up!

-Consider a restaurant fundraiser. There are many national chains that offer fundraising opportunities. [Here are some examples](#). Don't stop at chain restaurants, though. Talk to your local independently owned businesses as well. Local businesses love to support the community!

-Don't just limit your outreach to restaurants. Target other locally owned businesses – delis, dry cleaners, auto mechanics and others – and ask if you can place a donation jar during the week of rare disease day. The Network can provide the collection cans for you!

-Talk to your local firehouses about a pancake breakfast or similar fundraiser. Events like this bring out the community and give you an opportunity to support The Network and raise awareness at the same time!

There are many ways that you can raise funds to support The Network. Contact us at 518-527-6236 for information and support or to share your ideas with us!

RESOURCES

There are many resources available to help with Rare Disease Day. Here are some helpful documents and links to additional resources.

- [Rare Disease Day Information Pack](#)
- [Facts about XLH](#)
- [About The XLH Network, Inc.](#)
- [Social Media Tools](#)
- [Rare Disease Day Poster](#)
- Sample Letters to the Editor (see attached)
- Sample Press Release (see attached)

- Sample Proclamation Language (see attached)

Websites with additional information

www.rarediseaseday.org

<http://rarediseaseday.us/>

www.rarediseases.org

www.globalgenes.org



This sample Letter to the Editor can be used for your local or regional newspaper. The best way to submit it is to visit the newspaper’s website and search for the “contact us” information. The editor information should be listed with an email. *Email is the preferred method of communication.* Copy and paste the information below into the body of the email. If you have difficulty, call 518-527-6236 and we can help you! Once you see that your letter has been published, share the link on your social media and tag The Network @xlhnetwork and use the hashtag #rare diseaseday. Thank you for taking an active part in educating about XLH!

To the Editor:

On February 28, millions of people around the world will observe Rare Disease Day®. This day is significant because rare diseases affect 1 in 10 people, or 30 million nationwide, ensuring that each of us is likely to know someone living with a rare disease.

My family is affected by a rare disease called X-linked hypophosphatemia (XLH). XLH is a whole-body, whole-life, rare genetic disorder that affects approximately one in 20,000 people. Patients with XLH produce an excess of a hormone known as FGF23, which causes them to have low levels of phosphorus in the blood. Without an adequate source of phosphorus, the body cannot form strong bones and teeth or properly fuel muscles. In the absence of treatment, patients experience bone deformities (most commonly bowed legs or knock-knees), short stature, spontaneous tooth abscesses, bone pain and muscle pain/weakness.

The standard of care for patients living with XLH has been to treat the complications of the illness but no treatment has been available to address the underlying cause of the disease. That may all change in 2018 as clinical trials of a potential new treatment have shown very promising results. We are hopeful that this year will bring the approval of this medication for the treatment of XLH in both children and adults, providing hope for a future not defined by disability.

This Rare Disease Day, we call attention to the 7,000 known rare diseases and the importance of research in providing the path to new cures and treatments. ***Raising public awareness makes a difference.*** It gives families hope and can lead to new, life-changing treatments. I encourage your readers to learn more about XLH by visiting www.xlhnetwork.org. For more information on Rare Disease Day visit www.rare diseaseday.org or www.rare diseaseday.us. On behalf of the 1 in 20,000 affected by XLH, thank you for calling awareness to XLH and Rare Disease Day.

Sincerely,

[Insert your name]



This sample press release can be used for your local or regional newspaper as well as television and radio stations. Contact information can vary by media outlet, but we suggest sending the release to the editor or health reporter at your local newspaper, and to the assignment editor at television and radio news stations. Be sure and send it in advance of Rare Disease Day. We would suggest three – five days in advance. Email is the preferred method of communication. Copy and paste the information below into the body of an email. If you have difficulty, contact us at 518-527-6236 and we can help. Once you see your release published or a news story on television, share the link on your social media and tag The Network @xlhnetwork and use the hashtag #rare diseaseday. Thank you for taking an active part in educating about XLH!

FOR IMMEDIATE RELEASE

[Insert Town] Resident Joins Global Movement to Bring Awareness to Rare Disease Shares Personal Story to Help Others

[CITY], [STATE]—[Month] [XX], 2018—[Write out age]-year-old [insert town] resident [insert name] has a rare disease called X-linked Hypophosphatemia (XLH) and will take part in a global movement to raise important awareness for **Rare Disease Day®** on February 28.

XLH is a whole-body, whole-life, rare genetic disorder that affects approximately one in 20,000 people. Patients with XLH produce an excess of a hormone known as FGF23, which causes them to have low levels of phosphorus in the blood. Without an adequate source of phosphorus, the body cannot form strong bones and teeth or properly fuel muscles. In the absence of treatment, patients experience bone deformities (most commonly bowed legs or knock-knees), short stature, spontaneous tooth abscesses, bone pain and muscle pain/weakness.

The standard of care for patients living with XLH has been to treat the complications of the illness but no treatment has been available to address the underlying cause of the disease. That may all change in 2018 as clinical trials of a potential new treatment have shown very promising results.

(Share information here on when you or your loved one was diagnosed and how XLH has affected you).

“It’s important for everyone to understand rare disease and the importance of research in providing hope for patients, like me, that depend on that hope. Educating about rare disease can also help implement sound healthcare policies, improving lives and reducing the burden of healthcare.”

According to the National Institutes of Health (NIH), a disease is rare if it affects less than 200,000 people. One in 10 Americans have a rare disease—nearly 30 million people—and nearly half of these patients are children. For the 7,000 known rare diseases, there are only approximately 450 FDA-approved treatments.

Rare Disease Day takes place every year on the last day of February (February 28 or February 29 in a leap year)—the rarest date on the calendar—to underscore the nature of rare diseases and what patients face. It was established in Europe in 2008 by EURORDIS, the organization representing rare disease patients in Europe, and is now observed in more than 80 nations.

For more information about XLH visit www.xlhnetwork.org. For information on Rare Disease Day, visit <http://rarediseaseday.us/>. To search for information about rare diseases, visit the National Organization for Rare Disorder's website at www.rarediseases.org.

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You can use this sample proclamation language to encourage your Governor or your State Legislative body to recognize February 28 as Rare Disease Day. The earlier you send it, the better your chances of having a proclamation issued! If you do receive a proclamation, scan it and send it to us at info@xlhday.org, and we'll post it to our social media! Thank you for taking an active role in Rare Disease Day!

Dear _____,

On behalf of the XLH Network, Inc., I am writing to request that February 28, 2018 be proclaimed as Rare Disease Day in _____.

X-linked hypophosphatemia is a rare, chronic, progressive genetic disorder that affects about one in 20,000 people. At present, there is no cure and no effective treatment for the disease itself. Treatment focuses on managing the complications of the illness as opposed to treating the underlying cause. However, developments in research show promising results with a new effective treatment potentially coming to market in 2018.

Patients with XLH report life-long complications. Symptoms are usually apparent beginning in early childhood and can vary in severity. Everyone with XLH has a low serum phosphorus level. Other symptoms may include: lower limb deformities; waddling gait; short stature; spontaneous tooth abscesses; bone pain; muscle pain and weakness. Treatment of XLH is challenging. As a rare disease it is often misdiagnosed with the proper diagnoses not occurring until damage has already occurred.

The XLH Network, Inc. is the only worldwide organization dedicated to supporting those living with XLH and the professionals who care for them. Our mission is to promote XLH awareness and education for affected families, medical professionals, and the community at-large; to support physicians and other providers of medical care for better diagnosis and treatment; to create resources and a community for affected individuals and their families so they can understand and cope with the complications of the disease; and to foster the search for a cure.

On February 28, patients from around the globe will join together for Rare Disease Day, a day that is dedicated to educating and raising awareness of more than 7000 rare diseases. It's a time to place emphasis on the importance of research in advancing treatments for those living with a rare disease.

To help raise awareness of XLH and Rare Disease Day, we are asking you to declare February 28, 2018 as Rare Disease Day in _____. We have attached draft proclamation language for your use.

Thank you for your assistance. We will follow up with you shortly to answer any questions you might have.

Sincerely,

Draft Proclamation Language

WHEREAS

Rare Disease Day is a day of global awareness to educate about the 7,000 known rare diseases

WHEREAS

Research provides hope and a path to treatments and cures for those living with a rare disease

WHEREAS

50% of those affected by a rare disease are children

THEREFORE

I, the [Mayor or Governor] of [CITY or STATE] do hereby announce and proclaim to all citizens and set seal hereto, February 28, 2018 as Rare Disease Day.