National
FABRY DISEASE
Foundation

Programs and Services for the Fabry Disease Community

This document is updated frequently. The most current version can always be found at https://www.fabrydisease.org in the Featured Resources section just above the bottom right corner of the home page.

As of May 2024

NFDF Programs Handout

Table of Contents

National
FABRY DISEASE
Foundation

Who we are and what we do

The National Fabry Disease Foundation is an IRS 501(c)(3) nonprofit charitable organization.

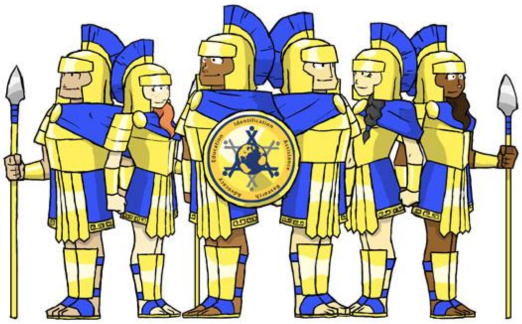
❑ We manage an incorporated charitable non-profit organization.

❑ We provide valuable education and community support programs and services to support the known and the yet-to-be-recognized (currently unknown) Fabry community, including programs to improve recognition, diagnoses, understanding, and care. Our two primary focus areas are:

  ✓ Education and Awareness

  ✓ Community Support and Assistance

❑ We raise funds from many organizations and individuals to provide programs and services to the Fabry community.



The Fabry Legion is made up of Fabry community members fighting against Fabry disease.

NFDF Medical Advisory Board

The National Fabry Disease Foundation's Medical Advisory Board (MAB) includes prominent members of the medical community who have a great amount of experience with management, treatment, and research of Fabry disease.

Rob Hopkin, MD
MAB Chair
Geneticist, Pediatrician
Cincinnati Children's Hospital

Dawn Laney, MS, CGC
Genetic Counselor, Instructor, Program Leader
Emory University Med Center

John Jefferies, MD, MPH
Cardiologist
The University of Tennessee Health Science Center

Eric Wallace, MD, FASN
Nephrologist
University of Alabama Birmingham

Vacant
Neurologist

Claire Zae-Kessler, MD
Gastroenterologist
Massachusetts General Hospital for Children

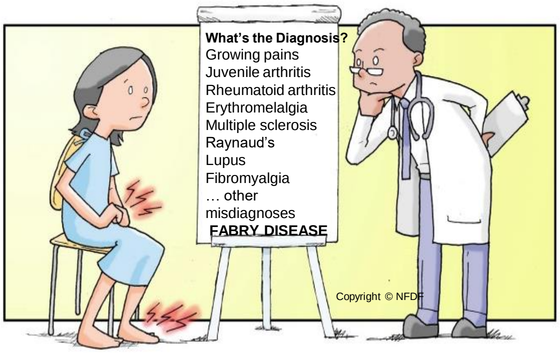
Vacant
Pulmonologist

Nadia Ali, PhD
Clinical Psychologist
Emory University Med Center

Casey McKenna, MS, LCGC
Genetic Counselor
MAB Scribe
NFDF Senior Program Manager

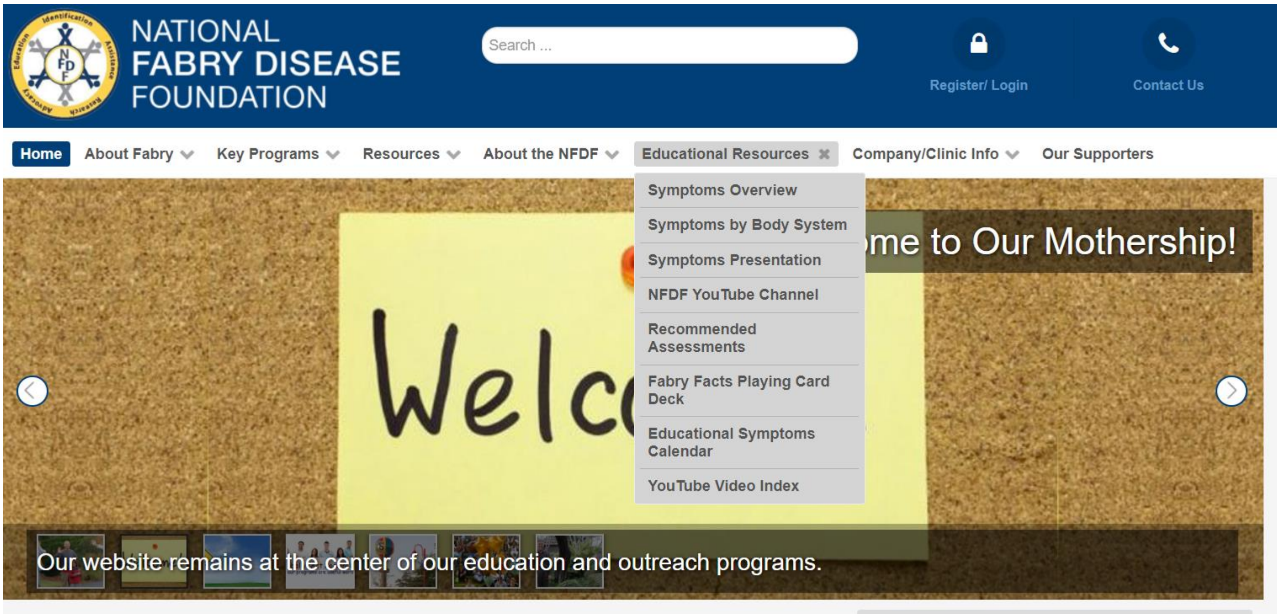
Our Multifaceted Education Program

The NFDF strives to provide our complimentary brand of education to patients, family members, healthcare providers, and staff, and the public to improve the recognition, diagnosis, understanding, and management of Fabry disease.



Examples of our many education and awareness initiatives include:

- A robust educational website at www.fabrydisease.org
- The annual NFDF Fabry Family Education Conference in Greensboro, NC, and an annual Fabry Family Camp at nearby Victory Junction.
- Virtual Fabry family education meetings throughout the year.
- Learning from the PROS (**P**atient **R**eported **O**utcomes **S**urvey) Program
- The educational Fabry Disease Symptoms presentation (PDF) and a symptoms calendar made using the same information.
- April Fabry Disease Awareness Month proclamation program
- The Educational Resources tab on our website's top menu bar will lead you to many of our resources as shown below in the dropdown menu.

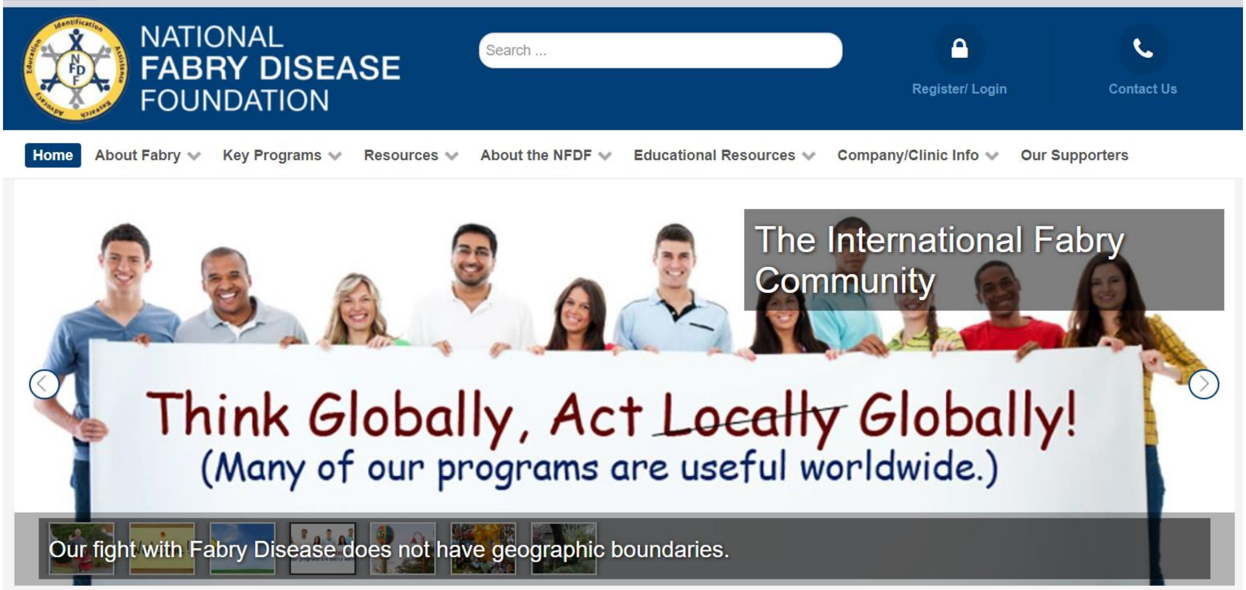


Our website remains at the center of our education and outreach programs.

Through increased education, we have a **R.A.R.E.** opportunity to **R**ecognize **A**nd **R**escue **E**veryone with Fabry disease.

Investigate Our Robust Information and Education Website

www.fabrydisease.org



The International Fabry Community

Think Globally, Act ~~Locally~~ Globally!
(Many of our programs are useful worldwide.)

Our fight with Fabry Disease does not have geographic boundaries.

The National Fabry Disease Foundation’s website contains news and information as well as access to many programs and services.

- The top menu bar tabs include access to information about primary financial assistance programs for Fabry. See the Resources tab on the top menu bar, then the Financial Assistance Programs tab.

- The top menu bar tabs include access to important industry resources and clinical trial information as well as clinic and support organization resources. See the Company/Clinic Info tab, then the Pharma Info, Clinic Info, or Support Organization (Spt Org) info tab as appropriate.

Examples of some of the many other information sections include:

- Community Announcements
- Upcoming Events
- Why Is Early Diagnosis So Important? (telling our story through examples)
- Featured Programs Section – Eight program blocks including:
  - Find a Fabry Specialist database
  - Family Assistance Program
- Featured Resources Section – Ten resource blocks
- Fabry Focus E-Newsletter subscription link
- … and many other education and information sections

Fabry Focus E-Newsletter and

Fabry Focus for Healthcare Providers

The National Fabry Disease Foundation (NFDF) provides a periodic community e-newsletter and periodic healthcare provider e-newsletter to keep the Fabry community and other stakeholders informed of relevant news and information.

Our e-newsletter subscription database serves as the NFDF's primary contact information database for community correspondence and for sending NFDF education, information, and awareness resources to the Fabry community. We do not share contact or personal information.

Please subscribe to the Fabry Focus e-newsletter from the orange "Newsletter" button on the right side of our website homepage in the "Connect With Us" section at www.fabrydisease.org.

✉ Newsletter

… or from this link: E-Newsletter Subscription Link

The ways the National Fabry Disease Foundation routinely corresponds with the Fabry disease community include:

- By email at info@fabrydisease.org
- By phone at: 1-800-651-9131
- Information is also distributed through Fabry healthcare providers

NFDF Virtual Educational Meetings

The NFDF hosts virtual education meetings about various aspects of Fabry disease as schedules and resources permit. The webinar registration page is 23-24 FABRY Webinars Site

Meeting details are provided in the periodic NFDF Fabry Focus e-newsletter and on the NFDF Facebook page as the meetings are scheduled. The meetings will usually include:

- a brief introduction and announcements
- A presentation by an experienced speaker (presentations are primarily about Fabry medical issues)
- a question-and-answer session
- a prize drawing for primary attendees. The prize drawing is used as an incentive to increase participation and to show our appreciation.

For virtual meetings, a video recording of each completed meeting will be posted on the NFDF website and on the NFDF's Facebook page unless unforeseen complications arise.

The 2023-2024 virtual education meeting recordings and many other NFDF educational videos can be found in the video index list on our https://linktr.ee/thenfdf.

Annual Fabry Family Education Conference

- Annual Conference in September or October - Began in 2011
- Total of 225 - 275 attendees each year
- Total of 120 -140 individuals with Fabry each year
    - Families attending the camp are the starting point, plus additional attendees only at the conference
    - Physicians and other healthcare speakers
    - Industry speakers
    - Organization speakers
    - Information sharing and study participation

- Separate children's activities
    - Children are chaperoned by nannies and tutors
    - Educational breakouts
    - Amazing teen and kid chat sessions
    - Entertainment

- Transportation, lodging, meals, & activities are provided.

- If you are in interested in attending the conference, email Jerry at jerry.walter@fabrydisease.org. Families attending camp are automatically signed up for the conference.

Our 2024 conference is planned for October 17-18, 2024. Travel on Wednesday, October 16th for many.

Location: Greensboro Airport Embassy Suites Hotel

Annual Fabry Family Weekend Camp

The NFDF's annual Fabry Family Camp is held at Victory Junction in Randleman, NC.

Activities

- Fuel Stop - Cafeteria
- Victory Lanes bowling
- Fishing at the Catch, Kiss and Release Marina
- Fab Shop for a new hairdo
- Pit Stop – Snack Shop
- Body Shop - Clinic
- Adam's Race Shop
- Archery
- Horse Barn - horseback riding
- Boating
- Mini-Golf
- Water games (weather dependent)
- Superdome indoor playing field
- Gymnasium
- Zipline for teens
- Arts and Crafts … and more

☐ The annual Fabry family camp is in September/October. Applications are usually accepted on June 1st or July 1st depending on camp dates.

☐ Children with Fabry disease ages 6-16 (primary campers) and immediate family members are eligible to attend.

☐ A Fabry family conference is held on Thursday/Friday followed by camp from Friday afternoon to Sunday noon (travel on Wednesday for many).

☐ Transportation, lodging and meals are provided.

☐ For more information about Victory Junction camp facilities please see www.victoryjunction.org

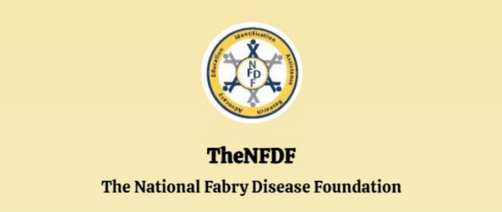
☐ Email jerry.walter@fabrydisease.org to let us know you are interested & to receive pre-application information.

Jackson kissing a fish

The 2024 Fabry Family Weekend Camp is on October 18-20, 2024

Victory Junction camp activities!

Keeping the Fabry Community Informed via our website at www.fabrydisease.org and NFDF social media sites



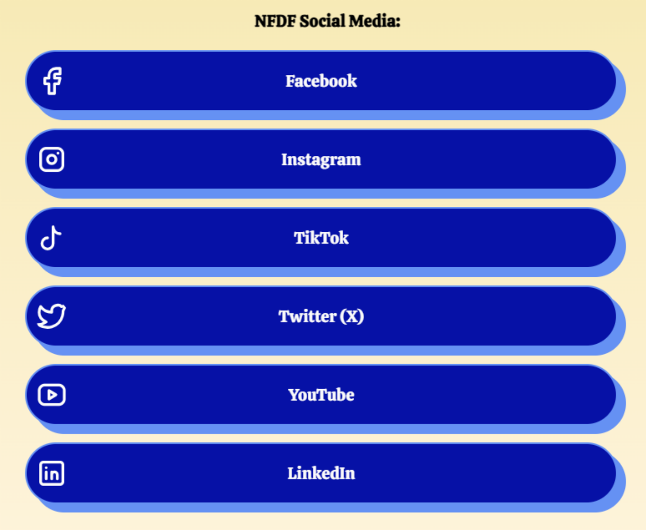
TheNFDF

The National Fabry Disease Foundation

Visit our Link Tree for links to important NFDF resources and social media sites.

NFDF Resources:

- NFDF Website
- Sign up for our Newsletter!
- NFDF's YouTube Video Index
- Educational Symptoms Presentation
- Fabry Facts Playing Cards – Answers to FAQs
- U.S. Primary Financial Assistance Programs
- NFDF Family Assistance Program (Code: nfdf)
- Sponsored (cost-free) U.S. Genetic Testing
- 2023-2024 NFDF Webinar Meeting Space



NFDF Social Media:

- Facebook
- Instagram
- TikTok
- Twitter (X)
- YouTube
- LinkedIn

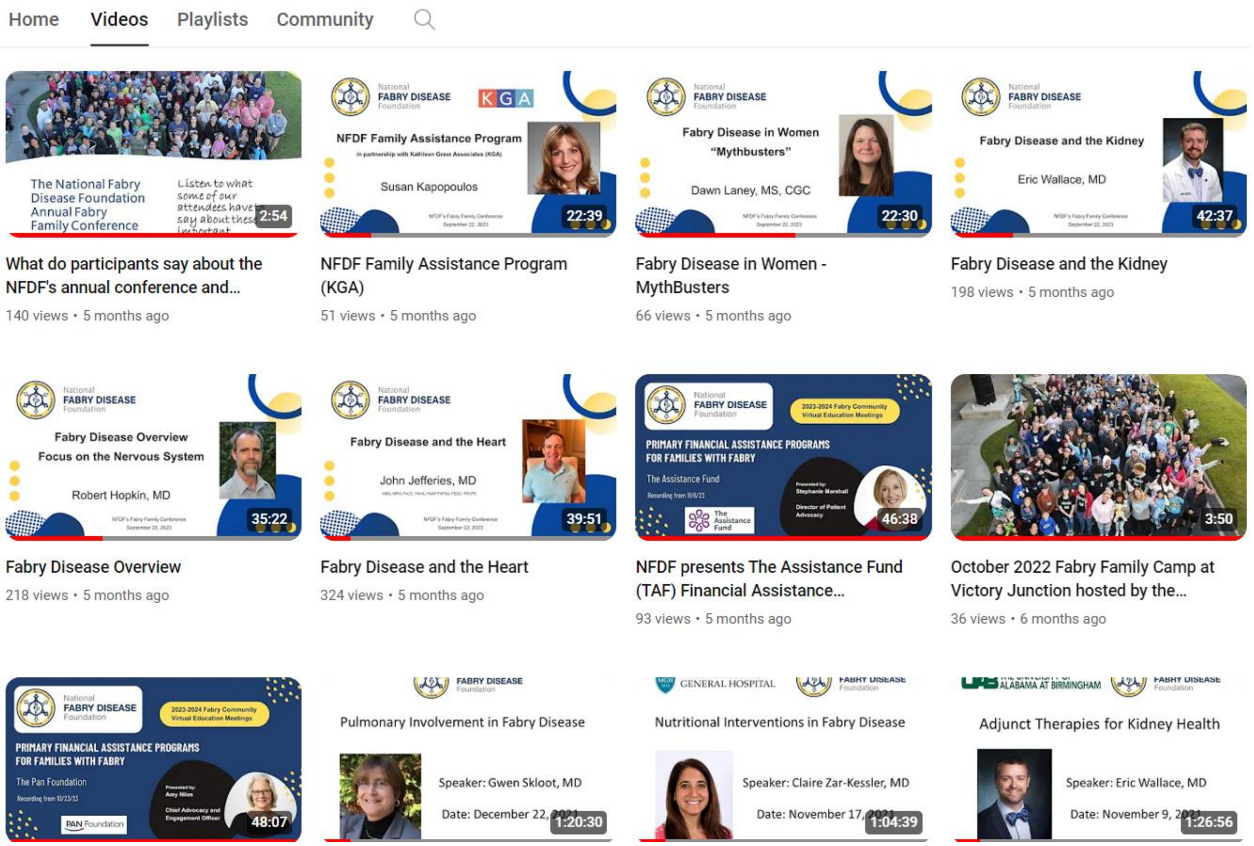
https://linktr.ee/thenfdf

https://linktr.ee/thenfdf

The NFDF’s YouTube Channel

The National Fabry Disease Foundation has produced more than 50 educational videos. While somewhat outdated, the NFDF symptoms video has been viewed over 23,000 times to date and remains a very valuable resource.

An index with links to the NFDF’s videos is:
https://www.fabrydisease.org/images/ArticlePDFs/NFDF-YouTube-Index.pdf



What do participants say about the NFDF's annual conference and...
140 views • 5 months ago

NFDF Family Assistance Program (KGA)
51 views • 5 months ago

Fabry Disease in Women - MythBusters
66 views • 5 months ago

Fabry Disease and the Kidney
198 views • 5 months ago

Fabry Disease Overview
218 views • 5 months ago

Fabry Disease and the Heart
324 views • 5 months ago

NFDF presents The Assistance Fund (TAF) Financial Assistance...
93 views • 5 months ago

October 2022 Fabry Family Camp at Victory Junction hosted by the...
36 views • 6 months ago

Please watch and share our videos and subscribe at
www.YouTube.com/TheNFDF.

Patient Reported Outcomes Survey Program

“Learning from the PROS”

Why? The NFDF collects information from brief periodic surveys to learn about Fabry disease in areas that have yet to be investigated and reported in formal studies.

The information collected is used to provide insights to:

- improve our understanding of Fabry disease.
- help you ask your doctors the right questions.
- assist in determining future research needs.
- assist in developing educational materials.

Personal information is not shared except to announce prize drawing winners using first names when applicable.

Who? Primarily individuals with Fabry who are 18 years old or older.

What? We collect information about various aspects of Fabry and the Fabry community. Collecting the GLA gene variants, along with other information, allows us to understand the differences in how Fabry affects people with different classic and later-onset variants.

When? Periodically

.

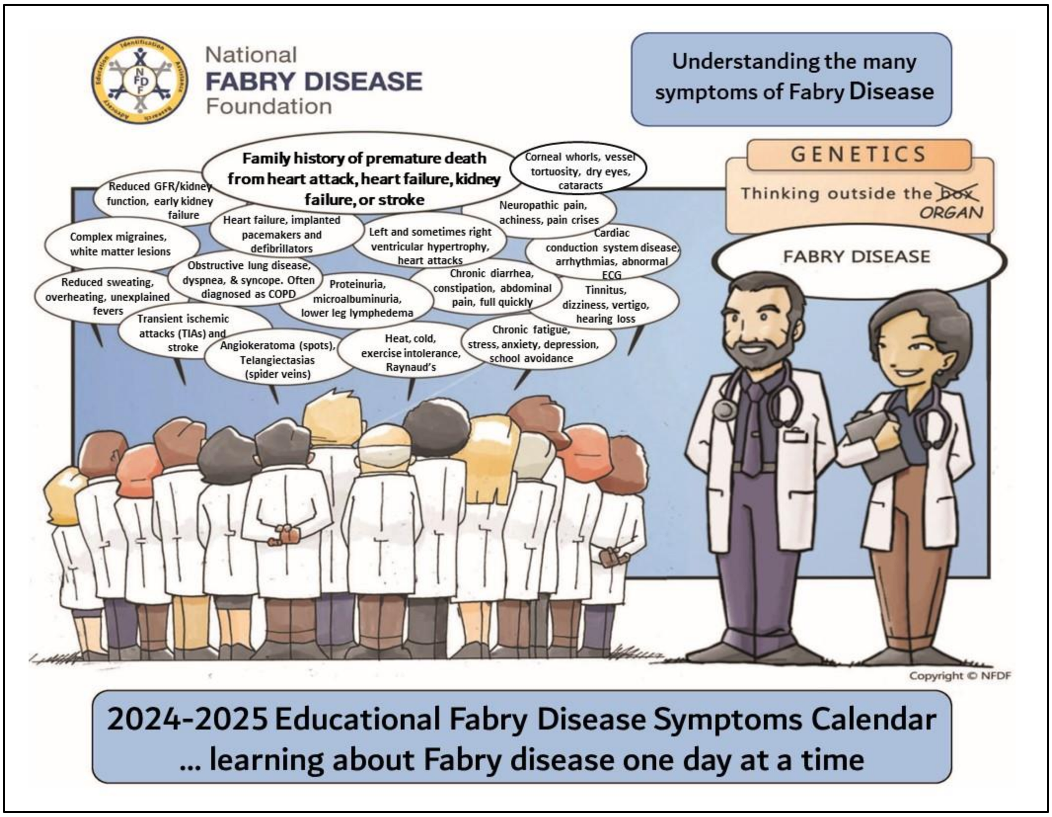
Where? Many surveys are open to the international Fabry community.

How? Online surveys are created via Survey Monkey. Links to each online survey are published in the NFDF e-newsletter. Please subscribe to our e-newsletter at the orange newsletter icon near the upper right area of our home page at www.fabrydisease.org. Please ensure your mailing address is correct.

When surveys are distributed, please share them with family members with Fabry disease.

2024 -2025 Educational Fabry Disease Symptoms Calendar

The NFDF's educational symptoms presentation, which we also configure and distribute as a calendar, provides an easy-to-understand description of most of the common symptoms of Fabry disease.



- ☐ Our 18-month educational calendar (2024 to 2025) is available.
- ☐ It is distributed at no cost to adults with Fabry and clinics worldwide. Healthcare providers and staff, please request a calendar for yourself and a sample calendar to show your patients at jerry.walter@fabrydisease.org.
- ☐ It is a great resource for learning about and educating others about the common symptoms of Fabry disease.
- ☐ **For individuals with Fabry to receive a calendar and other education and awareness materials, see page 21.**

Educational Playing Card Deck
Learning one card at a time

The NFDF’s educational playing card deck is intended to provide a better understanding of various aspects of Fabry disease by highlighting facts in published peer-reviewed literature and from other sources.

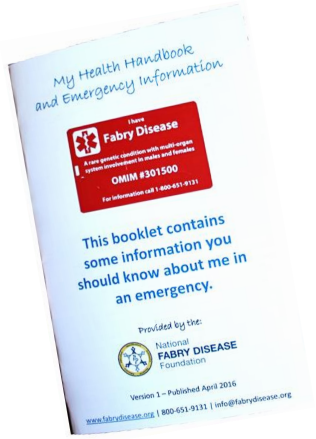
Fabry disease is caused by absent or deficient Alpha galactosidase A (α-Gal A) enzyme activity resulting in the buildup of fatty substances (glycosphingolipids), primarily globotriaosylceramide (GL-3/Gb3) and its derivative globotriaosylsphingosine (lyso GL-3/Gb3) in body fluids and a variety of tissues including the kidney, heart, and central and peripheral nervous systems.

https://tinyurl.com/GermainD2022

- ☐ **Adults with Fabry worldwide will receive a free playing card and other education and awareness materials when you subscribe to our Fabry Focus e-Newsletter.**
- ☐ Healthcare providers and staff, please request a playing card deck for yourself and a sample playing card deck to show your patients at jerry.walter@fabrydisease.org so they can obtain one.
- ☐ If you do not have Fabry or are not a Fabry healthcare provider or clinic staff, you may obtain a playing card deck from our website or Facebook page donate buttons for a donation of $20.00. Indicate “playing cards” in the comments section.

“My Health Handbook” Kits

In 2016 during Fabry Disease Awareness Month the NFDF began distributing a resource kit to individuals with Fabry disease. The kit includes a copy of the My Health Handbook and Emergency Information booklet shown below as well as the other items described below.

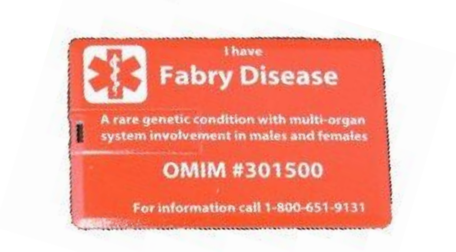


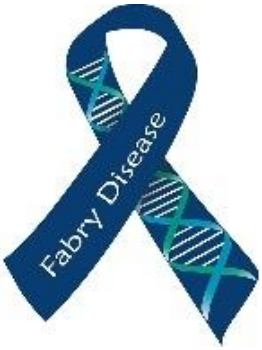
What does a healthcare provider need to know in an emergency?

Useful information can be stored in this booklet and on the included 8GB USB drive that you can keep with you!

The kits are available to our international friends also.

The kit contains a credit-card style USB Medical Alert Card that is initially loaded with the current NFDF Programs handout and the Fabry Community Landscape handout. Subsequent, more current, versions of these documents can be found on the NFDF website. Awareness wristbands and other awareness materials are also included in the kits.

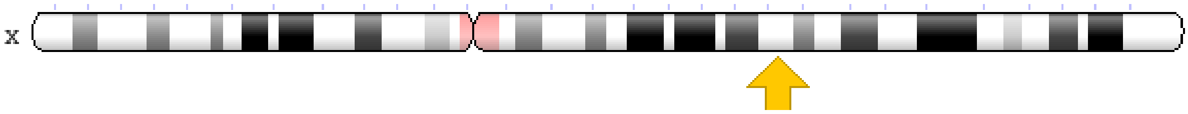




See page 21 for guidance about how to receive kits.

Fabry GLA Gene Variant Repository

This program is designed to facilitate further study and a better understanding of Fabry disease variants.



This image above is a representation of the X-chromosome with the location of the Fabry gene indicated by the arrow - location Xq 22.1.

PLEASE PARTICIPATE TO BE PART OF THE SOLUTION!

Adults with Fabry disease: In some of our programs, such as our PROS (survey) program and our calendar distribution program, we ask participants to provide their Fabry *GLA* gene variant (mutation).

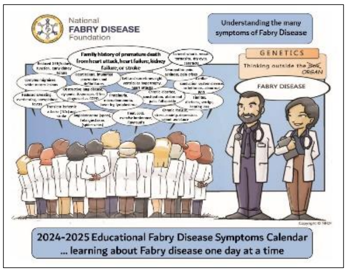
We hope that as we provide many programs and services for the benefit of our community, community members will be eager to take our surveys, respond to calls for action, provide their variant designation, and help in other ways as we ask for support.
It takes a village!

We do not share family variants with anyone. We contact participants about research opportunities and about reports on their family mutations when possible.

Note: A document entitled "Fabry Variants (an explanation for lay-people)" is located pages 15-18 of our Fabry Community Landscape handout. The current Community Landscape handout is located in the Featured Resources section just above the bottom right corner of www.fabrydisease.org. It is currently being revised.

NFDF educational calendars and playing cards, My Health Handbook Kit, awareness materials distribution

We use our e-newsletter subscription database as our distribution list for our Educational Symptoms Calendar and our My Health Handbook Kits. Adults with Fabry may request one complimentary educational symptoms calendar each and a My Health Handbook Kit for yourself and each of your children with Fabry. Providers and clinic staff, please request a calendar for yourself and a sample calendar and kit to show your patients. Materials are distributed at no cost to adults with Fabry and clinics worldwide.



To receive these resources, subscribe to our e-newsletter from the orange newsletter icon about halfway down the right side of our website home page at www.fabrydisease.org.

Access to Fabry publications … Register at the register/login link at the top of www.fabrydisease.org. Select "Don't have an account?" and complete the form. This enables access to selected Fabry publications.

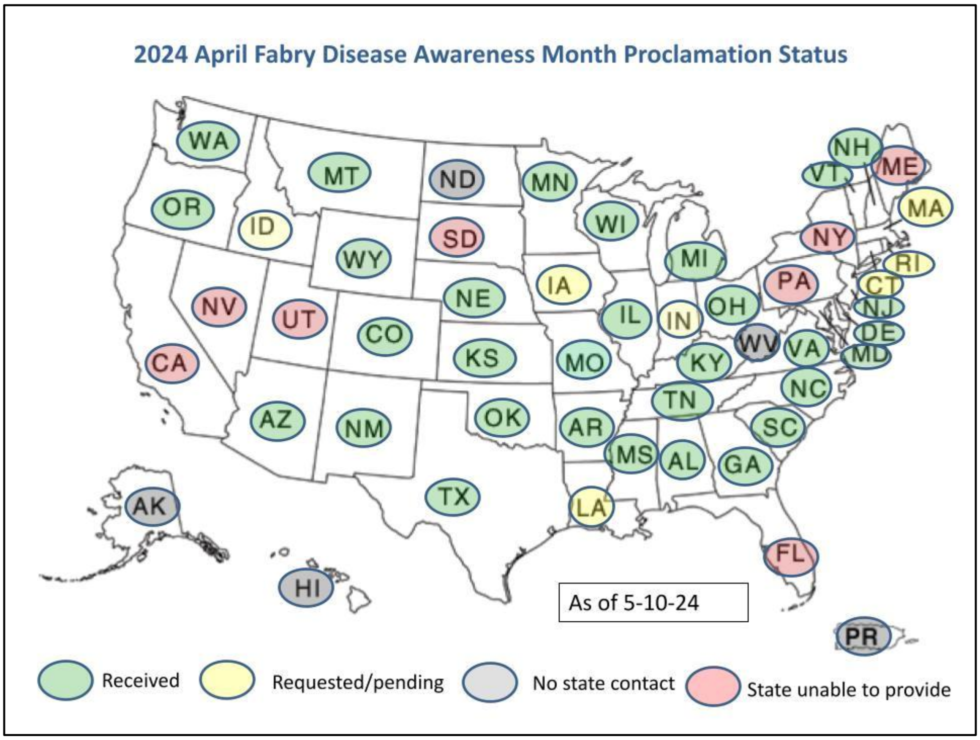
Fabry Variant Repository … Please provide your family variant to add to our repository. Contact jerry.walter@fabrydisease.org. We will not share your variant with anyone. We will use it for analyses of symptom similarities and differences between classic and later-onset variants

For a lay-person explanation of GLA gene variants, see our Fabry Community Landscape Handout, pages 15-18, near the bottom of our website at www.fabrydisease.org or at the direct link at: https://www.fabrydisease.org/images/The-Fabry-Disease-Community-Landscape-Handout-Nov-18.pdf currently being updated.

Fabry Disease Awareness Month Governors' Proclamation Program

We'll begin to contact Fabry community reps in December 2024 to begin the 2025 process.

Each year the Fabry community works together to request Governors' proclamations to designate April as Fabry Disease Awareness Month.



Each year, in January, we begin to contact Fabry community representatives in each state to facilitate coordination with their respective state Governors' offices.

Urgent and Unmet Needs Program

Provides short-term financial assistance when other primary programs are unavailable.

In many cases, individuals must be declined by Accessia Health (AH), The Assistance Fund (TAF), the PAN Foundation (PAN), and NORD first.

Information about the primary Fabry financial assistance programs is located at www.fabrydisease.org – on the top menu bar, select Fabry Resources, then Fabry Financial Assistance Programs.

Examples:

- First time insurance premiums payment support to get AH, TAF or PAN support started
- Short-term living expense support in emergencies
- Travel assistance to Fabry related meetings and appointments
- Medical expenses not covered due to unforeseen circumstances (doesn't include primary treatment)
- Hearing aids, hearing impaired phones, and other personal needs
- Emergency needs … and more

To request assistance, email info@fabrydisease.org

Please apply to Accessia Health (formerly PSI), PAN, and/or TAF, the primary financial assistance programs for Fabry disease, first as described on page 10 of this handout.

Accessia Health

American Kidney Fund®
FIGHTING ON ALL FRONTS

PAN Foundation

The Assistance Fund

NORD®
National Organization for Rare Disorders

Family Assistance Program

- We provide a **free, confidential** family assistance program through KGA, Inc.
- The program includes 24/7 telephone counseling referrals at 800-648-9557 and other services for families with Fabry disease at https://my.kgalifeservices.com/. If you are asked for your organization, indicate NFDF.
- **Any personal issue is appropriate.**
- See the Family Assistance Program tab on our homepage at www.fabrydisease.org.

The most common issues are:

- Stress Management Concerns
- Emotional Issues
- Depression, Anxiety and Panic Attacks
- Grief or Loss
- Relationship Problems
- Family Problems
- Chemical Dependency
- Eating Disorders
- Domestic Violence
- Job Stress
- Career Frustration
- Child Care Needs
- Elder Care Resources
- Legal Issues
- Financial Concerns
- Nutritional Questions
- Work Life Balance Issues
- Meditation Training

Many free webinars and other resources are also available.

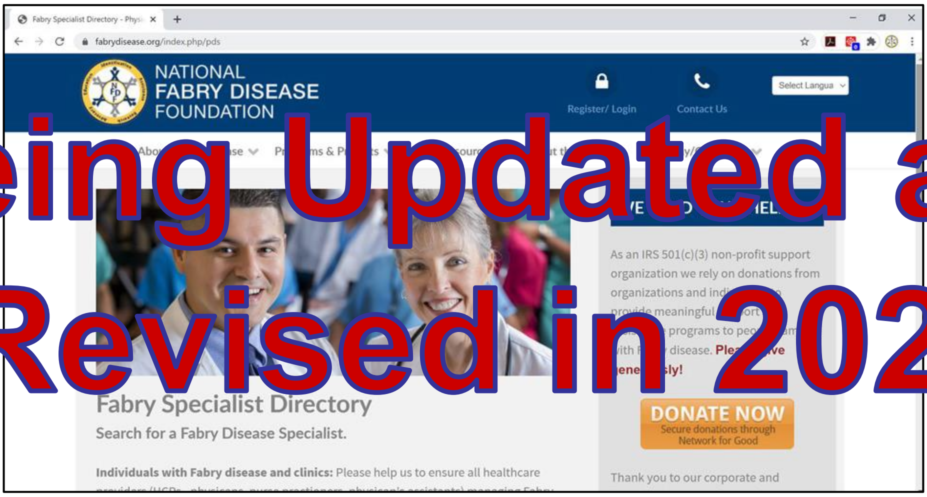
Copyright © NFDF

Find a Fabry Specialist Database

Fabry Clinics: Please participate in providing this important resource to the Fabry community! Please provide your information.

Dear Physicians, Nurse Practitioners, and Physician Assistants managing people with Fabry disease as a primary Fabry Specialist,

We continue to build a Find A Specialist database on our website at https://www.fabrydisease.org/index.php/pds. See the screenshot below.



Being Updated and Revised in 2024

Fabry Specialist Directory

Search for a Fabry Disease Specialist.

Individuals with Fabry disease and clinics: Please help us to ensure all healthcare

As an IRS 501(c)(3) non-profit support organization we rely on donations from organizations and indi

DONATE NOW
Secure donations through Network for Good

Thank you to our corporate and

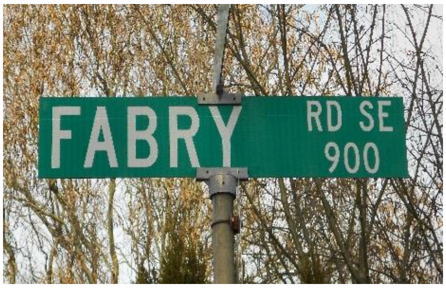
See examples in the database. Search the database by selecting the first letter of a state in the rotary wheel.

Please provide your clinic/provider information and provider photo to Jerry Walter at jerry.walter@fabrydisease.org. Please send the information below.

Facility /Clinic Name
Address line 1
Address line 2
City, State, and Zip Code
Primary Clinic Contact : Usually, your Fabry genetic counselor or similar staff
Primary Contact Phone
Website Address (If applicable)
Provider Specialty 1: Such as Clinical Genetics , Internal Medicine, or another
Provider Specialty 2

If your clinic is already listed, please verify that your information is correct and send updates as needed. Thank you for your participation! Jerry Walter

Patient Resource Education Packet (PREP) Program



"a road less traveled"

Clinics – PREP your patients for their journey!

Provide families with important information about NFDF programs.

Clinics: Please request enough Patient Resource Education Packets to provide to all your patients.

- Along with enough packets to provide to your patients, we'll send you a sample My Health Handbook Kit and a sample Fabry Symptoms Calendar for each of your staff who sees patients in clinic to show as an example.
- Please provide contact information so we may list your clinic in our website Find A Fabry Specialist database, a patient resource.
- The National Fabry Disease Foundation provides many programs and services to the Fabry community. **Physicians and clinic staff are key to ensuring that no one misses out on what the NFDF has to offer.**

Contact Jerry Walter at jerry.walter@fabrydisease.org

Fabry Community Publication Access Program

The NFDF obtains licenses to various peer-reviewed medical publications to provide free access to our community.

Registering at the top of our website enables access to the publications we post on our website at no cost.

This collection includes a diverse range of publications. Some are open access, while others are available at a discounted rate because we have agreed to place them in a members-only area of our website. This means you can access them without any additional cost.

You can access the publications we post from the Fabry Disease Publications tab in the Featured Resources section of our homepage at https://www.fabrydisease.org/index.php/all-publications?view=fjrelated&layout=blog. You can view an index of all the publications posted or view them by category.

There are currently about 6,000 peer-reviewed scientific articles accessible in PubMed.

“Why is Early Diagnosis so Important” Program

A part of the Fabry Community’s Story

WHY IS EARLY DIAGNOSIS IS SO IMPORTANT?

JERRY

Severe hearing loss/Hearing aids: Age 50

Heart attack: Age 52

Pacemaker/defibrillator implanted: Age 52

Heart surgery/mitral valve repair: Age 62

Heart Transplant: Age 65

LISA

BECKY

MANDY

GLEN

If you have Fabry disease and have experienced a major event, please provide your photo, the event, and your age when the event occurred.

Include: Implanted pacemaker/defibrillator, heart attacks, heart surgery, heart failure diagnosis, heart transplant, dialysis, kidney transplant, stroke, hearing loss with hearing aids or cochlear implants, and other major events.

Remembering Family and Friends

We encourage family members to submit information about those who have passed away from complications of Fabry disease. Please provide a photo, first and last name, dates of birth and death, and an obituary or something written about them (optional). Please see our website at https://www.fabrydisease.org/index.php/in-memory-of.

The Remembering Family and Friends section of the NFDF website is located 2/3 down the homepage in the Featured Programs area).

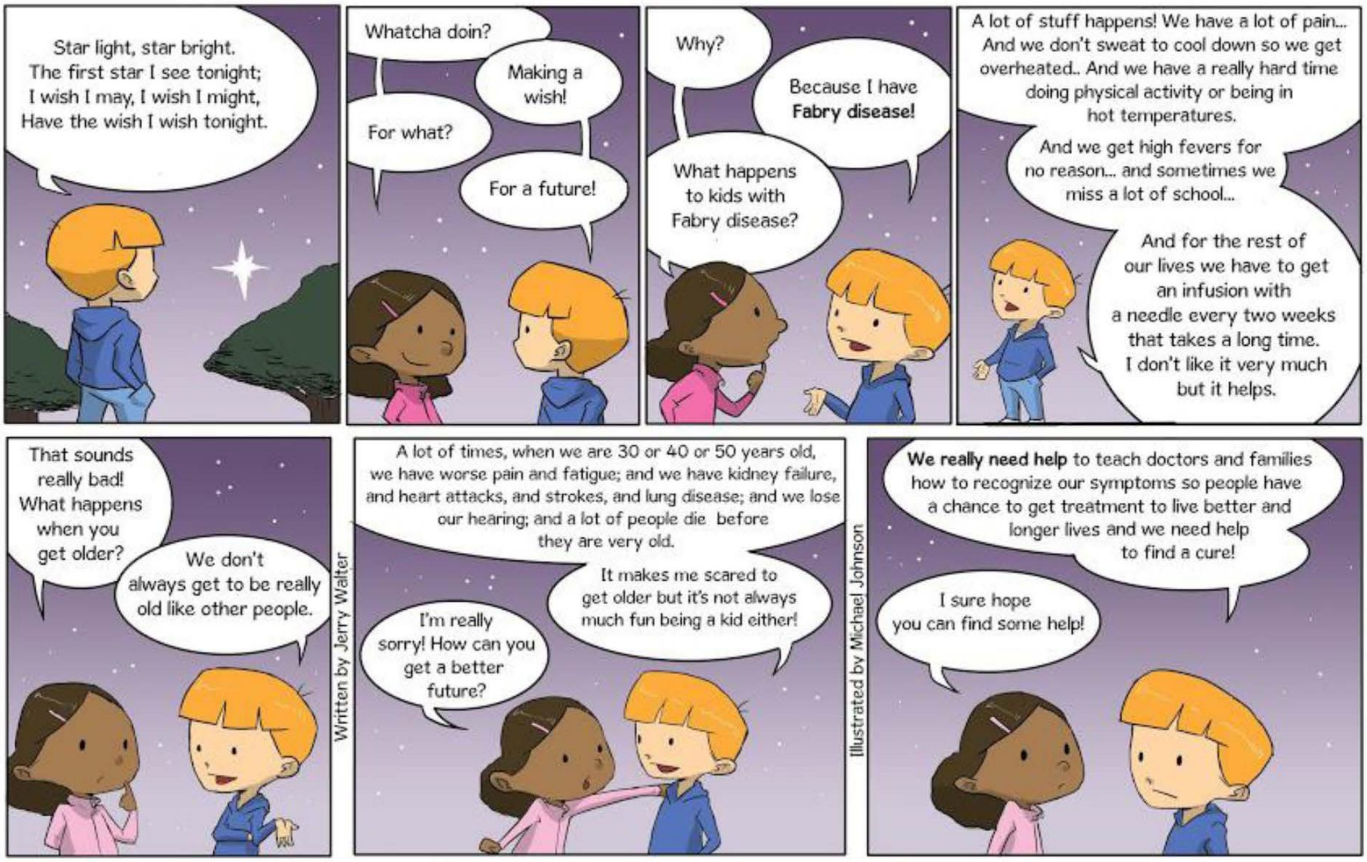
In addition to proving a place to visit and remember those who have passed away from Fabry disease complications, this section of our website is also a part of the Fabry community's story about the tragedies that often occur in our families.

Please contribute to this important awareness program.

Shining Star Campaign

Helping people with Fabry disease live better and longer lives!

Be the brightest star!



Will you be a shining star and help give people with Fabry disease a better life and a brighter future?

Please make a charitable contribution to the National Fabry Disease Foundation at **www.fabrydisease.org**

With treatment available, kids shouldn't have to live a poor quality of life and adults shouldn't die young because of Fabry Disease!

Be the Brightest Star!

Please give generously.

Donate online or mail a check to NFDF, 4301 Connecticut Ave. N.W, Suite 404, Washington, DC 20008 | info@fabrydisease.org | 800-651-9131
Permission is granted to copy and distribute this flyer unaltered to everyone you know. Please distribute it as widely as possible!

If you live outside the U.S., please donate to the Fabry support group in your country rather than the NFDF.

Fabry Community Fundraising

Ways to Give to the NFDF to Support the Fabry Community

The National Fabry Disease Foundation is a 501(c)(3) nonprofit charitable organization. We rely solely on charitable giving to support our many programs and services. Thank you for your generosity!

Make a charitable contribution by sending a check payable to the National Fabry Disease Foundation at 144 E King Street, Unit 1419, Hillsborough, NC 27278. Our nonprofit tax ID number is 202944028.

National
FABRY DISEASE
Foundation

Make a charitable contribution from the orange "Donate Now" button in the right column of our website homepage "We Need Your Help" section at www.fabrydisease.org.

DONATE NOW
Secure donations through
Network for Good

Give on face book – Use the blue Donate button at the top of the page or create a face book birthday fundraiser or other face book fundraiser by selecting the "Create" tab on the top menu bar of your face book page. Select fundraiser at the bottom, then select "Nonprofit and search for the National Fabry Disease Foundation. You take it from there. Face book does not charge any fees for non-profits. www.facebook.com/FabryDisease

National Fabry Disease Foundation (NFDF)
@FabryDisease · Charity Organization

You can donate using one of the options listed above on "Giving Tuesday", December 2, 2025, or December 1, 2026.

Giving Tuesday is a global generosity movement that unleashes the power of individuals and organizations to transform their communities and the world.

For assistance, please contact Jerry Walter at jerry.walter@fabrydisease.org.

National
FABRY DISEASE
Foundation

The National Fabry Disease Foundation, a non-profit charitable organization, provides valuable programs and services to support people with Fabry disease and their families … our motto is:

Fighting Fabry Disease … Living Better Longer

Please participate in our programs to help you stay informed, to help you cope with the burden of Fabry disease, to connect you with other families, and to help others through your participation. Here's a convenient checklist for things you can do to help you and your community.

☐ Visit our website at www.fabrydisease.org. There is something for everyone!

☐ Sign up for our e-newsletter to stay informed. Please subscribe at www.fabrydisease.org at the orange newsletter icon on the right side of the home page in the "Connect With Us" section.

☐ Please attend our annual Fabry family conference on Thursday and Friday before camp. The conference is open to all individuals with Fabry and family members, not just those attending camp. Transportation, lodging and meals are provided. See page 9.

☐ Apply to attend the annual NFDF Fabry Family Weekend Camp in September/October … our unique educational, expense free, camp for kids with Fabry disease 6 to 16 years old and their entire immediate family. Please see the separate flyer. Watch our e-newsletter for annual details. See pages 10.

☐ Please participate in the Fabry Family Assistance Program … a free, confidential, 24/7 service with counselors standing by when you need help. See page 22.

☐ Participate in our learning from the PROS (**P**atient **R**eported **O**utcomes **S**urvey) program. Please help us to better understand our disease and our community. See page 14.

☐ Request a "My Health Handbook" Kit for storing medical information and in case of emergency situations. The kit also contains Fabry awareness materials. See pages 17 and 19.

☐ Request an educational 2024 – 2025 Fabry Disease Symptoms Calendar, a great tool to better understand Fabry disease. See pages 15 and 19.

☐ View our educational YouTube videos and subscribe to our YouTube channel at www.youtube.com/TheNFDF. See page 13

☐ "Like, follow, or subscribe to our social media sites from our Link Tree on page 12.

☐ Please send us information about major medical events … remembrances … and community news and announcements. See pages 26 & 27.

☐ We rely solely on charitable donations to provide our programs and services. Please make a donation from the Donate Now button on our home page. See pages 28 and 29. **If you live outside the U.S., please make a donation to the Fabry support group in your country.**

☐ "Like" and "Follow" us on face book at www.facebook.com/FabryDisease. We often post news here first and you can post community news as well. We have over 4,200 followers. See page 12.

Please participate … Pay it forward … Pay it back … Together we're better!

We appreciate your support!

Please share NFDF information and resources with others who have Fabry disease.

See the Fabry Community Landscape Handout also.

Fighting Fabry Disease
… Living Better Longer!

We are giving more years to our children's lives and more life to our children's years.

Together
we're better
National Fabry
Disease
Foundation
Support Community

National Fabry Disease Foundation
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Hillsborough, NC 27278

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