National
FABRY DISEASE
Foundation

Programs, Services, and Resources for the Fabry Disease Community

(aka NFDF Programs Handout)

People with Fabry at our 2024 Fabry Family Education Conference

We strive to be a leader among individuals and organizations helping to enable people with Fabry disease to live better and longer lives.

This document is updated periodically and can be found at https://www.fabrydisease.org/images/ReferencePDFs/NFDFProgramsHandout.pdf

As of December 2024

NFDF Programs Handout

Table of Contents

National
FABRY DISEASE
Foundation

Who we are and what we do

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

☐ We manage an incorporated charitable non-profit organization.

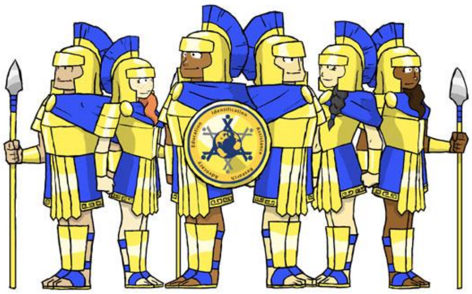
☐ We provide valuable Fabry disease education, community support and services programs to individuals with Fabry disease and their family members, and help to find those yet-to-be-diagnosed.

☐ We develop and collaborate with other stakeholders to implement initiatives to improve recognition, diagnoses, understanding, and management of Fabry disease.

☐ 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 shown in the concept image above is made up of Fabry community members fighting against Fabry disease for better and longer lives.

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 L Jefferies, MD, MBA, MPH
Cardiologist
University of Memphis

Eric Wallace, MD, FASN
Nephrologist
University of Alabama Birmingham

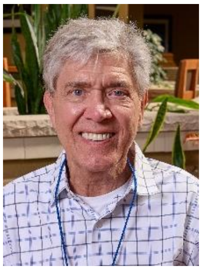
Nicols Abreu, MD
Neurologist
NYU School of Medicine

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

Vacant
Pulmonologist

Nadia Ali, PhD
Clinical Psychologist
Emory University Med Center

Casey McKenna, MS, CGC
Genetic Counselor
MAB Recorder
NFDF Senior Program Manager



Jerry Walter, MS
NFDF President
MAB Facilitator

Our Multifaceted Education Program

The NFDF provides our complimentary brand of education to people with Fabry disease, family members, healthcare providers, and the public to improve the recognition, diagnosis, understanding, and management of Fabry disease.

A robust educational website

Annual Fabry Family Education Conference

NFDF YouTube Channel – 50+ videos

Educational Webinar Program

Fabry Symptoms Presentation

Fabry Facts Educational Playing Card Deck

Fabry Disease Awareness Month (FDAM)

Governor's FDAM Proclamation Program

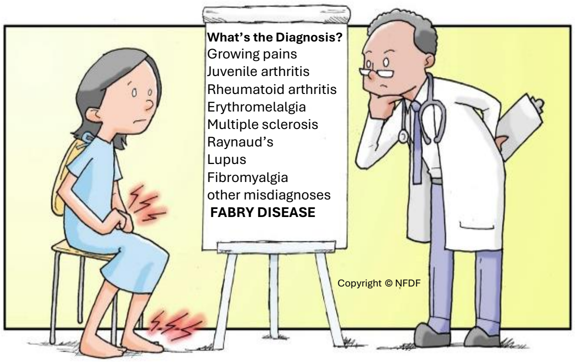
Patient Reported Outcomes Surveys

Connecting the Dots Campaign

The Eyes Have It Campaign

Fabry Focus newsletter

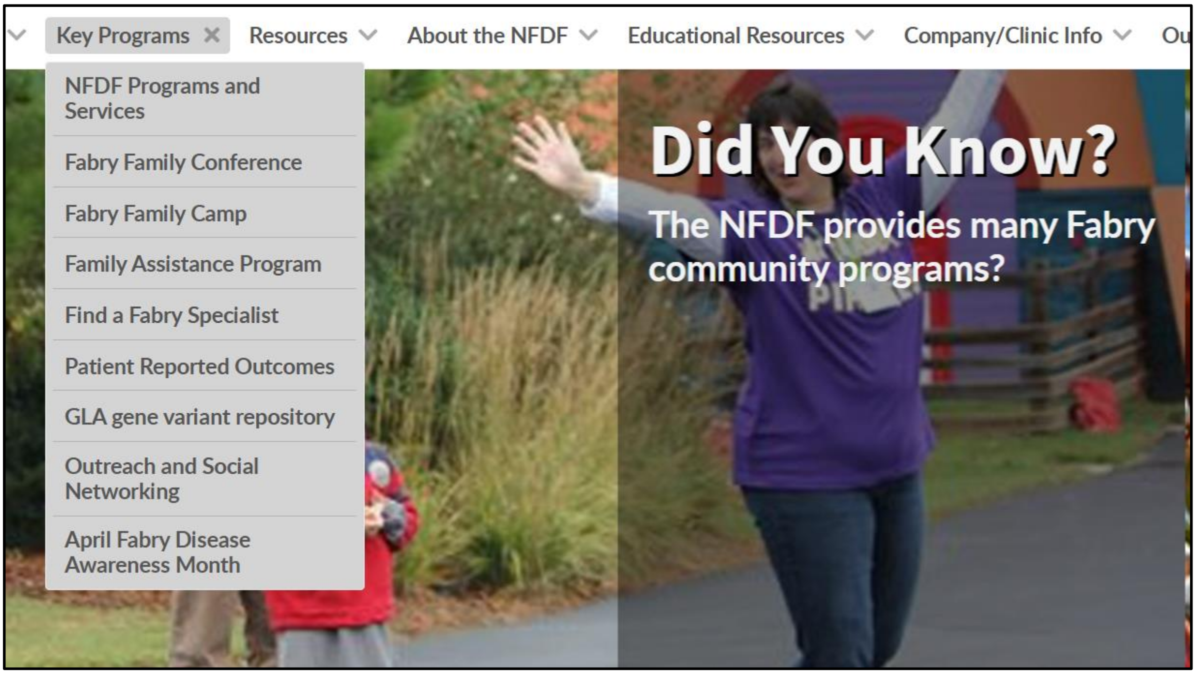
Located in the Connect With Us area on the mid-right column of www.fabrydisease.org



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

A Robust Educational Website

The top menu bar and drop-down menus on our robust educational website at www.fabrydisease.org are a guide to our content. Scroll to the bottom of the website homepage to see additional featured programs and resources. See example dropdown menus below.



Did You Know?

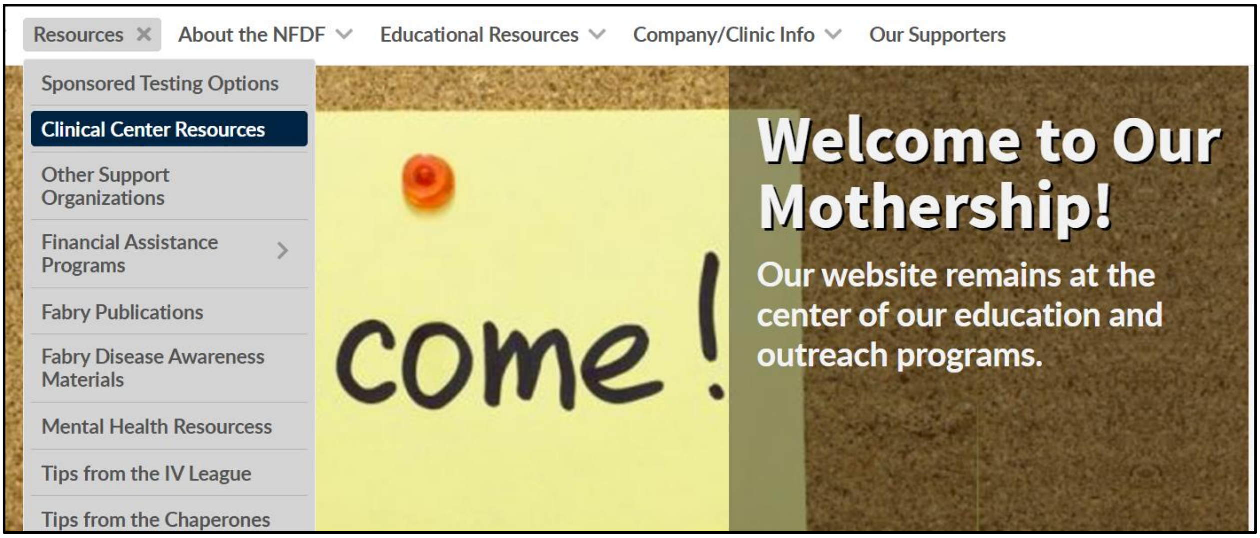
The NFDF provides many Fabry community programs?

The International Fabry Community

Our fight with Fabry Disease does not have geographic boundaries.

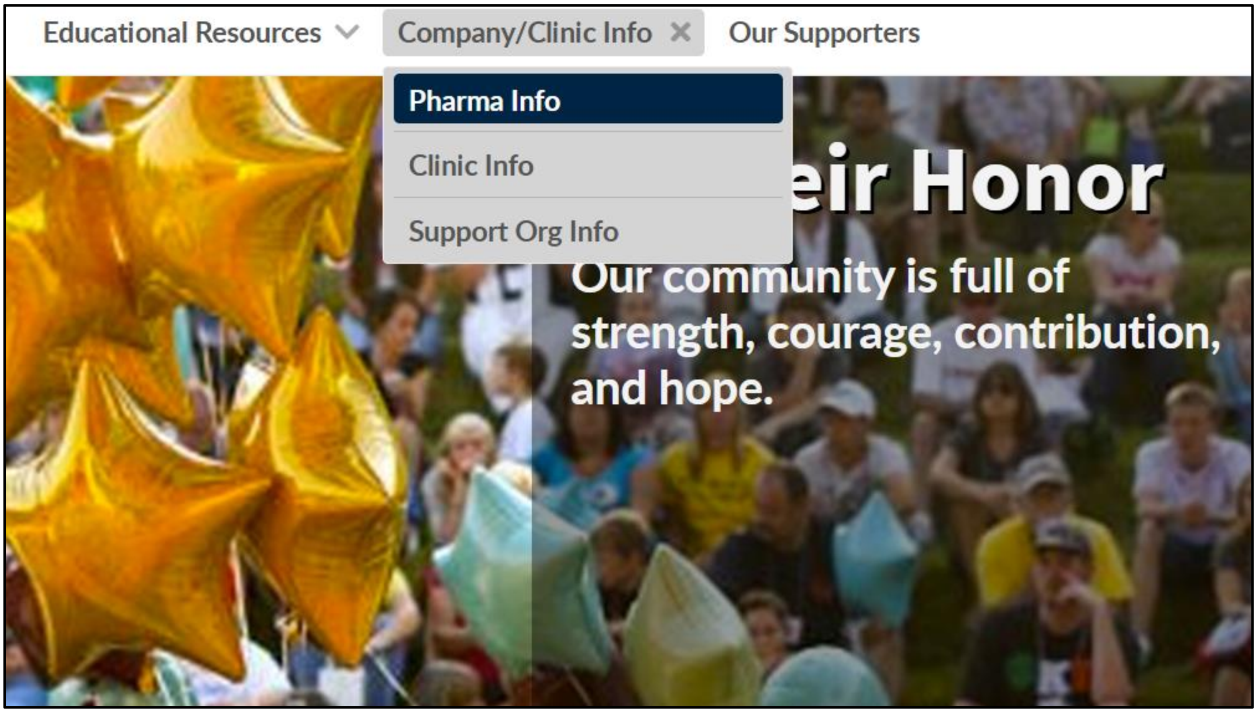
Our Robust Educational Website continued

Shown below are more screenshot examples of the top menu bar and drop-down menus on the NFDF website home page.



Welcome to Our Mothership!

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



eir Honor

Our community is full of strength, courage, contribution, and hope.

Annual Fabry Family Education Conference

- Annual Conference in September or October - Began in 2011
- Total of 225 - 275 attendees each year
- More than 100 individuals with Fabry usually attend.
  - Families attending the camp are the starting point plus additional attendees at the conference only.
  - Physicians and other healthcare speakers
  - Industry speakers
  - Organization speakers
  - Information sharing, focus groups, and study participation

- Separate Children's activities while adults are in education sessions
  - Children are chaperoned by nannies and sitters from Jovie.
  - Activities led by nannies and sitters are organized by age groups
  - Amazing facilitated 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.

The conference is held on Thursday and Friday in September or October with travel on Wednesday for most attendees.

2024 conference

Jovie nannies and sitters

2024 Friday lunch

Virtual Educational Meetings

The NFDF hosts regional face-to-face meetings and/or virtual education meetings about various aspects of Fabry disease and Fabry-related support programs as schedules and resources permit.

Meeting details are provided in the periodic NFDF Fabry Focus e-newsletter, the NFDF Facebook page, and other social media channels as the meetings are scheduled.

Meetings usually include:

- a brief introduction and announcements
- a presentation by an experienced speaker (presentations are about Fabry medical issues and important programs and resources).
- a question-and-answer session

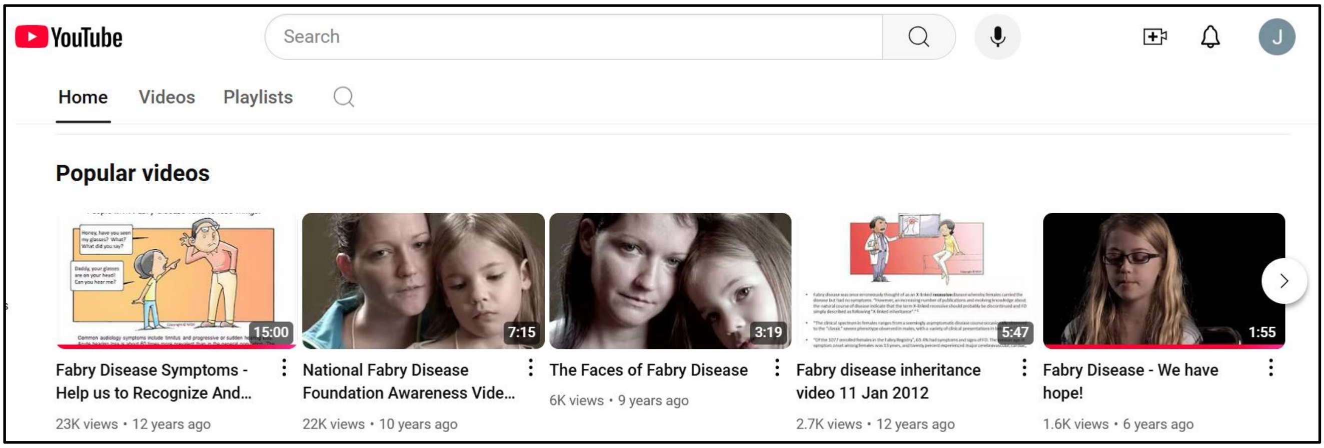
For virtual meetings, a video recording of each completed meeting will be posted on the NFDF's YouTube channel except when restricted by the presenter's organization.

See the NFDF's video index to locate videos at https://www.fabrydisease.org/images/ArticlePDFs/NFDF-YouTube-Index.pdf

Or see the NFDF video index from the NFDF Link Tree at https://linktr.ee/thenfdf

The NFDF's YouTube Channel

The National Fabry Disease Foundation has produced many educational videos. Although somewhat outdated, the NFDF symptoms video recorded in December 2011 has been viewed over 23,500 times to date and remains a very valuable resource.



Popular videos

Fabry Disease Symptoms - Help us to Recognize And...
23K views • 12 years ago

National Fabry Disease Foundation Awareness Vide...
22K views • 10 years ago

The Faces of Fabry Disease
6K views • 9 years ago

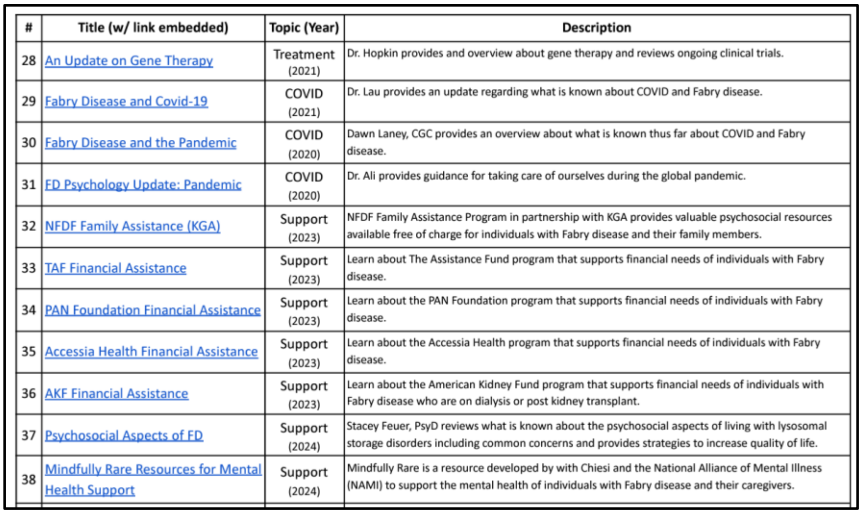
Fabry disease inheritance video 11 Jan 2012
2.7K views • 12 years ago

Fabry Disease - We have hope!
1.6K views • 6 years ago

Fabry Disease in Children with Dr. Robert Hopkin
19 views • 10 days ago

Fabry Disease and Adults with Dr. Staci Kallish
34 views • 10 days ago

YouTube List – more than 50 videos



#	Title (w/ link embedded)	Topic (Year)	Description
28	An Update on Gene Therapy	Treatment (2021)	Dr. Hopkin provides and overview about gene therapy and reviews ongoing clinical trials.
29	Fabry Disease and Covid-19	COVID (2021)	Dr. Lau provides an update regarding what is known about COVID and Fabry disease.
30	Fabry Disease and the Pandemic	COVID (2020)	Dawn Laney, CGC provides an overview about what is known thus far about COVID and Fabry disease.
31	FD Psychology Update: Pandemic	COVID (2020)	Dr. Ali provides guidance for taking care of ourselves during the global pandemic.
32	NFDF Family Assistance (KGA)	Support (2023)	NFDF Family Assistance Program in partnership with KGA provides valuable psychosocial resources available free of charge for individuals with Fabry disease and their family members.
33	TAF Financial Assistance	Support (2023)	Learn about The Assistance Fund program that supports financial needs of individuals with Fabry disease.
34	PAN Foundation Financial Assistance	Support (2023)	Learn about the PAN Foundation program that supports financial needs of individuals with Fabry disease.
35	Accessia Health Financial Assistance	Support (2023)	Learn about the Accessia Health program that supports financial needs of individuals with Fabry disease.
36	AKF Financial Assistance	Support (2023)	Learn about the American Kidney Fund program that supports financial needs of individuals with Fabry disease who are on dialysis or post kidney transplant.
37	Psychosocial Aspects of FD	Support (2024)	Stacey Feuer, PsyD reviews what is known about the psychosocial aspects of living with lysosomal storage disorders including common concerns and provides strategies to increase quality of life.
38	Mindfully Rare Resources for Mental Health Support	Support (2024)	Mindfully Rare is a resource developed by with Chiesi and the National Alliance of Mental Illness (NAMI) to support the mental health of individuals with Fabry disease and their caregivers.

https://www.fabrydisease.org/images/ArticlePDFs/NFDF-YouTube-Index.pdf

Please watch and share our videos and subscribe at https://www.youtube.com/thenfdf

Patient Reported Outcomes Survey Program

"Learning from the PROS"

The NFDF collects information from brief periodic surveys to continue to learn about Fabry disease and to discover areas that may not yet have been fully investigated and reported in formal studies.

Why?

The information gathered is used to provide insights to:
- improve our understanding of Fabry disease
- help you ask your doctors the right questions
- assist to determine future research needs
- assist to develop educational materials

Personal information is not shared!

Who?

People with Fabry disease 18 years old and older may participate.

What?

Survey Monkey surveys

Where?

Most surveys are open to the international Fabry community.

When?

We hope to distribute surveys quarterly to enable continuous learning about Fabry.

How?

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.

Learning about Fabry disease does not have geographic boundaries.

NFDF Social Media Channels

National Fabry Disease Foundation (NFDF)
@FabryDisease · Medical & Health

The National Fabry Disease Foundation's Facebook page at http://www.facebook.com/FabryDisease (displayed above) has over 4,200 followers as of this handbook revision.

Follow us on social media

Access NFDF social media channels from our Link Tree at https://linktr.ee/thenfdf

In consideration of community members not using Facebook, we are committed to increasing use of our e-newsletter service and others social media sites for day-to-day news.

Nat Fabry Diseas Fdn
399 Tweets

Nat Fabry Diseas Fdn
@FabryDisease1

Supporting people with Fabry disease, a rare genetic disorder. Primary focus is education to enable early diagnosis and treatment. @jerrywalter

Hillsborough, NC https://t.co/b2hUXpMCVe
Joined September 2009

38 Following 693 Followers

The National Fabry Disease Foundation's X account is https://x.com/FabryDisease1 (displayed to the left) has almost 750 followers as of this handbook revision.

Fabry Focus E-Newsletter and Fabry Focus for Healthcare Providers

The National Fabry Disease Foundation (NFDF) provides a periodic e-newsletter to keep the Fabry community and other stakeholders informed about relevant news and information. We also have an e-newsletter just for healthcare providers.

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

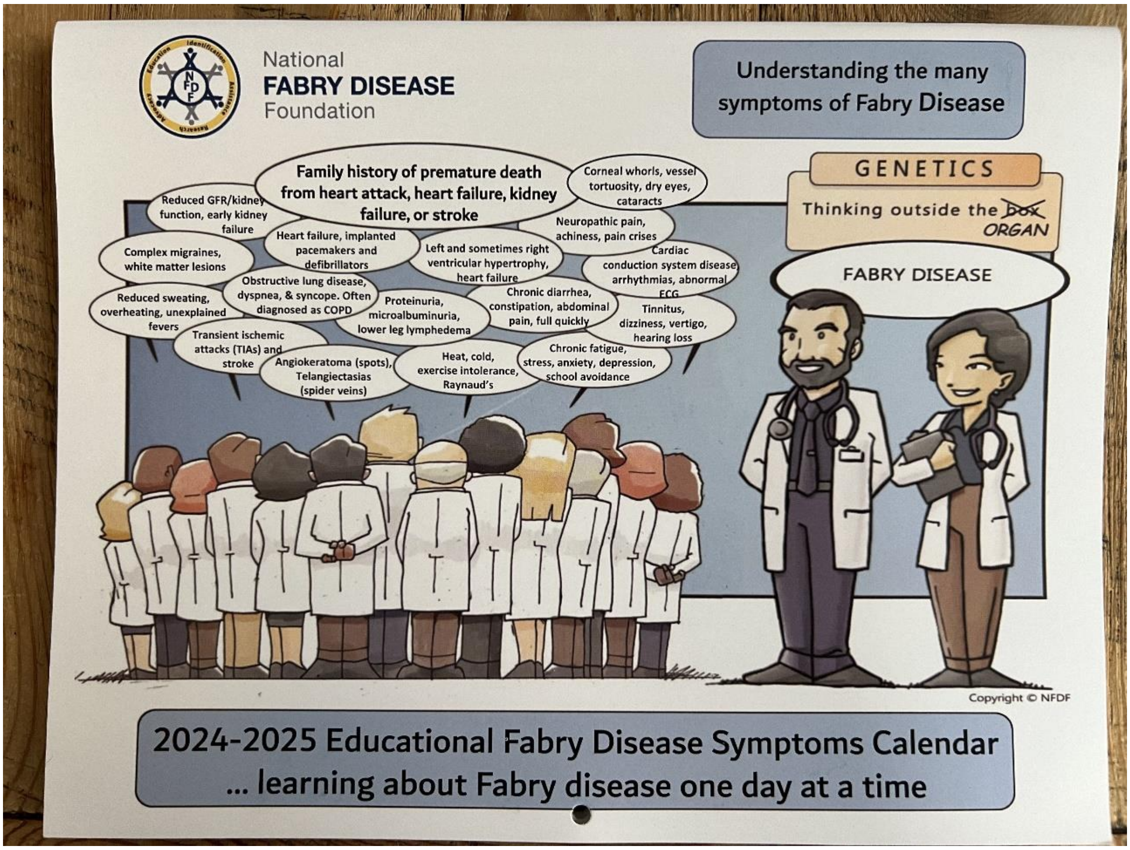
… or from this link: E-Newsletter Subscription Link

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

- Email at info@fabrydisease.org
- Our periodic e-newsletter (the Fabry Focus)
- Patient-Reported-Outcomes surveys PROs (learning from the PROs)
- Facebook page at www.facebook.com/FabryDisease
- X at www.X.com/FabryDisease1
- Instagram at https://www.instagram.com/nationalfabrydiseasefoundation/
- TikTok at https://www.tiktok.com/@nationalfabrydiseasefdn
- By phone at: 1-800-651-9131
- and via information distributed through Fabry healthcare providers

2024 -2025 Educational Fabry Disease Symptoms Presentation and Calendar

The NFDF's educational symptoms presentation and calendar provide an easy-to-understand description of most of the common symptoms of Fabry disease.



The symptoms presentation is available at https://www.fabry.rightforleft.com/images/ReferencePDFs/NFDF%202024-2025-Symptoms-Presentation-FINAL-6-4-2024.pdf.

The 18-month educational calendar is available along with other education and awareness resources by contacting info@fabrydisease.org.

Educational Fabry Facts 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 from published peer-reviewed literature and from other sources.

Select the Frequently Asked Questions button on the right-hand column of the NFDF website homepage below the “Do you have Questions” banner, to open a PDF document of all the FAQ answers on the cards.

- ☐ The card deck is available along with other education and awareness resources by contacting info@fabrydisease.org.
- ☐ Healthcare providers, please request a complimentary playing card deck for yourself and a sample playing card deck to show your patients info@fabrydisease.org so they can obtain one.
- ☐ If you do not have Fabry or are not a Fabry healthcare provider 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.

The NFDF Link Tree makes access to some of our most important resources easy.

National
FABRY DISEASE
Foundation

Visit the National Fabry Disease Foundation's (NFDF's) robust educational website for the whole story at www.fabrydisease.org.

Visit the NFDF's Link Tree (shown on right) at https://linktr.ee/thenfdf for quick access to our most important resources and our social media sites.

The NFDF Team
Jerry, Casey, and Hannah

Empowered, Connected, Determined (An NFDF themed T-shirt above)

TheNFDF

The National Fabry Disease Foundation

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)
- Mental Health Resources
- Sponsored (cost-free) U.S. Genetic Testing
- 2023-2024 NFDF Webinar Meeting Registration
- Jerry Walter's Fabry Disease News Column

NFDF Social Media:

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

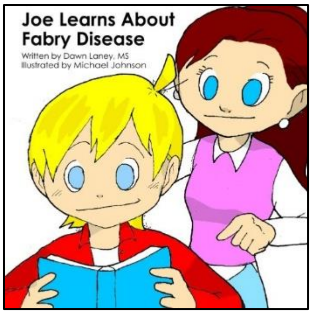
Community Support and Assistance Programs

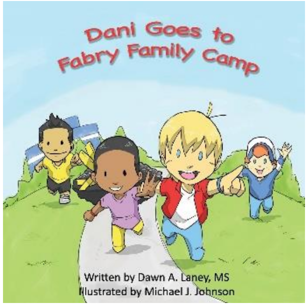
The NFDF provides valuable community support programs to help people with Fabry and their family members on their journey with this burdensome disease. See the following pages on the NFDF website.

- Annual Fabry Family Weekend Camp
- Family Assistance Program (KGA, Inc.)
- Find a Fabry Specialist Database
- Urgent and Unmet Needs Programs
- Keeping the community Informed
- Daily phone, email, and written correspondence
- Sponsored Testing Handout
- Financial Assistant Programs Handout
- Mental Health Resources Handout

More Website Resources

- Fabry Community Announcements
- Why Early Diagnosis and Treatment are So Important
- The NFDF and the Fabry Community Landscape
- Fabry Disease Publications and Illustrated Books
- Jerry's monthly column – Fabry: A Road Less Traveled
- Remembering Family and Friends.





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
- Animal adventure
- 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 most families).

☐ Transportation, lodging and meals are provided.

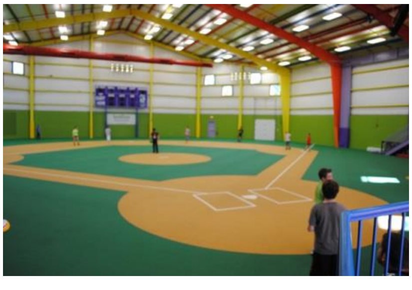
☐ For more information about Victory Junction camp facilities please see www.victoryjunction.org

☐ Email jerry.walter@fabrydisease.org to let us know you are interested in attending camp and subscribe to the NFDF e-newsletter to ensure you receive camp application guidance.

a brave camper kissing a fish

The Fabry Family Weekend Camp is usually held in September or October. See the community announcements in the upper left area of www.fabrydisease.org .

Victory Junction camp activities!



Family Assistance Program

- ☐ The National Fabry Disease Foundation (NFDF) and the Canadian Fabry Association (CFA) partner to provide a **free, confidential** family assistance program (FAP) through Kathleen Greer Associates, Inc. (KGA).

- ☐ The FAP includes 24/7 telephone counseling and referrals at 800-648-9557.

- ☐ Plus, get access to **online training, tools and resources** to help you thrive. All available to you and your adult household members, at **no cost** to you at **https://my.kgalifeservices.com/** When using KGA services, use "**fabry**" as your company code.

- ☐ See the Family Assistance Program tab on our website at https://www.fabrydisease.org/programs-projects/family-assistance-program.

Any personal issue is appropriate.

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.

Urgent and Unmet Needs Program

If resources are available, provides short-term financial assistance when other primary programs are unavailable.

In most cases, individuals must be declined by NORD, Accessia Health (AH), The Assistance Fund (TAF), PAN Foundation (PAN) and/or American Kidney Fund (AKF) first.

Information about the primary Fabry financial assistance programs is located at https://www.fabrydisease.org/images/ReferencePDFs/PrimaryFinancialAssistanceProgramsForFabryDisease-4-20-2024.pdf

Examples:

- Support for making the first payment of your monthly insurance premium while your application for assistance from one of the other organizations is processed.
- 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 Fabry specific treatment)
- Emergency needs … and more

To request NFDF assistance, email info@fabrydisease.org

First apply to the primary financial assistance programs for Fabry disease: Accessia Health (AH - formerly PSI), PAN, TAF, NORD, and/or the America Kidney Fund (AKF), first before contacting the NFDF.

Accessia Health
PAN Foundation
The Assistance Fund
American Kidney Fund® FIGHTING ON ALL FRONTS
NORD® National Organization for Rare Disorders

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.

Some publications we post are open access (free). We also purchase access to other publications at a discounted rate by agreeing to place them in a members-only area of our website not available for general public use. Then, there is no cost to users.

You can access the publications we post from the Fabry Disease Publications tab in the Featured Resources section of our website homepage. You can view an index of all the publications posted or view them by category.

We posted the comprehensive Revisited Management and Treatment Recommendations for Adult Patients by Ortiz et al, April 2018. We merged the main document and eight appendices (A-H) into one document for much easier access and use. The recommendations were published before the oral chaperone Therapy Galafold© was approved so the treatment sections of the paper are limited to discussing treatment with ERT.

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, Physician Assistants managing people with Fabry disease as a primary Fabry Specialist,

We continue build a Find A Fabry Specialist database on our website at https://www.fabrydisease.org/find-a-fabry-specialist.

Fabry Specialist Directory

Search for a Fabry Disease Specialist.

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

WE NEED YOUR HELP

As an IRS 501(c)(3) non-profit support organization we rely on donations from organizations and individuals to provide meaningful support and assistance programs to people/families with Fabry disease. **Please give generously!**

Thank you to our corporate and

To search, select a state in the field next to the “filters” icon. Then select the facility/clinic name to access the facility and provider information.

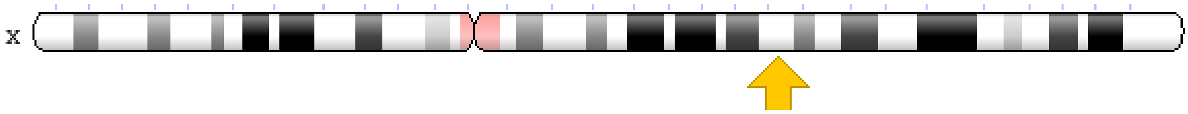
Providers are listed as “Prescribing Providers” (Physicians, Physician Assistants, and Nurse Practitioners) and Coordinating Providers (Genetic Counselors, Nurses, and other appropriate staff members).

To add your facility/clinic to the Find A Fabry Specialist database, please provide the following to info@fabrydisease.org.

- Facility/clinic name and address where you see patients
- Facility website
- Mailing address if it is different
- Primary contact name and credentials
- Main contact phone number and email address
- Number of adults and children with Fabry in you care
- Name, credentials MD, PhD, PA, NP, CGC, Nurse, etc.
- Specialty: Genetics, Internal Medicine, Nephrology, etc.

Fabry *GLA* Gene Variant Repository

This program is designed to facilitate further study and a better understanding of Fabry disease gene 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!

It takes a village!

Please provide your family variant to add to our repository to info@fabrydisease.org.

Variants are first classified into five classes: benign, likely benign, variant of unknown significance (VUS), likely pathogenic , and pathogenic (disease-causing).

GLA gene variants are further classified as classic (little to no alpha-galactosidase A enzyme activity with earlier manifestations) or non-classic (more enzyme sufficient to delay symptoms onset into adulthood in most cases).

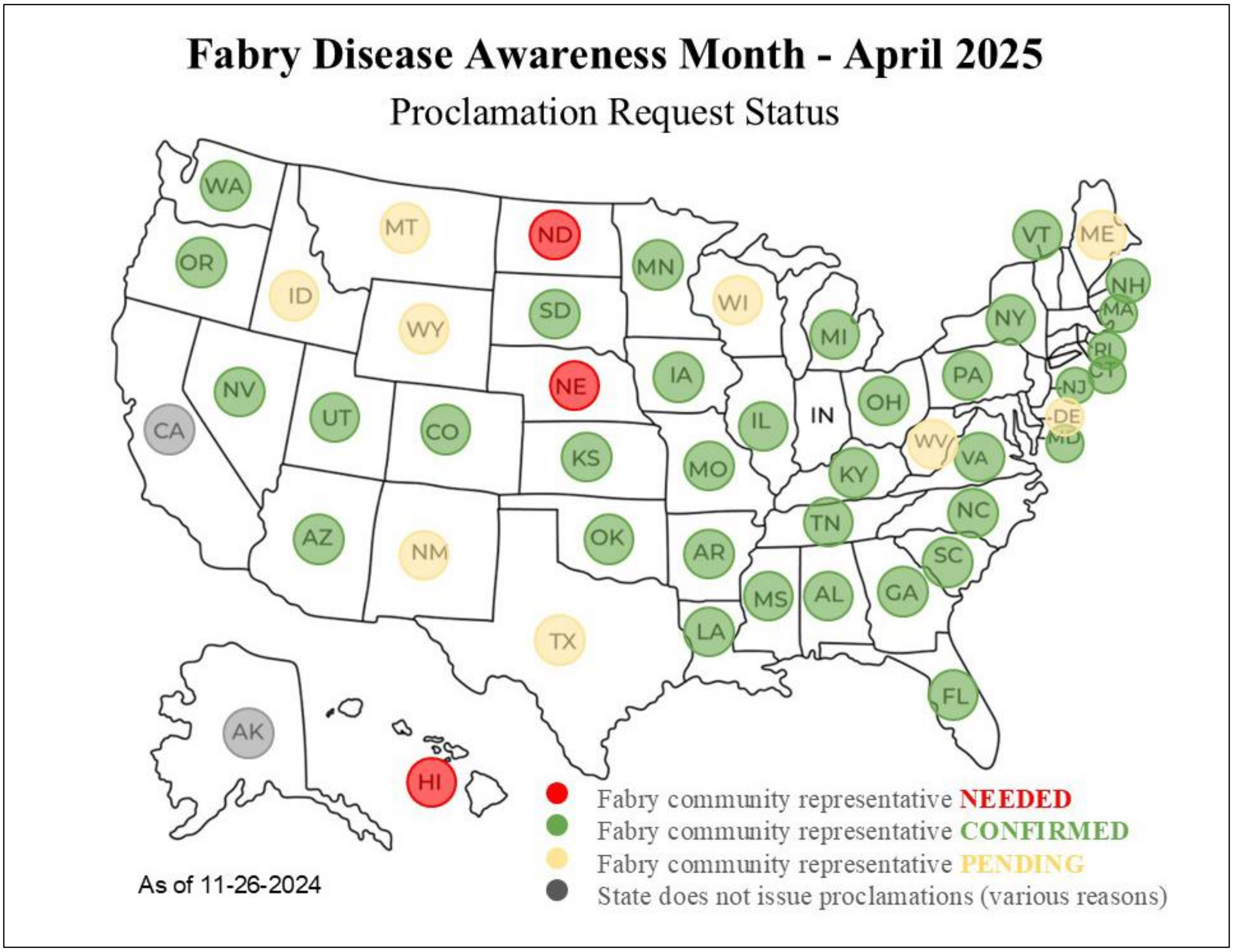
The NFDF facilitates analysis of the similarities, differences, and trends between males and females of difference age groups and different classic and non-classic variants.

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

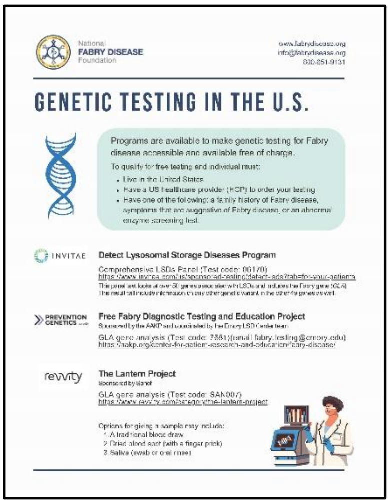
Fabry Disease Awareness Month Governors' Proclamation Program

We begin contacting Fabry community representatives in each state in November of the prior year.

Fabry community representatives in each state work with the NFDF to request Governors' proclamations to designate April as Fabry Disease Awareness Month.



Other Useful Resources



National
FABRY DISEASE
Foundation

www.fabrydisease.org
info@fabrydisease.org
800-651-9131

GENETIC TESTING IN THE U.S.

Programs are available to make genetic testing for Fabry disease accessible and available free of charge.

To qualify for free testing and individual must:

- Live in the United States
- Have a US healthcare provider (HCP) to order your testing
- Have one of the following: a family history of Fabry disease, symptoms that are suggestive of Fabry disease, or an abnormal enzyme screening test.

INVITAE **Detect Lysosomal Storage Diseases Program**

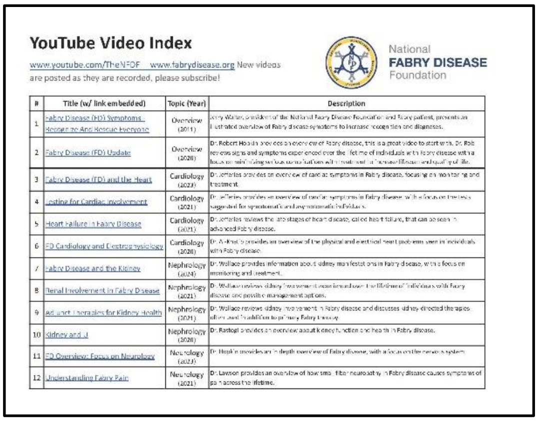
Comprehensive LSDs Panel (Test code: 06170)
https://www.invitae.com/us/sponsored-testing/detect-lsds?tab=for-your-patients
This panel test looks at over 50 genes associated with LSDs and includes the Fabry gene (GLA). This result will include information on any other genetic variant in the other 49 genes as well.

PREVENTION GENETICS **Free Fabry Diagnostic Testing and Education Project**
Sponsored by the AAKP and coordinated by the Emory LSD Center team
GLA gene analysis (Test code: 7851)(email fabry.testing@emory.edu)
https://aakp.org/center-for-patient-research-and-education/fabry-disease/

revvity **The Lantern Project**
Sponsored by Sanofi
GLA gene analysis (Test code: SAN007)
https://www.revvity.com/category/the-lantern-project

Options for giving a sample may include:
1. A traditional blood draw
2. Dried blood spot (with a finger prick)
3. Saliva (swab or oral rinse)

Sponsored Testing Programs



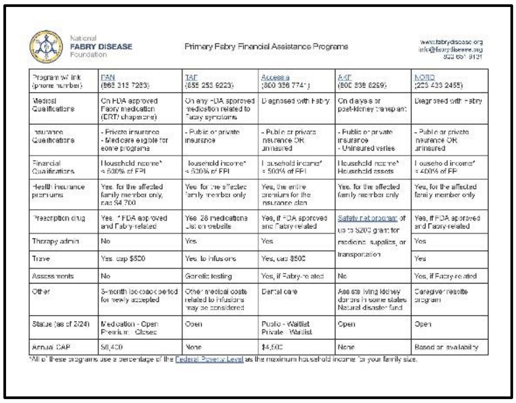
YouTube Video Index

www.youtube.com/TheNFDF www.fabrydisease.org New videos are posted as they are recorded, please subscribe!

National
FABRY DISEASE
Foundation

#	Title (w/ link embedded)	Topic (Year)	Description
1	Fabry Disease (FD) Symptoms – Recognize And Rescue Everyone	Overview (2011)	Jerry Walter, president of the National Fabry Disease Foundation and Fabry patient, presents an illustrated overview of Fabry disease symptoms to increase recognition and diagnoses.
2	Fabry Disease (FD) Update	Overview (2020)	Dr. Robert Hopkin provides an overview of Fabry disease, this is a great video to start with. Dr. Rob reviews signs and symptoms experienced over the lifetime of individuals with Fabry disease with a focus on minimizing serious complications with treatment to increase lifespan and quality of life.
3	Fabry Disease (FD) and the Heart	Cardiology (2023)	Dr. Jefferies provides an overview of cardiac symptoms in Fabry disease, focusing on monitoring and treatment.
4	Testing for Cardiac Involvement	Cardiology (2021)	Dr. Jefferies provides an overview of cardiac symptoms in Fabry disease with a focus on the tests suggested for symptomatic and asymptomatic individuals.
5	Heart Failure in Fabry Disease	Cardiology (2021)	Dr. Jefferies reviews the late stages of heart disease, called heart failure, that can be seen in advanced Fabry disease.
6	FD Cardiology and Electrophysiology	Cardiology (2020)	Dr. Al-Khatib provides an overview of the physical and electrical heart problems seen in individuals with Fabry disease.
7	Fabry Disease and the Kidney	Nephrology (2024)	Dr. Wallace provides information about kidney manifestations in Fabry disease, with a focus on monitoring and treatment.
8	Renal Involvement in Fabry Disease	Nephrology (2021)	Dr. Wallace reviews kidney involvement experienced over the lifetime of individuals with Fabry disease and possible management options.
9	Adjunct Therapies for Kidney Health	Nephrology (2021)	Dr. Wallace reviews kidney involvement in Fabry disease and discusses kidney directed therapies often used in addition to primary Fabry therapy.
10	Kidney and [illegible]	Nephrology (2020)	Dr. Rastogi provides an overview about kidney function and health in Fabry disease.
11	FD Overview: Focus on Neurology	Neurology (2023)	Dr. Hopkin provides an in depth overview of Fabry disease, with a focus on the nervous system.
12	Understanding Fabry Pain	Neurology (2021)	Dr. Lawson provides an overview of how small fiber neuropathy in Fabry disease causes symptoms of pain across the lifetime.

YouTube Video Index



National
FABRY DISEASE
Foundation

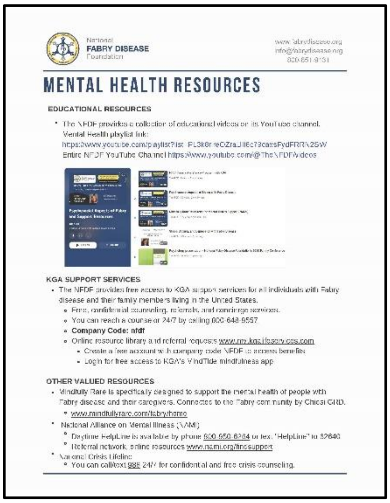
Primary Fabry Financial Assistance Programs

www.fabrydisease.org
info@fabrydisease.org
800 651 9131

Program w/ link (phone number)	PAN (866 316 7263)	TAF (855 253 9223)	Accessia (800 366 7741)	AKF (800 638 8299)	NORD (203 433 2455)
Medical Qualifications	On FDA approved Fabry medication (ERT/ chaperone)	On any FDA approved medication related to Fabry symptoms	Diagnosed with Fabry	On dialysis or post-kidney transplant	Diagnosed with Fabry
Insurance Qualifications	- Private insurance - Medicare eligible for some programs	- Public or private insurance	- Public or private insurance OR uninsured	- Public or private insurance - Uninsured varies	- Public or private insurance OR uninsured
Financial Qualifications	Household income* ≤ 500% of FPL	Household income* ≤ 500% of FPL	Household income* ≤ 500% of FPL	Household income* Household assets	Household income* ≤ 400% of FPL
Health insurance premiums	Yes, for the affected family member only, cap $4,700	Yes, for the affected family member only	Yes, the entire premium for the insurance plan	Yes, for the affected family member only	Yes, for the affected family member only
Prescription drug	Yes, if FDA approved and Fabry-related	Yes, 28 medications List on website	Yes, if FDA approved and Fabry-related	Safety net program of up to $200 grant for medicine, supplies, or transportation	Yes, if FDA approved and Fabry-related
Therapy admin	No	Yes	Yes		Yes
Travel	Yes, cap $500	Yes, to infusions	Yes, cap $500		Yes
Assessments	No	Genetic testing	Yes, if Fabry-related	No	Yes, if Fabry-related
Other	6-month lookback period for newly accepted	Other medical costs related to infusions may be considered	Dental care	Assists living kidney donors in some states Natural disaster fund	Caregiver respite program
Status (as of 2/24)	Medication - Open Premium - Closed	Open	Public - Waitlist Private - Waitlist	Open	Open
Annual CAP	$6,400	None	$4,500	None	Based on availability

*All of these programs use a percentage of the Federal Poverty Level as the maximum household income for your family size.

Financial Assistance Programs



National
FABRY DISEASE
Foundation

www.fabrydisease.org
info@fabrydisease.org
800-651-9131

MENTAL HEALTH RESOURCES

EDUCATIONAL RESOURCES

- The NFDF provides a collection of educational videos on its YouTube channel.
  Mental Health playlist link:
  https://www.youtube.com/playlist?list=PL3k8rreOZraJll6c73caxsFydFRRN2SW
  Entire NFDF YouTube Channel https://www.youtube.com/@TheNFDF/videos

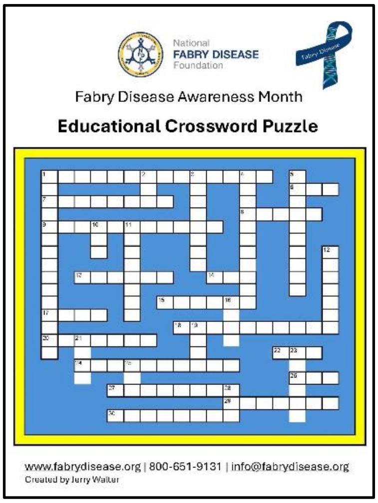
KGA SUPPORT SERVICES

- The NFDF provides free access to KGA support services for all individuals with Fabry disease and their family members living in the United States.
  - Free, confidential counseling, referrals, and concierge services.
  - You can reach a counselor 24/7 by calling 800-648-9557
  - **Company Code: nfdf**
  - Online resource library and referral requests www.my.kgalifeservices.com
    - Create a free account with company code NFDF to access benefits
    - Login for free access to KGA's MindTide mindfulness app

OTHER VALUED RESOURCES

- Mindfully Rare is specifically designed to support the mental health of people with Fabry disease and their caregivers. Connected to the Fabry community by Chiesi GRD.
  - www.mindfullyrare.com/fabry/home
- National Alliance on Mental Illness (NAMI)
  - Daytime HelpLine is available by phone 800-950-6264 or text "HelpLine" to 62640
  - Referral network, online resources www.nami.org/findsupport
- National Crisis Lifeline
  - You can call/text 988 24/7 for confidential and free crisis counseling.

Mental Health Resources



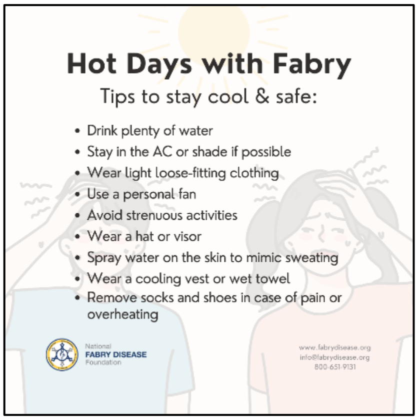
National
FABRY DISEASE
Foundation

Fabry Disease Awareness Month

Educational Crossword Puzzle

www.fabrydisease.org | 800-651-9131 | info@fabrydisease.org
Created by Jerry Walter

Educational Crossword Puzzle



Hot Days with Fabry

Tips to stay cool & safe:

- Drink plenty of water
- Stay in the AC or shade if possible
- Wear light loose-fitting clothing
- Use a personal fan
- Avoid strenuous activities
- Wear a hat or visor
- Spray water on the skin to mimic sweating
- Wear a cooling vest or wet towel
- Remove socks and shoes in case of pain or overheating

National
FABRY DISEASE
Foundation

www.fabrydisease.org
info@fabrydisease.org
800-651-9131

Hot Days with Fabry

NFDF Collaborations

LYSOSOMAL STORAGE DISEASES
LSD Advocacy Coalition

The Lysosomal Storage Diseases Advocacy (LSDAC) is a coalition of multiple patient advocacy organizations dedicated to advancing public policy issues that benefit and improve the quality of life for patients living with lysosomal storage disorders (LSDs).

The National Fabry Disease Foundation is a founding member of the LSDAC.

Fabry Disease NEWS™
A BIONEWS™ BRAND

The National Fabry Disease Foundation (NFDF) has partnered with Bionews, Inc., the parent company of Fabry Disease NewsTM, to help further the mission of ensuring that patients and caregivers are able to get the support, assistance, and information they need to help them in their daily lives.

This mutually beneficial partnership allow both the NFDF and Bionews to reach more patient and caregiver audiences and share more news, information, and resources with the community.

https://fabrydiseasenews.com/advocacy-partners/

Subscribe to the Fabry Disease News newsletter near the bottom of https://fabrydiseasenews.com/

Subscribe to Jerry Walter’s column at https://fabrydiseasenews.com/fabry-a-road-less-traveled-jerry-walter/

Keeping the Fabry Community Informed via our website
Example: Pharma, Clinic and Support Organizations

The Fabry Community is fortunate to have three approved treatments for Fabry disease in the U.S. (Fabrazyme enzyme replacement therapy (ERT)), Galafold oral chaperone therapy, and Elfabrio, also an ERT, and four approved treatments outside the U.S. (the three mentioned above and Replagal ERT).

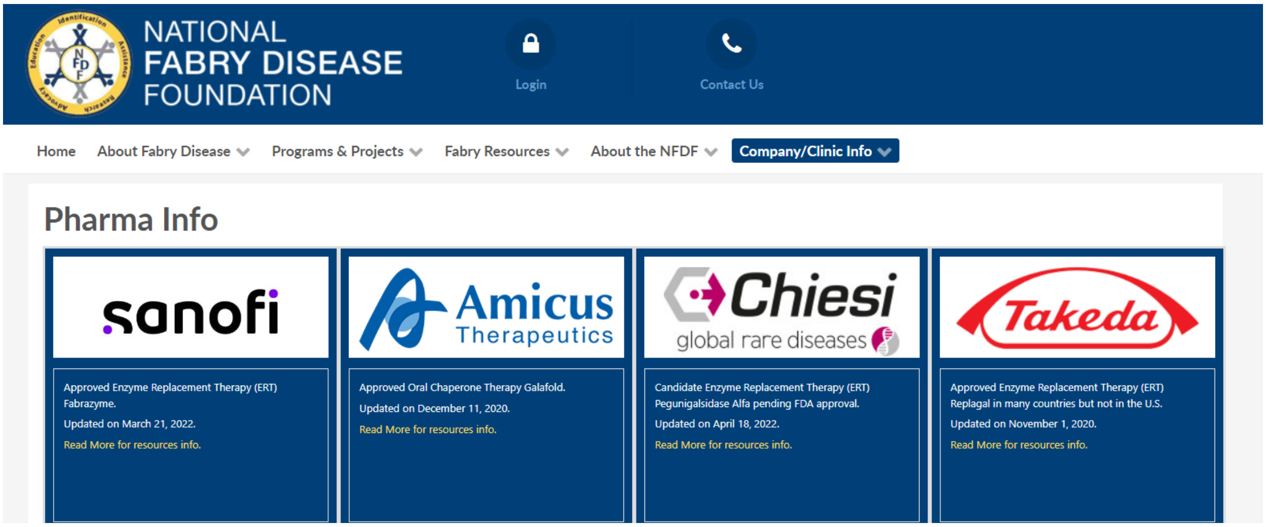
There are also investigational treatment solutions conducting or preparing to begin clinical trials including a potential oral substrate reduction therapy (Sanofi) and gene therapy solutions (Sangamo, uniQure, and 4DMT), to mention a few.

To stay updated about the status of each treatment/potential treatment and some of the associated resources available, please visit the Company/Clinic tab, then the Pharma Info tab on the top menu bar of www.fabrydisease.org.

You can also learn about Clinic Info and Support Organization Info (Spt Org Info) from their respective tabs.

This feature of our website is a work in progress that we will continue to update for your use.

See the screenshot below to help with website navigation.



Pharma Info

Approved Enzyme Replacement Therapy (ERT) Fabrazyme.
Updated on March 21, 2022.
Read More for resources info.

Approved Oral Chaperone Therapy Galafold.
Updated on December 11, 2020.
Read More for resources info.

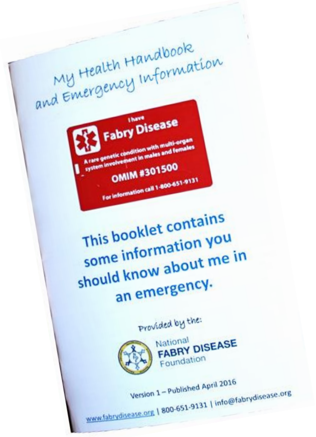
Candidate Enzyme Replacement Therapy (ERT) Pegunigalsidase Alfa pending FDA approval.
Updated on April 18, 2022.
Read More for resources info.

Approved Enzyme Replacement Therapy (ERT) Replagal in many countries but not in the U.S.
Updated on November 1, 2020.
Read More for resources info.

Clinics and other organizations who wish to develop a grid square, please contact Jerry Walter at jerry.walter@fabrydisease.org

“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.



My Health Handbook
and Emergency Information

I have
Fabry Disease
A rare genetic condition with multi-organ system involvement in males and females
OMIM #301500
For information call 1-800-651-9131

This booklet contains some information you should know about me in an emergency.

Provided by the:
National FABRY DISEASE Foundation

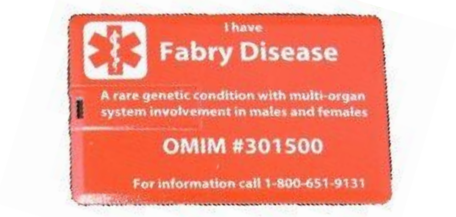
Version 1 – Published April 2016
www.fabrydisease.org | 800-651-9131 | info@fabrydisease.org

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 two useful medical references. Subsequent, more current, versions of these documents can be found on the NFDF website. Awareness wristbands and other awareness materials are included in the kits.

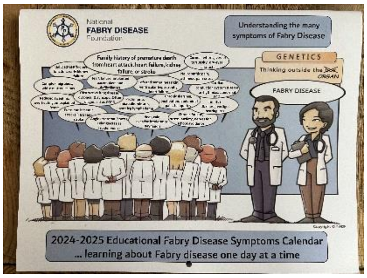


NFDF educational calendars and playing cards, My Health Handbook Kit, and awareness materials distribution

We use our e-newsletter subscription database as our primary contact database and distribution list for our educational Symptoms Calendar, educational Fabry Facts playing card deck, and My Health Handbook Kits.

Adults with Fabry may request one complimentary educational symptoms calendar and playing card deck each and a My Health Handbook Kit for yourself and each of your children with Fabry.

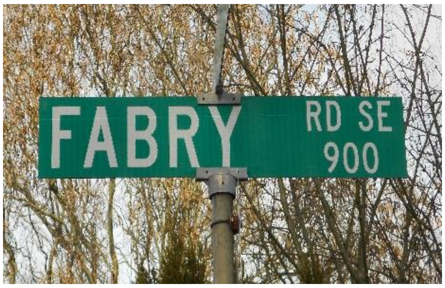
Providers, please request a calendar and card deck for yourself and a sample calendar and kit to show your patients. Materials are distributed at no cost to adults with Fabry and clinics worldwide.



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. See page 13 herein.

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.

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.

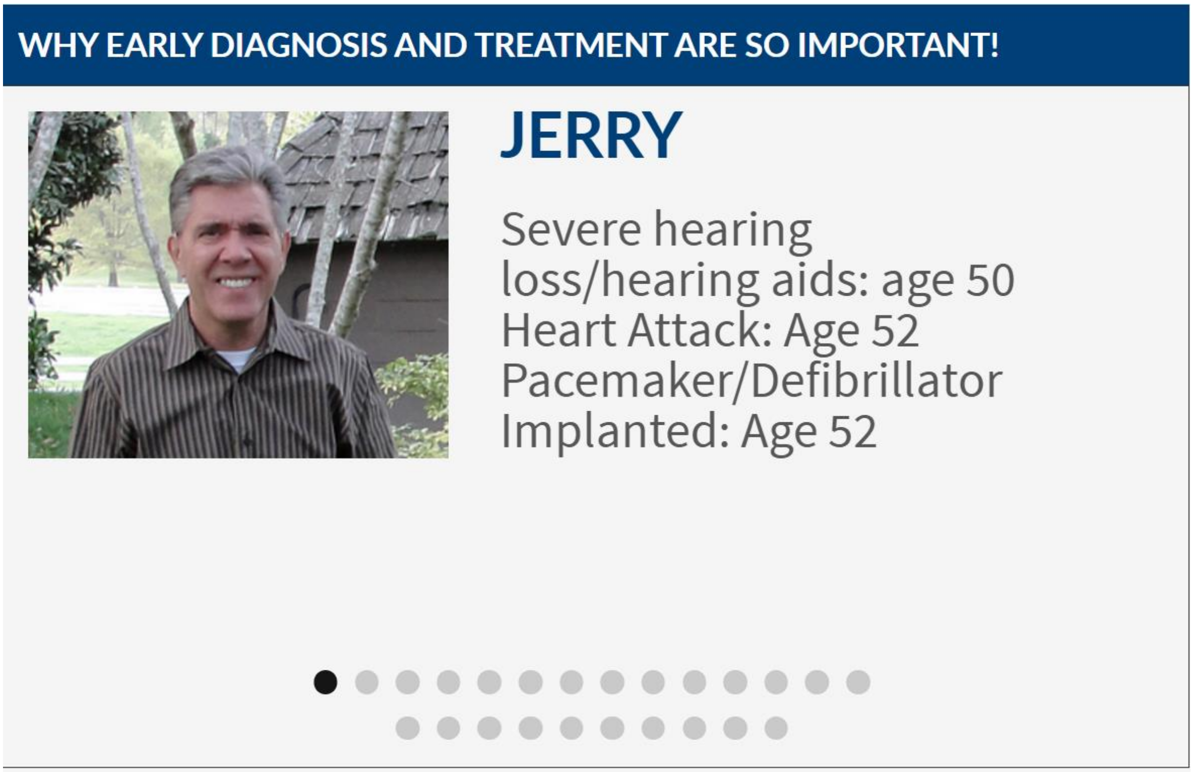
Clinics: Please request enough Patient Resource Education Packets to provide to all your patients.

- 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 the key to ensure no one misses out on our what the NFDF has to offer.**

Contact Jerry Walter at jerry.walter@fabrydisease.org

“Why Early Diagnosis And Treatment Are So Important!

A part of the Fabry community’s story



WHY EARLY DIAGNOSIS AND TREATMENT ARE SO IMPORTANT!

JERRY

Severe hearing loss/hearing aids: age 50
Heart Attack: Age 52
Pacemaker/Defibrillator Implanted: Age 52

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).

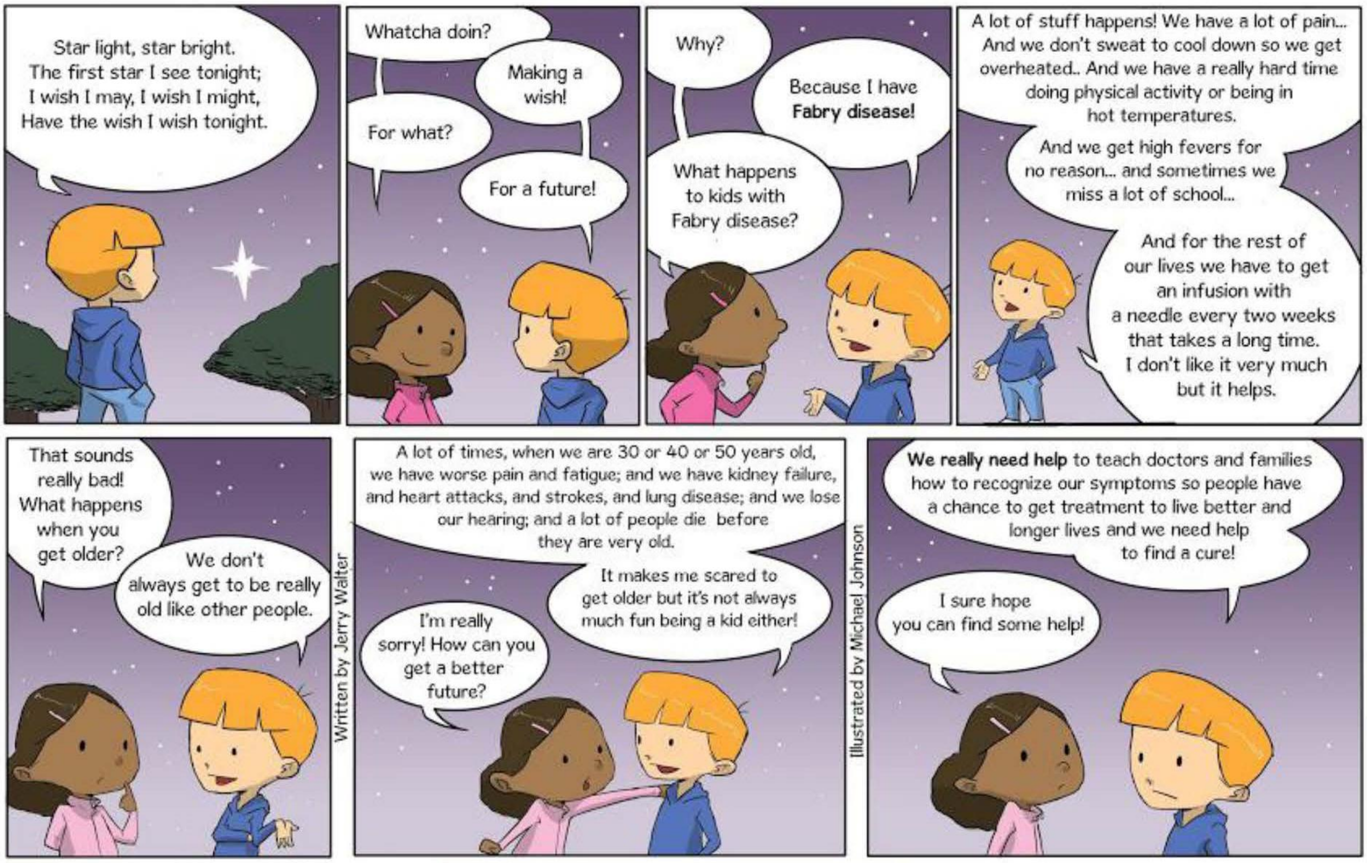
In addition to proving a place to visit and remember those who have passed away from Fabry disease complications, this section of our website is also a part of the Fabry community's story about the tragedies that often occur in our families.

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 make a donation 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 almost 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 in the "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 Facebook 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. www.facebook.com/FabryDisease

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

Donate on "Giving Tuesday" held each year on the Tuesday after Thanksgiving. Giving Tuesday is a global generosity movement, unleashing the power of people and organizations to transform their communities and the world. Donate using any of the donate options here.

GIVING TUESDAY

Donor Box - Give at https://donorbox.org/enabling-fabry-education-and-community-support-programs
Text-to-Give Text Fabry (not case sensitive) to 801801.

donorbox

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

National Fabry Disease Foundation
144 E King St, Unit 1419
Hillsborough, NC 27278

U.S. Toll Free Phone: 800-651-9131
Non Toll Free Phone: 919-732-2799

Email: info@FabryDisease.org

Website: www.FabryDisease.org