



National **FABRY DISEASE** Foundation

Programs and Services for the Fabry Disease Community



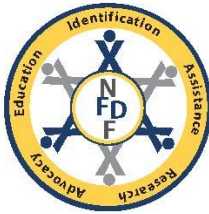
This document is updated frequently. The most current version can always be found at <https://www.fabrydisease.org> in the Featured Resources section just above the bottom right corner of the home page.

As of May 2023

NFDF Programs Handout

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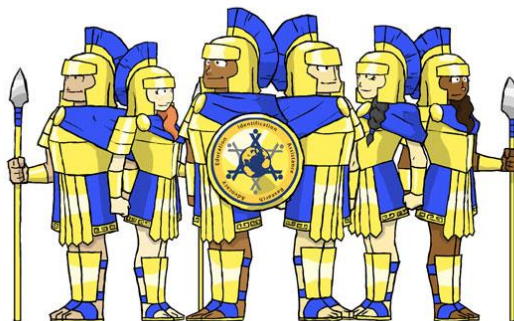


National
FABRY DISEASE
Foundation

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 community is the Fabry Legion 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



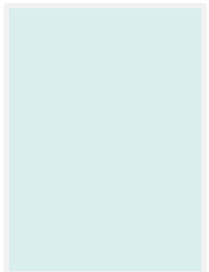
Eric Wallace, MD, FASN
Nephrologist
University of Alabama
Birmingham



Heather Lau, MD, MS
Neurologist
NYU School of
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Claire Zae-Kessler, MD
Gastroenterologist
Massachusetts General
Hospital for Children



Vacant
Pulmonologist



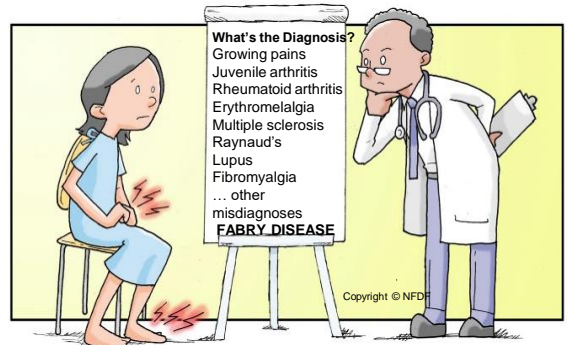
Nadia Ali, PhD
Clinical Psychologist
Emory University Med Center



Gwen Gunn, PhD, MS
MAB Recorder/Scribe
Genetic Counselor
Research Coordinator
Emory University Med
Center

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, diagnoses, understanding and management of Fabry disease.



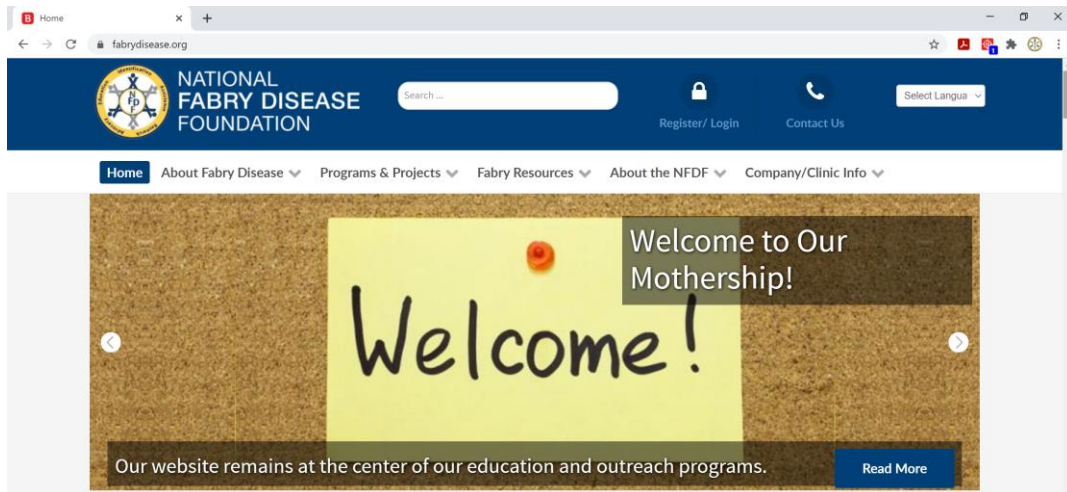
Examples of our many education and awareness initiatives include:

- 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 Camp.
 - 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 Calendar
 - Other educational resources like our symptoms presentation and calendar, and educational playing card deck.
 - Patient and family member resources
 - YouTube videos at www.youtube.com/TheNFDF
 - Targeted education by physicians – physician meetings and handouts
 - Patient-implemented physician education
 - “The Eyes have It” campaign
 - The “Connecting the Dots” campaign
 - The PREP (Patient Resource Education Package) program
 - Social networking – at www.facebook.com/FabryDisease.org (over 4,000 followers to date) and www.twitter.com/FabryDisease1
 - April Fabry Disease Awareness Month proclamation program
- ... and much more!

Through increased education we have a **R.A.R.E.** opportunity to: **Recognize And Rescue Everyone** with Fabry disease.

Our Robust Information and Education Website

www.fabrydisease.org



The National Fabry Disease Foundation's website contains news and information as well as access to many programs and services. For example:

- The top menu bar tabs include access to information about primary financial assistance programs for Fabry. See the "Fabry Resources tab, then 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 resources blocks
- Fabry Focus E-Newsletter subscription link
- ... and many other education and information sections

Fabry Focus E-Newsletter and Fabry Focus for Healthcare Providers and Supporters

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

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.



... or from this link: [E-Newsletter Subscription Link](#)

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

- Our periodic e-newsletter (The Fabry Focus)
- Patient-Reported-Outcomes surveys PROs (learning from the PROs)
- The NFDF Face Book page at www.facebook.com/FabryDisease
- The NFDF Twitter account at www.twitter.com/FabryDisease1
- By email at info@fabrydisease.org
- By phone at: 1-800-651-9131
- and via information distributed through Fabry healthcare providers



2021 Virtual Educational Meeting Series

The NFDF will host regional face-to-face meetings and/or virtual education meetings about various aspects of Fabry disease as schedules and resources permit.

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.

Recordings for the 17 virtual education meetings held in 2021 are available at

<https://www.fabrydisease.org/index.php/company-clinic-info/support-org-info> in the middle NFDF grid square on the top row. Select the "Read More" button at the bottom of the square.



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

Our 2023 conference is planned for September 20-24, 2023. Travel on Wednesday, September 20th 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 2023 Fabry Family Weekend Camp is on
September 22-24, 2023**

Victory Junction camp activities!



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 and 4DMT), to mention a couple.

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.

The screenshot displays the National Fabry Disease Foundation website. The top navigation bar includes the NFDF logo, 'Login', and 'Contact Us'. Below this, a secondary menu bar highlights 'Company/Clinic Info'. The 'Pharma Info' section features a grid of four cards for Sanofi, Amicus Therapeutics, Chiesi, and Takeda. Each card lists the treatment type, the specific therapy, and the last update date.

Company	Treatment Type	Therapy	Last Updated
Sanofi	Approved Enzyme Replacement Therapy (ERT)	Fabrazyme	Updated on March 21, 2022
Amicus Therapeutics	Approved Oral Chaperone Therapy	Galafold	Updated on December 11, 2020
Chiesi	Candidate Enzyme Replacement Therapy (ERT)	Pegunigalsidase Alfa pending FDA approval	Updated on April 18, 2022
Takeda	Approved Enzyme Replacement Therapy (ERT)	Replagal in many countries but not in the U.S.	Updated on November 1, 2020

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

Keeping the Fabry Community Informed via our website

Example: Financial Assistance Programs for Fabry Disease

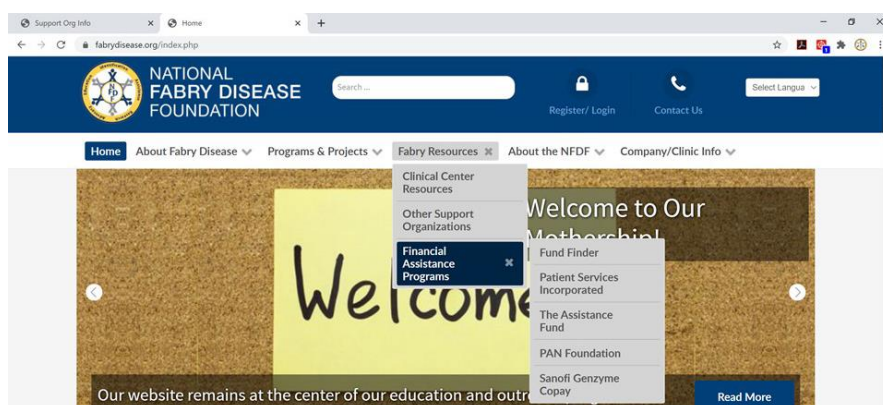
There are three primary financial assistance programs available to people who have Fabry disease. They are:

Accessia Health at <https://accessiahealth.org/>

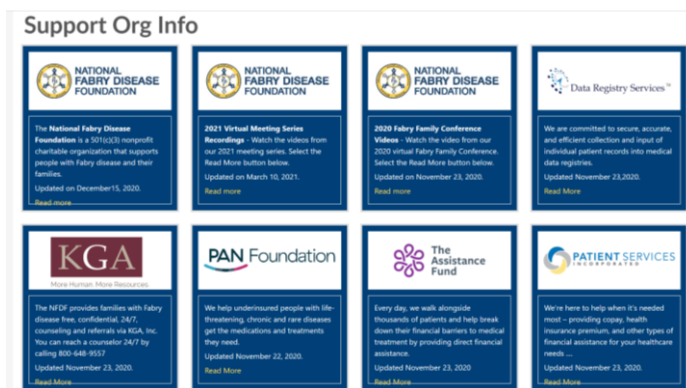
The PAN Foundation (PAN) at <https://www.panfoundation.org/>

The Assistance Fund (TAF) at <https://tafcares.org/>

On the top menu bar of our website homepage at www.fabrydisease.org, select Fabry resources, then Financial Assistance Programs, then program you wish to learn about or submit an application. See the screenshot below.



Presentations by provided by Accessia Health, Inc and the PAN Foundation at the 2020 virtual Fabry Family Conference can be accessed from the third NFDF grid-square from the Spt Org tab. See the screenshot below.



In addition to the programs listed above, the NFDF offers the Urgent and Unmet Needs Program described on the next page. The above grid square images will be revised soon to change to the new KGA logo and to change from PSI to Accessia Health.

NFDF Social Media Channels



The National Fabry Disease Foundation's Facebook page at <http://www.facebook.com/FabryDisease> (displayed above) has over 4,000 followers as of this handbook revision.

The NFDF's Facebook page is often our first method of communication with the Fabry community due to its ease of use. Please follow our page to get current news promptly. We make very frequent posts to keep the Fabry community informed.

In consideration of community members not using Facebook, we are committed to increasing our use of Twitter and our e-newsletter service for day-to-day news output as resources allow.



The National Fabry Disease Foundation's Twitter account at www.twitter.com/FabryDisease1 (displayed to the left) has almost 700 followers as of this handbook revision.



The NFDF's YouTube Channel

The National Fabry Disease Foundation has produced many educational videos. While somewhat outdated, the NFDF symptoms video has been **viewed over 22,000 times to date** and remains a very valuable resource.

All of the 2020 virtual conference videos and 2021 virtual meeting series videos are uploaded on our YouTube channel (TheNFDF) and are also accessible on our website at





<https://www.fabrydisease.org/index.php/company-clinic-info/support-org-info>.

Select the “Read More” buttons in the second and third NFDF blocks. There are more than 30 NFDF produced videos on our channel.

Our seventeen 2021 webinar series videos are accessible from the announcements section in the upper right area of the NFDF website.

 Speaker: Gwen Skloot, MD Date: December 22, 2021 1:20:30	 Speaker: Claire Zar-Kessler, MD Date: November 12, 2021 1:04:39	 Speaker: Eric Wallace, MD Date: November 9, 2021 1:26:56	 Speaker: Dr. Langis Michaud Date: August 28, 2021 1:15:16
Pulmonary Involvement in Fabry Disease 112 views • 1 year ago	Nutritional Interventions in Fabry Disease 247 views • 1 year ago	Adjunct Therapies for Kidney Health 73 views • 1 year ago	Eye Involvement in Fabry Disease 180 views • 1 year ago

Popular videos ▶ Play all

 15:00 Fabry Disease Symptoms - Help us to Recognize And... 22K views • 11 years ago	 7:15 National Fabry Disease Foundation Awareness Vide... 15K views • 8 years ago	 3:19 The Faces of Fabry Disease 5K views • 7 years ago	 5:47 Fabry disease inheritance video 11 Jan 2012 2.6K views • 11 years ago
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Please watch and share our videos and subscribe at
www.YouTube.com/TheNFDF.

Patient Reported Outcomes Survey Program

“Learning from the PROS”

The information below pertains to our standard survey program. Our December 2022 survey for U.S. and non-U.S. adults with Fabry will remain open most of 2023 with an array of education and awareness incentives including a \$50 gift card. Email jerry.walter@fabrydisease.org for information. Please do not send messages, emails only.

Why?

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



The information 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 except to announce contest winners using first names only.

Who?

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

What?

A survey during selected months with prize drawings of \$25.00 to \$100.00 USD plus a year-end drawing for those who qualify.

Where?

A separate drawing and award for **U.S. and global (non-U.S.) participants**

When?

Surveys, drawings and awards are completed for selected months as well as end-of-year awards.

How?

1. Take each periodic survey by its due date to be eligible for that survey's prize drawing. If you miss it, still take the surveys you missed after the initial due date to be eligible for the year-end drawing.

2. For each survey, the amount of the award for U.S. and non-U.S. participants is \$25.00 to \$100.00 each, plus a year-end award.

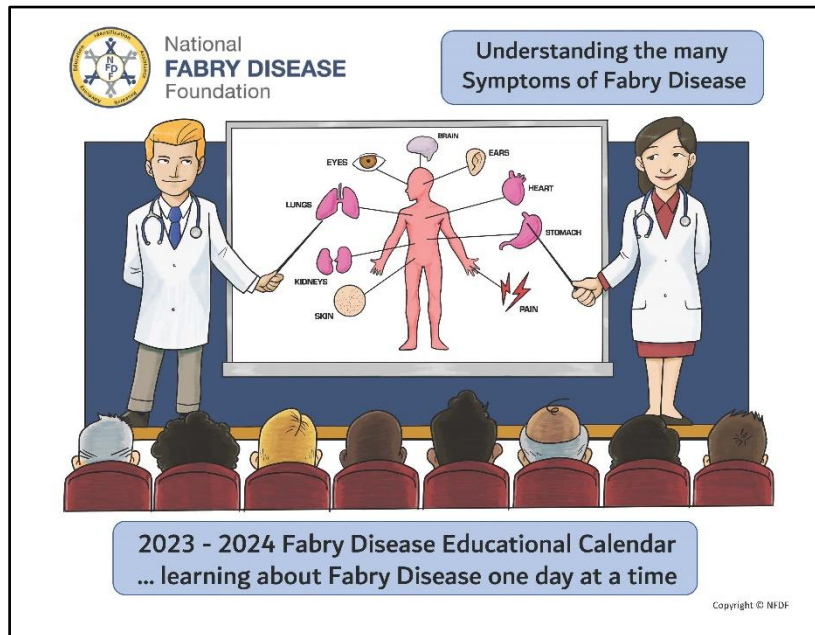
3. Links to each online survey are published in the NFDF e-newsletter. Please subscribe to our e-newsletter at the orange newsletter icon near the upper right area of our home page at www.fabrydisease.org.

Please ensure your mailing address is correct.

Please share with family members with Fabry disease.

2023 -2024 Educational Fabry Disease Symptoms Calendar

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



- ☐ Our 18-month educational calendar (2023 to 2024) 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.
- ☐ **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

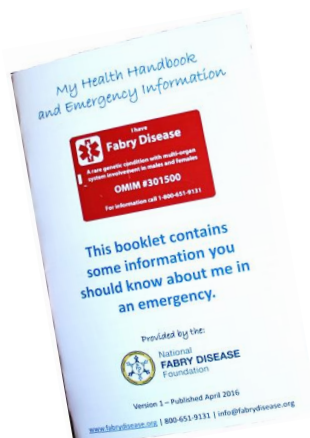
The NFDF's educational playing card deck is intended to provide a better understanding of various aspects of Fabry disease by highlighting facts in published peer-reviewed literature and from other sources.



- ☐ **Adults with Fabry worldwide will receive a free playing card and other education and awareness materials when you complete our December 2022 PROS survey.**
- ☐ 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.

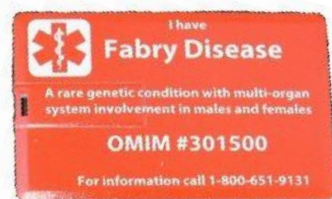


What does a healthcare provider need to know in an emergency?

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.

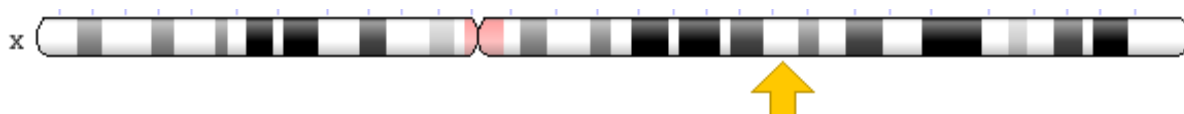
The kit contains a credit-card style USB Medical Alert Card that is initially loaded with the current NFDF Programs handout and the Fabry Community Landscape handout. Subsequent, more current, versions of these documents can be found on the NFDF website. Awareness wristbands and other awareness materials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

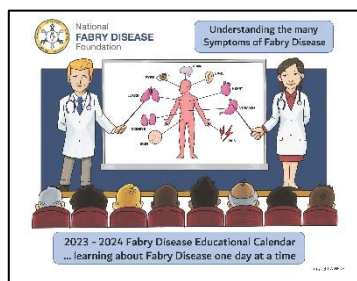
It takes a village!

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 Mutations \(an explanation for lay-people\)](#)” 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.

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. Then take our **December 2022 survey**.

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 Mutation Repository ... Please provide your family mutation to add to our repository. Contact jerry.walter@fabrydisease.org. We will not share your mutation with anyone. We will use it for analyses of similaFor 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.

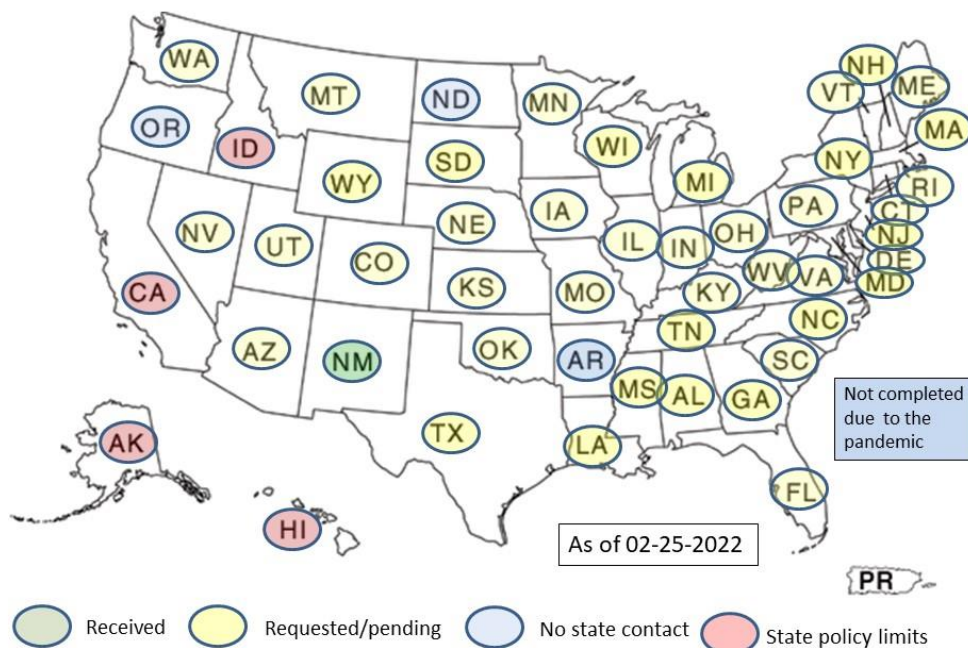
Fabry Disease Awareness Month Governors' Proclamation Program

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



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

2022 April Fabry Disease Awareness Month Proclamation Status



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) and the PAN Foundation (PAN) 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

 PAN Foundation

 The
Assistance
Fund

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.

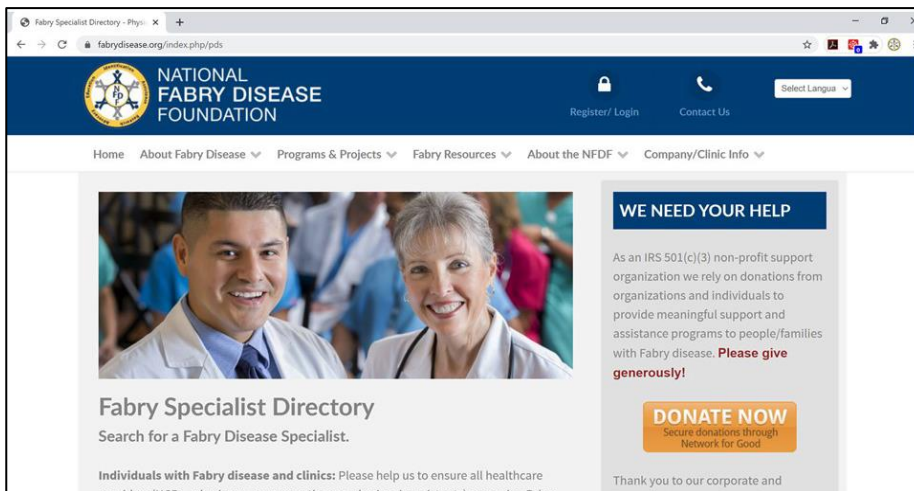


Find a Fabry Specialist Database

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 Specialist database on our website at <https://www.fabrydisease.org/index.php/pds>. See the screenshot below.



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

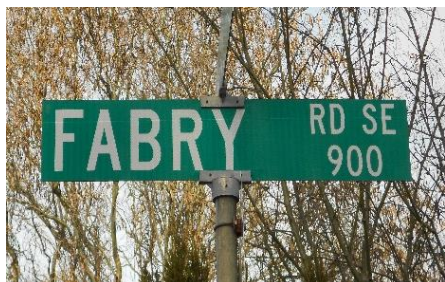
Website Address (If applicable)

Provider Specialty 1: Such as Clinical Genetics , Internal Medicine, or another

Provider Specialty 2

If your clinic is already listed, please verify 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. See page 25.
- 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

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 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.


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.

“Why is Early Diagnosis so Important” Program


A part of the Fabry Community’s Story

https://www.fabrydisease.org


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

● ● ● ● ● ●

Scroll for more

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 providing 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!

Star light, star bright.
The first star I see tonight;
I wish I may, I wish I might,
Have the wish I wish tonight.

Whatcha doin?
Making a wish!
For what?
For a future!

Why?
Because I have Fabry disease!

What happens to kids with Fabry disease?

A lot of stuff happens! We have a lot of pain... And we don't sweat to cool down so we get overheated. And we have a really hard time doing physical activity or being in hot temperatures.

And we get high fevers for no reason... and sometimes we miss a lot of school...

And for the rest of our lives we have to get an infusion with a needle every two weeks that takes a long time. I don't like it very much but it helps.

That sounds really bad! What happens when you get older?

We don't always get to be really old like other people.

A lot of times, when we are 30 or 40 or 50 years old, we have worse pain and fatigue; and we have kidney failure, and heart attacks, and strokes, and lung disease; and we lose our hearing; and a lot of people die before they are very old.

It makes me scared to get older but it's not always much fun being a kid either!

I'm really sorry! How can you get a better future?

We really need help to teach doctors and families how to recognize our symptoms so people have a chance to get treatment to live better and longer lives and we need help to find a cure!

I sure hope you can find some help!

There are millions of stars out there. Maybe we can find a bright star for me and for everyone with Fabry disease.

That sounds great! Then we can be friends for a really long time.

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 solely on charitable giving to support our many programs and services. Thank you for your generosity!

Make a charitable contribution by ending a check payable to the National Fabry Disease Foundation at NFDF NC Office, PO Box 1325, Carrboro, NC 27510. 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 “Non profit 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 - Charitable Organization

Donate on “Giving Tuesday” December 1, 2020 and November 30, 2022 using one of the option listed above.

Giving Tuesday is a global generosity movement, unleashing the power of people and organizations to transform their communities and the world.



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



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 24.
- ☐ Participate in our learning from the PROS (Patient Reported Outcomes Survey) program. Please help us to better understand our disease and our community. See page 16.
- ☐ 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 19 and 21.
- ☐ Request an educational 2023 – 2024 Fabry Disease Symptoms Calendar, a great tool to better understand Fabry disease. See pages 12 and 21.
- ☐ View our educational YouTube videos and subscribe to our YouTube channel at www.youtube.com/TheNFDF. See page 15
- ☐ "Follow" us on Twitter at www.twitter.com/FabryDisease1.
- ☐ Please send us information about major medical events ... remembrances ... and community news and announcements. See pages 28 & 29.
- ☐ 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 30 and 31. **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 2,9000 Likes. See page 14.

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.**



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