



National **FABRY DISEASE** Foundation

Programs and Services for the Fabry Disease Community

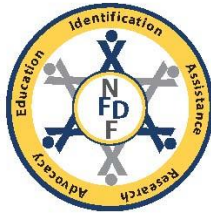


This document is updated frequently. The most current version can always be found at <https://www.fabrydisease.org> in the Featured Resources section just above the bottom right corner of the home page.

NFDF Programs Handout

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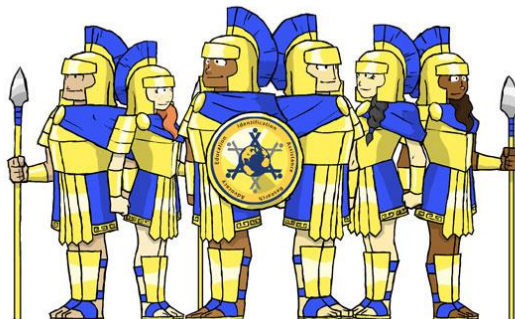


National
FABRY DISEASE
Foundation

Who we are and what we do

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

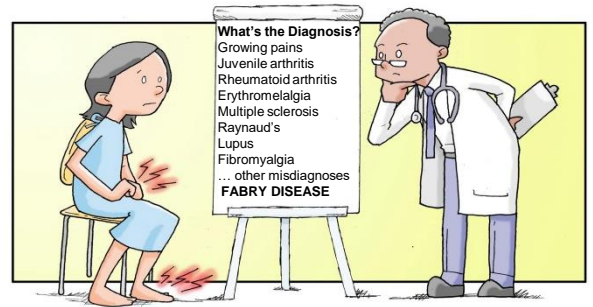
- We manage a small non-profit corporation.
- We provide valuable programs and services to support the known and the yet to be recognized (currently unknown) Fabry community including programs to improve recognition, diagnoses, understanding, and care.
 - ✓ Education and Awareness
 - ✓ Community Support and Assistance
- We raise funds from many organizations and individuals to provide programs and services to the Fabry community.



As a community, we are the Fabry Legion fighting against Fabry disease.

Our Multifaceted Education Program

We strive to increase the recognition, diagnoses, and understanding of Fabry disease among families, physicians, and the public.



Examples of our many education and awareness initiatives include:

- A robust educational website at www.fabrydisease.org
 - The annual NFDF Fabry Family Education Conference and Fabry Family Camp each year in September
 - Regional Fabry family meetings around the country
 - Learning from the PROS (**P**atient **R**eported **O**utcomes **S**urvey) Program
 - 2018-2019 educational Fabry Disease Symptoms Calendar
 - Other disease education resources like our Symptoms Presentation
 - Patient and family member resources
 - YouTube videos at www.youtube.com/TheNFDF
 - Targeted physician education – physician meetings and handouts
 - Patient-implemented physician education
 - “The Eyes have It” campaign
 - The “Connecting the Dots” campaign
 - Clinic-implemented PREP (Patient Resource Education Package) program
 - Social networking – at www.facebook.com/FabryDisease.org (over 2,900 “Likes” 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.

Annual Fabry Family Education Conference

- Annual conference in September - Began in 2011
- Total of 200 - 250 attendees each year
- Total of 100 -120 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 initiatives
- Separate Children's activities
 - Children are chaperoned by nannies and tutors
 - Educational breakouts
 - Amazing teen and kid chat sessions
 - Entertainment
- Transportation and lodging assistance is available for individuals/families with financial limitations.
- **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.**



Annual Fabry Family Weekend Camp

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



(photo used with permission)

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. 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

Please read our periodic e-newsletter to stay informed about camp application information and due dates to apply.

Victory Junction camp fun!



Family Assistance Program



The most common issues are:

- ❑ We provide a **free, confidential** family assistance program through KGA, Inc.
 - ❑ The program includes **24/7 telephone counseling** at 800-648-9557 and other services for families with Fabry disease.
 - ❑ **Any personal issue is appropriate.**
 - ❑ See the Family Assistance Program tab on our homepage at www.fabrydisease.org.
- 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



Urgent and Unmet Needs Program



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

In many cases, individuals must be declined by Patient Services Incorporated (PSI) and The Assistance Fund (TAF) first.

Examples:

- First time insurance premiums payment support to get PSI or TAF support started
 - Living expense support in emergencies
 - Travel assistance to Fabry related meetings
 - 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

Contact Jerry Walter at jerry.walter@fabrydisease.org

Patient Reported Outcomes Survey Program

“Learning from the PROS”

Our survey program provides insights for patients to ask physicians about and to guide future formal research.

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 in determining 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 \$250.00 USD plus a year-end drawing for \$500.00.

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 \$250.00 each, then the year-end award is \$500.00.

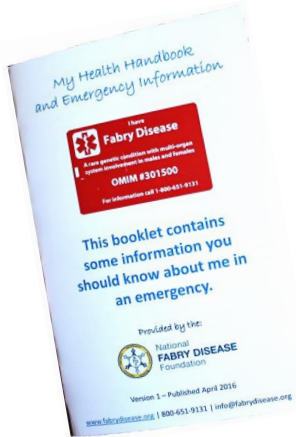
3. Links to each online survey are published in the NFDF newsletter. Please subscribe to our e-newsletter at the orange newsletter icon near the upper right area of our home page at www.fabrydisease.org.

Please ensure your mailing address is correct.

Please share with family members with Fabry disease.

“My Health Handbook” Kits

In 2016 during Fabry Disease Awareness Month we 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 below. About 1,000 kits have been distributed.



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

Useful information can be stored in this booklet that you can keep with you!

The kits are available to our international friends also.

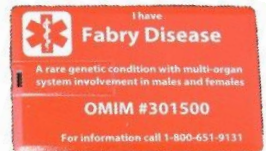
The kit also contains a credit-card style USB Medical Alert Card that is initially loaded with the current NFDf Programs handout and the Fabry Community Landscape handout. Subsequent, more current, versions of these documents can be found on the NFDf website at www.fabrydisease.org.

Awareness wristbands and ribbons are also included.

To receive the kit, register on the NFDf website at www.fabrydisease.org. See page 12.

The kits will be mailed in the order of the registration dates so register early. Ensure you register with a current email and phone number so we can contact you to verify your shipping address and to find out how many wristbands and other materials you need for your immediate family.

Contact Jerry Walter at jerry.walter@fabrydisease.org



My Health Handbook Kit Distribution

The National Fabry Disease Foundation distributes our “My Health Handbook” kits worldwide to people with Fabry disease. If you would like a kit, please register at www.fabrydisease.org. Select register/login at the top of the page, then select “Don’t have an account?” and complete the form. We use our website registration database to manage kit distribution.

Once you register on the website, we’ll contact you to ask how many kits you need for you and your children with Fabry. Adults ages 18 and over must register separately. Children will receive kits based on their parent’s registration.

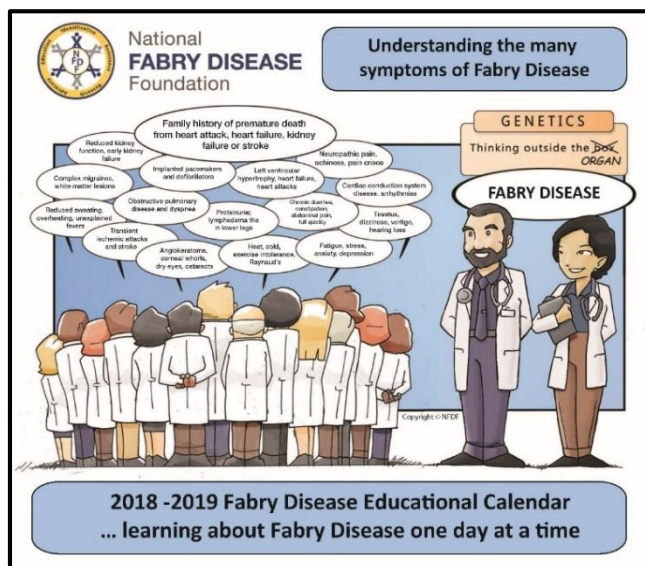
... Jerry Walter, Founder and President, NDFD

Contact us at jerry.walter@fabrydisease.org | 800-651-9131 | 919-732-2799



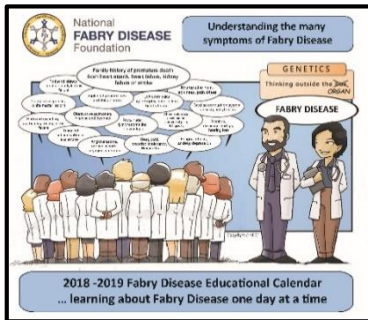
2018 -2019 Educational Fabry Disease Symptoms Calendar

The NFDF's educational symptoms calendar serves to provide an easy to understand description of most of the common symptoms of Fabry disease. For patients, it is distributed upon completion of a short survey (see page 14).



- Our 18 month educational calendar (September 2018 to December 2019) became available in September 2018.
- It is distributed at no cost to adults with Fabry and clinics worldwide. Clinic 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.
- To receive a calendar, see the separate distribution guidance on page 14.

Fabry Disease Symptoms Calendar Distribution



Individuals with Fabry may request one complimentary educational calendar each. Please inform others so they may also request a calendar according to the guidance below.

Individuals with Fabry disease (3 easy steps):

- Register at the top of our website at www.fabrydisease.org
- Subscribe to our e-newsletter at the orange newsletter icon under the upper right area of our website.
- Provide your information at the survey link below:

<https://www.surveymonkey.com/r/FabrySymptomsCalendar>

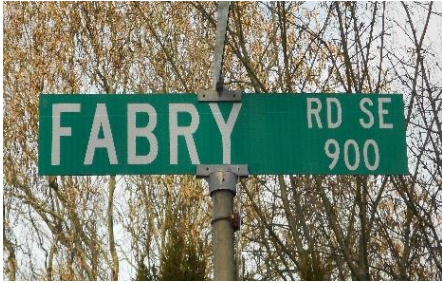
Physicians and staff in Fabry clinics, and home infusion providers:

- Medical professionals working with Fabry patients may obtain an educational calendar for yourself and one more as an example to show your patients.
- Email jerry.walter@fabrydisease.org with your mailing address and contact information to request an calendar.

Others supporting people with Fabry disease:

- Email jerry.walter@fabrydisease.org to request a calendar.
- Please do not request a calendar for other people, just for yourself. Provide this flyer to them instead. Thank you!

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 16.
- 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

Find a Fabry Specialist Database



Individuals with Fabry disease:

Use our convenient search application and map locator at the link below to find a Fabry specialist near you.

<https://www.fabrydisease.org/index.php/pds>

To search the database, select the letter that corresponds to the first letter in the name of your State for U.S. physicians. For non-U.S. physicians (not well populated yet), select the letter corresponding to the first letter of the Province or County you wish to search.

Clinics:

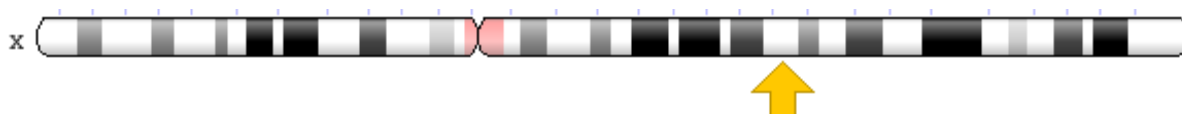
Please provide physician photos and information and main clinic contact information so we may list your clinic in our website Find a Fabry Specialist database.

Thank you for your support!

For more information, contact Jerry Walter at jerry.walter@fabrydisease.org

Fabry Gene Mutation Repository

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



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 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 mutation designation, and help in other ways as we ask for support. **It takes a village!**

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

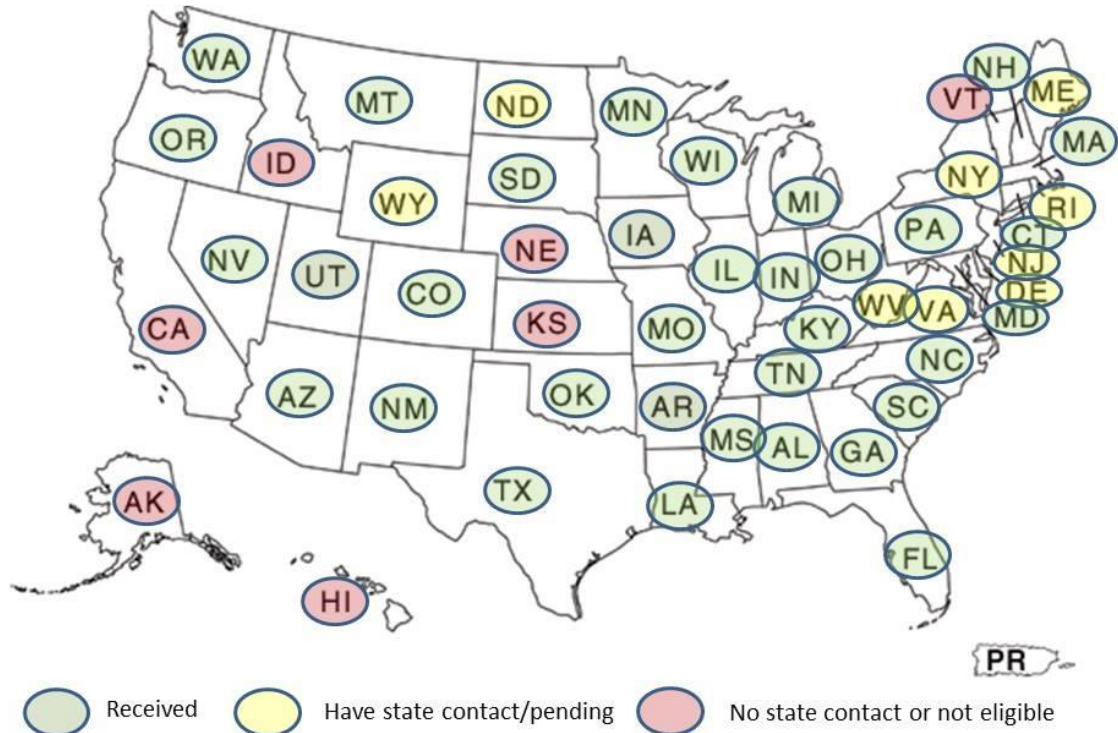
Note: A document entitled “[Fabry Mutations \(an explanation for lay-people\)](#)” is located pages 15-18 of our Fabry Community Landscape handout. The current Community Landscape handout is located in the Featured Resources section just above the bottom right corner of www.FabryDisease.org.

Fabry Disease Awareness Month Governors' Proclamation Program



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

2018 April Fabry Disease Awareness Month Proclamation Status



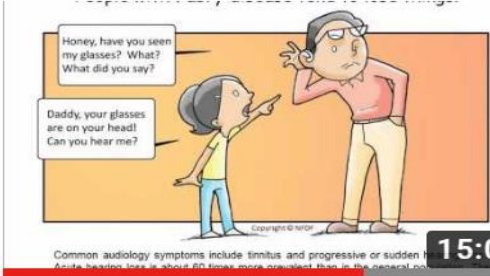
Each year, in January, we begin to contact Fabry community representatives in each state to facilitate coordination with their respective state Governors' offices.

The NFDF's YouTube Channel



The National Fabry Disease Foundation has produced seven educational videos. While somewhat outdated, the NFDF symptoms video has been viewed approximately 18,000 times to date and remains a very valuable resource.


Popular uploads PLAY ALL



Honey, have you seen my glasses? What? What did you say?
Daddy, your glasses are on your head! Can you hear me?

Common audiology symptoms include tinnitus and progressive or sudden hearing loss. Acute hearing loss is about 60 times more prevalent than in the general population.

15:00



7:15

Fabry Disease Symptoms - Help us to Recognize And...

18K views • 6 years ago

National Fabry Disease Foundation Awareness Vide...

13K views • 4 years ago



3:19



5:47

The Faces of Fabry Disease

3.1K views • 3 years ago

Fabry disease inheritance video 11 Jan 2012

2.5K views • 6 years ago

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

Fabry Disease Awareness

... by telling our story

To better tell the story of how Fabry disease affects the lives of individuals and families, **please contribute** to the following awareness programs.

The NFDF website includes a section (a large orange block midway down the homepage) called:

“Why is early diagnosis so important?”

We encourage individuals to submit a photo, first name, and the age of major medical events caused by Fabry disease. Please see examples on our website.



The NFDF website includes a section (2/3 down the homepage in the Featured Programs area) called:

“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 (optional). Please see our website at <https://www.fabrydisease.org/index.php/in-memory-of>.

Fabry Community

Publication Access Program



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

Registering on our website serves two purposes. One is to manage distribution of our My Health Handbook Kits for people with Fabry. **The second** is to enable our registered community members to have access to the publications we post 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.

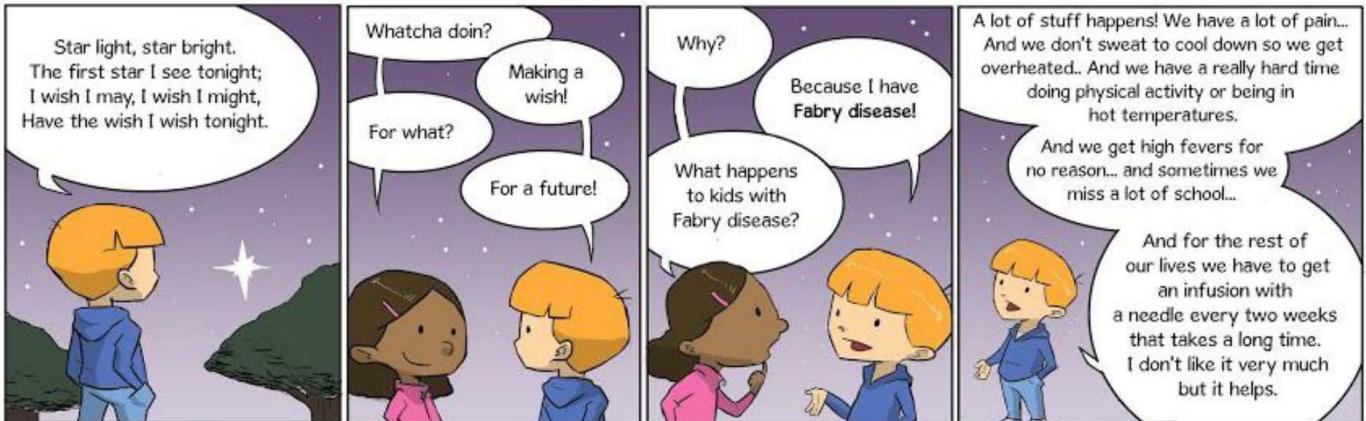
We recently posted the comprehensive Revisited Management and Treatment Recommendations for Adult Patients by Ortiz et al, April 2018. We merged the main document and eight appendices (A-H) into one document for much easier access and use. The new recommendations were published before the oral chaperone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



Shining Star Campaign

Helping people with Fabry disease live better and longer lives!

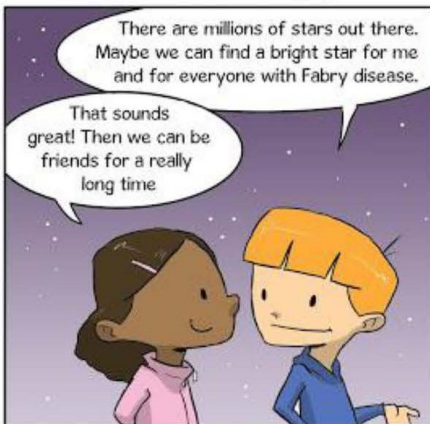
Be the brightest star!



Written by Jerry Walter



Illustrated by Michael Johnson



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 NFD, 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!

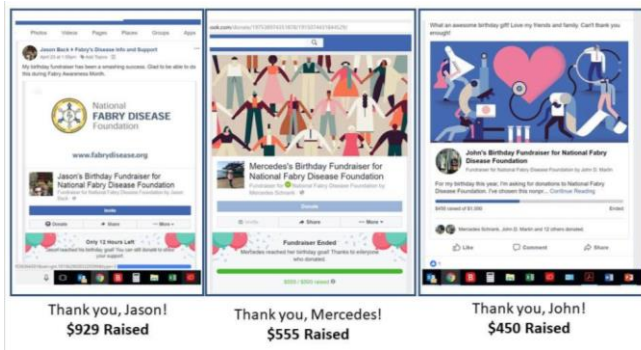
Fabry Community Fundraising

Fundraising by community members to support the National Fabry Disease Foundation is a critical component of our ability to provide valuable programs and services to our community.

With your help, the NFDf can accomplish much more to support individuals with Fabry disease and their families.

- Make an individual donation or become a sustainer by making a **monthly recurring donation** at:

<https://donatenow.networkforgood.org/FightingFabryDisease?code=2016%20Primary>



- Please hold a face book birthday fundraiser or another type of face book fundraiser. Face book fundraisers have provided tremendous support.

- Hold a fundraiser at your home or business. Shirley Lewis recently held a very successful fundraiser at her dog grooming business “California Groomin”. We provided flyers.



- Request a Diplar to use at your fundraising event to support the National Fabry Disease Foundation. They provide a simple way to collect credit card donations and can be set at the amount you choose.

We have many partially implemented community programs waiting for funds. Become a Fabry community fundraiser!

Fabry Community Engagement

(one component)

Please "Like" our face book page at www.facebook.com/FabryDisease.

Visit often!

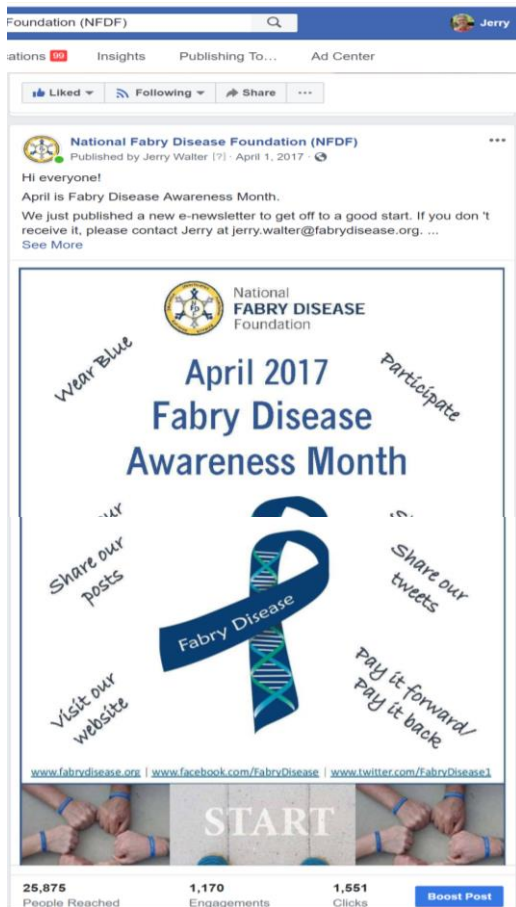
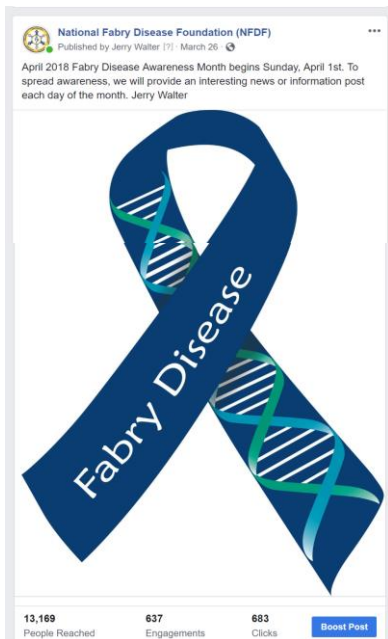
We appreciate you support!

Sample Posts

People reached
6,550



People reached
10,893



People reached
13,169



People reached
20,007

People reached
25,875



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 in September on Thursday and Friday before camp. The conference is open to all individuals with Fabry and family members, not just those attending camp. Lodging and meals are provided. Transportation assistance is available. Page 5.
- Apply to attend the annual NFDf Fabry Family Weekend Camp in September ... our fun-filled, 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 page 6.
- Please participate in the Fabry Family Assistance Program ... a free, confidential, 24/7 service with counselors standing by when you need help. See page 8.
- 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 10.
- 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 11 and 12.
- Request an educational 2018 – 2019 Fabry Disease Symptoms Calendar, a great tool to better understand Fabry disease. See pages 13 and 14.
- View our educational YouTube videos and subscribe to our YouTube channel at www.youtube.com/TheNFDf. See page 18
- "Follow" us on Twitter at www.twitter.com/FabryDisease1.
- Please send us information about major medical events ... remembrances ... and community news and announcements. See page 19.
- 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 20 and 21. **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 22.

National Fabry Disease Foundation

**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.**



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Carrboro, NC 27510**

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Non Toll Free Phone: 919-732-2799**

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Website: www.FabryDisease.org