National
FABRY DISEASE
Foundation

Programs and Services for the Fabry Disease Community

Family camp, annual conference and much more!
… something for everyone!

As of November 2016

NFDF Program Handout Contents

Who are we and what do we do?

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

☐ We manage a small non-profit organization.

☐ We provide programs and services to support the known and the yet to be recognized unknown Fabry community (programs to increase recognition and diagnoses).

- ✓ Disease Education and Awareness
- ✓ Community Support and Assistance

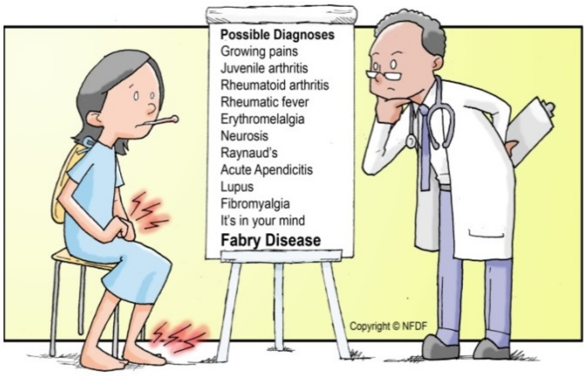
☐ We raise funds through charitable giving programs to support our many programs and services.

www.fabrydisease.org
www.facebook.com/FabryDisease
www.twitter.com/FabryDisease1
www.YouTube.com/TheNFDF

info@fabrydisease.org
800-651-9131 or 919-932-7785

A Multifaceted Education Program

Our goal is to increase the recognition and understanding of Fabry disease among families, physicians, and the public.



Examples of our education initiatives include:

- A robust educational website at www.fabrydisease.org
- The annual Charles Kleinschmidt Fabry Family Camp and annual family conference each year in September
- Fabry family meetings around the country
- Fabry Patient Reported Outcomes Survey Program
- Patient and family member resources
- Disease education like our symptoms presentation
- YouTube videos at www.youtube.com/TheNFDF
- Targeted physician education – physician conferences and handouts
- Patient-implemented physician education
  - "The Eyes have It" campaign
  - The "Connecting the Dots" campaign
- Social networking sites – www.facebook.com/FabryDisease.org (over 2,250 likes)
- www.twitter.com/FabryDisease1
- Fabry Disease Awareness Month proclamation program

Fabry Family Weekend Camp

The Charles Kleinschmidt Fabry Family Weekend Camp is held at Victory Junction in Randleman, NC

(photo used with permission)

- 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
- Superdome indoor playing filed
- Gymnasium
- Arts and Crafts … and more

☐ The annual Fabry family camp is in September. Applications are usually accepted on July 1st.

☐ 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.

☐ Transportation, lodging and meals are provided.

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

☐ Contact Jerry at jerry.walter@fabrydisease.org to let us know you are interested and to receive pre-application info.

Jackson kissing a fish

Thank you to the Kleinschmidt Family Foundation, Sanofi - Genzyme, Shire, Amicus, Protalix and our many other supporters for making this a reality!

A little Victory Junction fun!














Annual Fabry Family Educational Conference

- Annual conference in September - Began in 2011
- Total of 200 - 250 attendees each year
- Total of 100 -120 individuals with Fabry each year
- Camper families plus attendees not at camp
    - Physicians and other healthcare speakers
    - Industry speakers
    - Organization speakers
    - Research initiatives

- Separate Children's activities
    - Chaperoned by Nannies and Tutors
    - Educational breakouts
    - Amazing teen and kid chat sessions
    - Entertainment

- Transportation and lodging assistance is available for individuals/families with a financial limitations.

- If you are interested in attending the conference email Jerry at jerry.walter@fabrydisease.org.

Family Assistance Program

- ☐ 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.

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

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Urgent and Unmet Needs Program

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

In many cases you must be declined by Patient Services Incorporated (PSI) first.

Examples:

- First time insurance premiums to get Patient Services Incorporated (PSI) or other support started
- Travel assistance to medical care appointments
- Travel assistance to Fabry related meetings
- Medical expenses not covered due to unforeseen circumstances
- Emergency needs
- Hearing aids, hearing impaired phones, and other personal needs

… and more

Contact Jerry Walter at jerry.walter@fabrydisease.org

PROS Program – We learn from the pros!

(PROS = Patient Reported Outcomes Surveys)

aka the “Take Our Surveys” Contest

The 2014 survey program was a huge success.
Program resumed in 2016.

Why?

The NFDF collects information from brief periodic surveys to learn about Fabry disease in areas that may not yet have been investigated 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 for up to $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 monthly for selected months as well as two end-of-year awards.

Share with family members with Fabry.

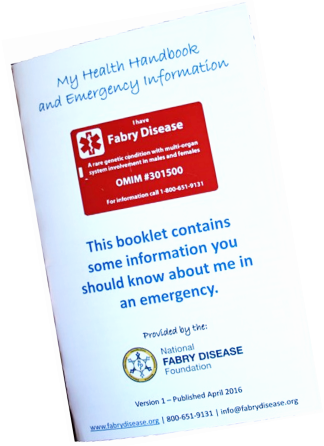
How?

1. Take each survey in the month it is issued to be eligible in that month’s drawing. If you miss it, still take the surveys you missed later to be eligible for the year-end drawing.

2. The amount of each award will be determined by awarding $1 USD for each survey participant up to $250.00.

3. Links to each online survey are published in the e-newsletter. Please subscribe at the upper right area of our home page www.fabrydisease.org. Please ensure your mailing address is correct.

“My Health Handbook and Emergency Information” Booklet



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?

It’s all in this booklet you can keep with you!

The booklet is available to our international friends also.

In April 2016 we began mailing our “My Health Handbook” kit to individuals with Fabry disease. (Photo on next slide.)

The resource packet includes a copy of the My Health Handbook and Emergency Information booklet and other awarene materials for all family members with the Fabry gene.

A credit-card style USB Medical Alert card loaded with our NFDF Programs Handout and The Fabry Community Landscape Handout.

Awareness wristbands, ribbons, lapel pins and awareness car magnets.

To receive our new My Health Handbook kit re-register on the updated NFDF website at www.fabrydisease.org. The resource packets 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 kits you need.

For questions contact Jerry Walter at jerry.walter@fabrydisease.org

Don’t Miss Out! Register today.

We are tracking distribution of kits using our website registration. Please register at the register/login link at the top of our website homepage at www.fabrydisease.org. Select the link for register/login, then "Don't have an account", and complete the form. Afterwards we'll contact you to see how many kits you need for your family.

We restarted our registration database when we upgraded our website. If you previously registered but it was before April 2016, please re-register.

Other Notable Programs and Resources

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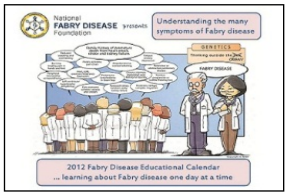
A primary focus of NFDF education programs is to help find unrecognized people with Fabry disease. We have a **R.A.R.E.** opportunity to **R**ecognize **A**nd **R**escue **E**veryone with Fabry disease. Everyone should have the opportunity to be recognized and diagnosed to enable the best possible disease management and care to give people a chance to live better and longer lives.

The NFDF produces YouTube videos about "symptoms" (15 minutes), "inheritance" (5 minutes) and "Fabry disease awareness" (7 and 3 minutes). The symptoms video has been viewed almost 14,000 times to date. **Please watch and share our videos and subscribe to our www.YouTube.com/TheNFDF.**

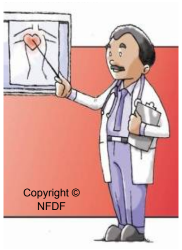
The NFDF provides free periodic e-newsletters. Sign up on our home page on the right side in the "Connect With Us" section using the orange newsletter button.

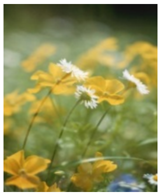
Each year the NFDF and FSIG work together with Fabry community members to submit requests to their respective state Governors to proclaim April as Fabry Disease Awareness Month.



The NFDF's Fabry disease symptoms presentation found in the Featured Resources section of our website home page uses the same slides as our 15 minute symptoms video It is also a great tool to educate family members and friends.

We would like information from you to increase awareness about the seriousness of our disease. **Please email us about the age you experienced events such as strokes, heart attacks, kidney failure/dialysis, kidney transplants, severe hearing loss, etc.** We use first names only on our website and in other awareness efforts.





The NFDF posts remembrances in the Remembering Family and Friends section of our website about those who have passed away from Fabry disease. **Please honor your family members or friends.**

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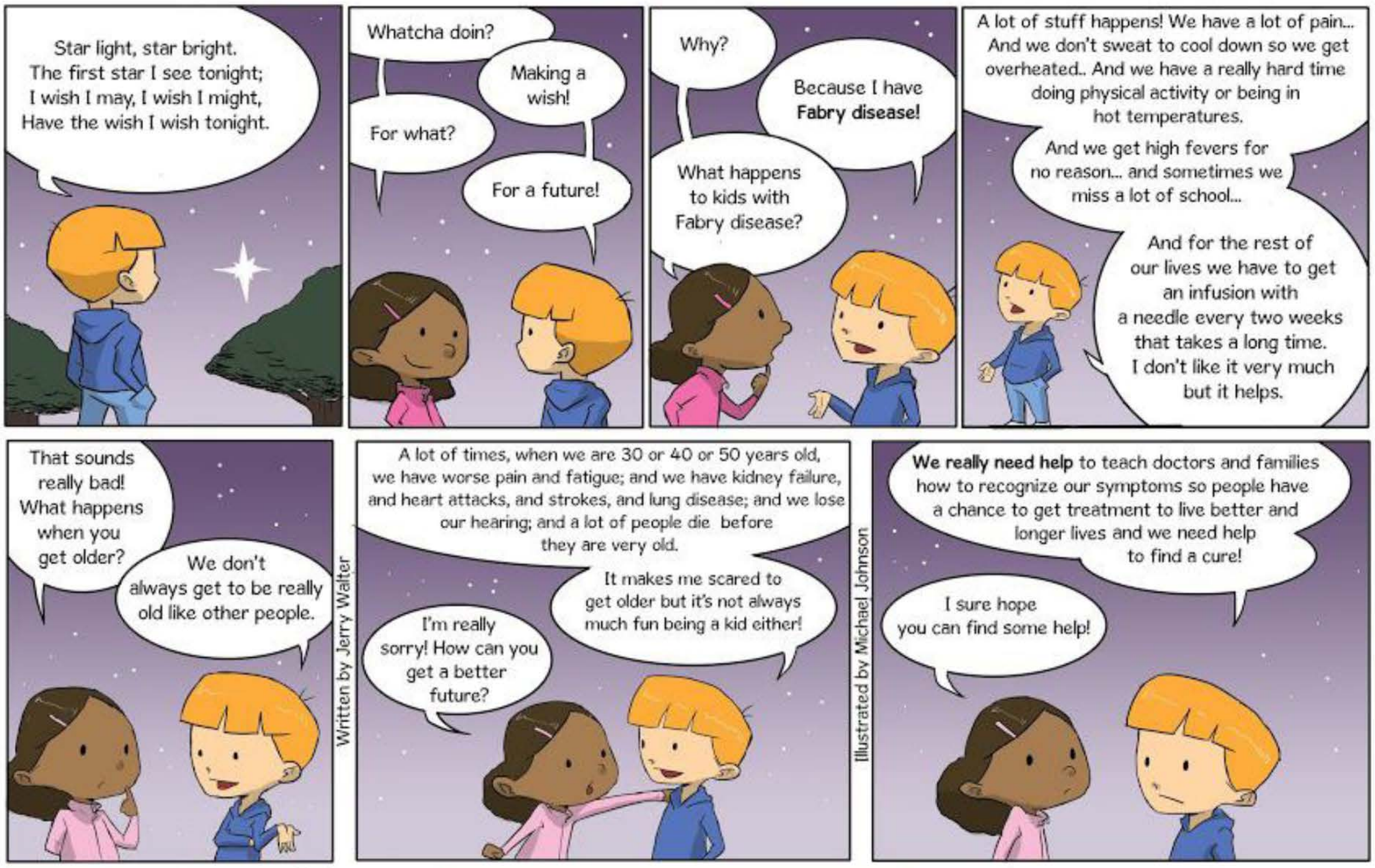
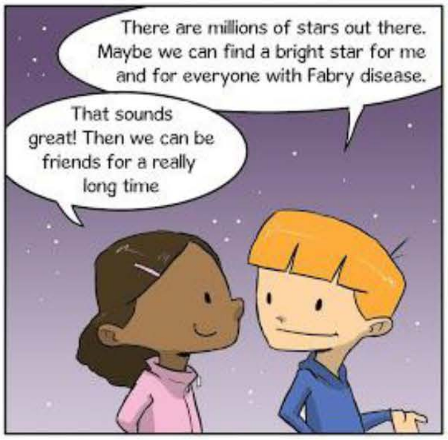
Shining Star Campaign

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!

National
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As of November 2016

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

Fighting Fabry Disease … Living Better Longer (request a wristband with our motto)

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 like you, to give you opportunities to help others through your participation. Here's a convenient checklist about our programs.

☐ Sign up for our e-newsletter to stay informed. Please include your mailing address to receive resources we send by mail. Subscribe at www.fabrydisease.org on the right side of the home page in the "Connect With Us" section using the orange newsletter button.

☐ Apply to attend the annual Charles Kleinschmidt 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 slide.

☐ 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

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

☐ We have an Urgent and Unmet Needs Fund for individuals with Fabry on a limited income when you have a need not covered by insurance or Patient Services Incorporated. (separate slide)

☐ Participate in our "Patient Reported Outcomes (PROS) program… If you are 18 or older with Fabry, please help us to better understand our disease and our community. See separate slide.

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

☐ "Like" 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 2,250 Likes.

☐ "Follow" us on Twitter at www.twitter.com/FabryDisease1.

☆ **Visit our new website at www.fabrydisease.org. There is something for everyone!**
If you previously registered prior to April 2016, please re-register. We are using our registrations from April 2016 onwards to track our "My Health Handbook" kit distribution.

☐ Please send us information about major medical events … remembrances … and community news and announcements. See these sections of our website.

☐ We rely solely on charitable donations to provide our programs and services. If you are able, please make a semi-annual or annual donation from the Donate Now button on our home page.

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

For information please contact us at jerry.walter@fabrydisease.org or 1-800-651-9131