



National
FABRY DISEASE
Foundation

National Fabry Disease Foundation
4301 Connecticut Ave. N.W.
Suite 404
Washington, DC 20008-2369

"The Eyes Have It Campaign"

Volunteer Introduction

Dear Ophthalmologist/Optometrist,

Greetings! I am participating as a volunteer in the National Fabry Disease Foundation's (NFDF's) nationwide **"The Eyes Have It Campaign"**. I have Fabry disease, a rare, progressive, destructive and life-threatening genetic disorder. Symptoms of Fabry disease often include corneal verticillata, the tell-tale corneal whorling seen in Fabry disease. Many of us also have "Fabry cataracts". While our eye symptoms do not usually affect vision, recognizing them in your patients may significantly improve or even save their lives. Fabry disease is treatable! Please learn to search for a recognize Fabry disease in the daily slit-lamp examinations you perform. While evaluating patients, please be aware that use of the medication Amioderone can cause corneal verticillata that mimics those caused by Fabry disease.

Fabry disease is a severely under-recognized disorder. It is difficult for physicians to connect the many symptoms of Fabry disease to enable a correct diagnosis. However, the tell-tale eye findings of Fabry disease make it possible for eye doctors to provide much earlier diagnoses than many of the other medical specialties involved.

To increase recognition of Fabry disease I would like to offer your staff Ophthalmologists and/or Optometrists an opportunity to view my corneal whorling and cataracts if I have them. We believe that if eye doctors see these in person, you will be better able to better recognize Fabry disease in others. Everyone with Fabry disease should have an opportunity to be recognized, diagnosed and treated in time to avoid a diminished quality of life and a shortened life-span. Together, we can help to improve Fabry disease recognition and avert tragedy in many lives.

I understand and agree with the normal protocol for these clinical education events. They require me to undergo a slit lamp examination and viewing by your staff.

Please take the time to look for my corneal opacities now or let's arrange a more suitable time for a Fabry disease educational event. Please contact me at the phone number or email below to schedule a date and time at our mutual convenience. For your convenience, a guide for finding Fabry disease corneal verticillata is attached.

Upon completion of this effort, please annotate the date and approximate number of participants on the bottom of this letter. Fax the letter to the NFDF so they may evaluate the success of this program. Please include a point of contact, your address, phone and email on your fax cover sheet. If you are not able to see corneal verticillata in my eyes, please contact the NFDF to arrange to see another person with Fabry disease in your area.

We greatly appreciate your help! Lives depend on it! I am proud to be a part of the NFDF's Fabry disease awareness efforts being implemented "for the Fabry community, by the Fabry community".

Sincerely,

Volunteer Signature

Printed First Name and Last Name

Date (mm/dd/yyyy)

Volunteer contact info: Phone _____ Email: _____

Event date: _____ Approx. # of participants: _____

Email: Info@TheNFDF.org

Website: www.TheNFDF.org

Phone: **1-800-651-9131**

FAX: 1-800-651-9135