

# My Health Handbook and Emergency Information



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

*Provided by the:*



National  
**FABRY DISEASE**  
Foundation

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## **A resource for our U.S. and international Fabry community**

The **My Health Handbook and Emergency Information** booklet was produced by the National Fabry Disease Foundation for individuals with Fabry disease to always keep with them. **It is available internationally.**

The booklet provides information that will be helpful to emergency care providers in an emergency medical situation.

To receive this booklet along with our resource packet register or re-register on our website at [www.fabrydisease.org](http://www.fabrydisease.org). Include your email and phone number so we can contact you to verify your address before shipping.

Our resource packets will be mailed according to the order the registrations are received.

The following page is the first inside page of this 24 page booklet (including covers). He booklet also includes pages to record your health information, track labs, and more.

# Dear Doctor,

## I have Fabry disease ...

Fabry disease patients may experience cardiovascular, cerebrovascular and renal disease at a younger age than the general population which, in addition to many other symptoms, may include:

- coronary disease
- arrhythmias
- heart failure
- TIA/stroke
- proteinuria and other symptoms of kidney dysfunction

Emergency medical personnel may want to check kidney function as it can be low in Fabry patients. This may affect which type of initial testing is obtained as well as alert care providers about prescribing any medications potentially toxic to the kidneys.

Historically physicians believed Fabry disease was an X-linked recessive disease in which females are carriers only. This misunderstanding has long since been dispelled. It is not a recessive disease. One large study indicates females without symptoms are the exception.

Thank you for contributions from these experienced Fabry disease physicians: Dr. Rob Hopkin (Geneticist), Dr. William Wilcox (Geneticist), Dr. John Jefferies (Cardiologist), Dr. Andrew Lundquist (Nephrologist), Dr. Katherine Sims (Neurologist), and Dr. David Warnock (Nephrologist).