

SAMPLE NOTE TO FAMILY MEMBERS

The following is a sample of a letter that can help explain Fabry disease to family members. You may want to consider personalizing it and using it with members of your family.

Hello,

Recently, I learned some important news about my health. I'm writing to share it with you because it could also affect you, or other members of our family.

I have been diagnosed with a condition called Fabry disease. Fabry disease is a genetic condition that affects a small number of people, so you or your doctor may not have heard of it. Fabry disease runs in families related by blood, so it is possible you too may have inherited it.

People affected by Fabry disease can experience symptoms differently, even people within the same family. Some people may look and feel healthy and have very few symptoms. Others may have fatigue, inability to sweat, pain in hands and feet, or stomach pain and diarrhea. Fabry disease gets worse over time and could lead to medical issues such as heart failure, kidney failure, and stroke.

- Men have a 50% chance of inheriting Fabry disease from an affected mother, and will never inherit the gene from an affected father
- Women will always inherit Fabry disease from an affected father, and have a 50% chance of getting the altered gene from an affected mother



A simple blood or saliva test can be used to confirm whether you inherited this condition. To learn more about Fabry disease or testing options, talk to your doctor, or you can visit www.discoverfabry.com to connect with a CareConnectPSS Patient Education Liaison. The sooner you know if you have Fabry disease, the sooner your doctor can begin helping you!

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