TALKING TO YOUR FAMILY ABOUT FABRY DISEASE

FOR PATIENTS

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Being diagnosed with Fabry disease can be a difficult time for you as an individual. However, because it is an inherited condition, it is very important to consider discussing your diagnosis with your wider family.

This can help your relatives to make decisions about their own health, and give them the opportunity to be tested for Fabry disease and receive appropriate healthcare.

You should seek advice from your doctor, genetic counsellor or a healthcare professional before discussing your diagnosis of Fabry disease with your family.

It may not be possible to have a face-to-face conversation with all your family members. Alternative ways to tell your family include a phone call, email or letter.

It may be a good idea to make a note of the key points to cover, and to keep this with you during the conversation so that you don't forget. Some of the points you may want to consider are shown in the template below – you should discuss this with your doctor, genetic counsellor or a healthcare professional.

Points to consider	Your story in your words
Let your family know that you have been diagnosed with Fabry disease	
Explain what Fabry disease is ● Fabry disease is a rare inherited disorder that, over time, results in accumulation of a lipid (a fatty acid) in the body	

Points to consider	Your story in your words
Tell the story of how you came to be diagnosed	
Your Fabry symptoms ● You may find that other family members have had similar experiences and they may find it reassuring to know your experience	
Other members of the family may have Fabry disease ● Once you have explained that Fabry disease is inherited, your relatives may be worried about their risk of having the condition ● To work out the risk of your relatives having Fabry disease, your doctor or genetic counsellor will ask about your family's medical history, and will map out a family tree to show the genetic relationships (this is called pedigree analysis) – Because of the way it is inherited, only some members of the family will have Fabry disease – A mother with Fabry disease will have a 50/50 chance of passing it on to her children, and an affected father will pass it on to his daughters but not his sons	

Points to consider	Your story in your words
A test for Fabry disease is available ● Your doctor will be able to arrange for family members to be tested locally, if they would like this – Your family may want time to think about whether they want to be tested for Fabry disease – Although you may want someone to be tested, for a variety of reasons some people will not want to know if they have a genetic condition – Your doctor will not contact your family members without your consent ● The test involves taking a very small blood sample, which will be sent off for tests	
Fabry disease can be managed ● Although there is no cure, there are treatments for Fabry disease and its symptoms	
Where they can find further information or support ● Let your family know which sources of information you have found most helpful ● The society for Mucopolysaccharide Disease (the MPS Society) is a UK charity supporting individuals and families affected by MPS, Fabry and related diseases – further details can be found at www.mpssociety.org.uk	

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