

Medical Family Tree

Exploring Your Roots

MEDICAL FAMILY TREE: EXPLORING YOUR ROOTS

PURPOSE: You or someone in your family has been diagnosed with Fabry disease. We know that Fabry disease is an inherited disorder, which means that others in your family may also be at-risk for having the disorder. A medical family tree can be used to determine who in the family is at-risk for Fabry disease. The purpose of this worksheet is to organize your family history so that you may better understand which relatives may be at risk of the disease. Your Patient Education Liaison (PEL) is available to help you with your family tree and to discuss your family tree.

On the next page, please list your relatives and provide as much information as you can. You may find it helpful to check with other family members for more information. This worksheet is meant to be a starting point to your medical family tree, so do not worry if you cannot complete the entire worksheet. You can use the questions below to help guide you.

Questions to consider: *

- Does anyone complain of constant stomachaches, having to go to the bathroom a lot or frequently having diarrhea? Does anyone have irritable bowel disease?
- Is there anyone who does not sweat or sweats only a little? Is there anyone who does not like to go outside when it is hot or cold out?
- Is there anyone who says they have a history of burning pain in their hands or feet?
- Is there anyone who has described their hands or feet as feeling that they are "on fire" or as having "pins and needles" in them?
- Is anyone on dialysis?
- Does anyone see a doctor for their kidneys (nephrologist)?
- Has anyone had a kidney transplant?
- Does anyone see a doctor for their heart (cardiologist)?
- Has anyone had a stroke?
- Is there anyone who passed away at a young age (prematurely)?
- Has anyone ever been told they have whorls/swirls in their eyes, or a distinctive pattern on the cornea, called corneal whorling or corneal verticillata?
- Does anyone have difficulty hearing or complain of ringing in their ears?
- Does anyone have unexplained pain or been told they had "growing pains"?
- Has anyone been diagnosed with Rheumatoid Arthritis, Multiple Sclerosis or Fibromyalgia?
- Does anyone have red spots or dark dots on their torso or bathing suit area?

*If you are comfortable doing so, consider reaching out to your relatives as resources for this information.

Your Parents *(check all that apply)*

Mother (Name):

- | | | | |
|--|--|--|-------------------------------------|
| <input type="checkbox"/> DIAGNOSED WITH FABRY DISEASE | <input type="checkbox"/> TESTED FOR FABRY DISEASE | | |
| <input type="checkbox"/> Heart issues | <input type="checkbox"/> Kidney/Dialysis | <input type="checkbox"/> Stroke | <input type="checkbox"/> Eye whorls |
| <input type="checkbox"/> Stomach/GI* issues | <input type="checkbox"/> Little/No sweat | <input type="checkbox"/> Premature death | <input type="checkbox"/> Pain |

Father (Name):

- | | | | |
|--|--|--|-------------------------------------|
| <input type="checkbox"/> DIAGNOSED WITH FABRY DISEASE | <input type="checkbox"/> TESTED FOR FABRY DISEASE | | |
| <input type="checkbox"/> Heart issues | <input type="checkbox"/> Kidney/Dialysis | <input type="checkbox"/> Stroke | <input type="checkbox"/> Eye whorls |
| <input type="checkbox"/> Stomach/GI issues | <input type="checkbox"/> Little/No sweat | <input type="checkbox"/> Premature death | <input type="checkbox"/> Pain |

If you have additional details about the boxes you checked for any of your relatives, please note them here:

*Gastrointestinal

For patient's personal use only.

Your Children *(check all that apply)*

Child 1 (Name):

- | | | | |
|--|--|--|-------------------------------------|
| <input type="checkbox"/> DIAGNOSED WITH FABRY DISEASE | <input type="checkbox"/> TESTED FOR FABRY DISEASE | | |
| <input type="checkbox"/> Heart issues | <input type="checkbox"/> Kidney/Dialysis | <input type="checkbox"/> Stroke | <input type="checkbox"/> Eye whorls |
| <input type="checkbox"/> Stomach/GI issues | <input type="checkbox"/> Little/No sweat | <input type="checkbox"/> Premature death | <input type="checkbox"/> Pain |

Child 2 (Name):

- | | | | |
|--|--|--|-------------------------------------|
| <input type="checkbox"/> DIAGNOSED WITH FABRY DISEASE | <input type="checkbox"/> TESTED FOR FABRY DISEASE | | |
| <input type="checkbox"/> Heart issues | <input type="checkbox"/> Kidney/Dialysis | <input type="checkbox"/> Stroke | <input type="checkbox"/> Eye whorls |
| <input type="checkbox"/> Stomach/GI issues | <input type="checkbox"/> Little/No sweat | <input type="checkbox"/> Premature death | <input type="checkbox"/> Pain |

Child 3 (Name):

- | | | | |
|--|--|--|-------------------------------------|
| <input type="checkbox"/> DIAGNOSED WITH FABRY DISEASE | <input type="checkbox"/> TESTED FOR FABRY DISEASE | | |
| <input type="checkbox"/> Heart issues | <input type="checkbox"/> Kidney/Dialysis | <input type="checkbox"/> Stroke | <input type="checkbox"/> Eye whorls |
| <input type="checkbox"/> Stomach/GI issues | <input type="checkbox"/> Little/No sweat | <input type="checkbox"/> Premature death | <input type="checkbox"/> Pain |

Child 4 (Name):

- | | | | |
|--|--|--|-------------------------------------|
| <input type="checkbox"/> DIAGNOSED WITH FABRY DISEASE | <input type="checkbox"/> TESTED FOR FABRY DISEASE | | |
| <input type="checkbox"/> Heart issues | <input type="checkbox"/> Kidney/Dialysis | <input type="checkbox"/> Stroke | <input type="checkbox"/> Eye whorls |
| <input type="checkbox"/> Stomach/GI issues | <input type="checkbox"/> Little/No sweat | <input type="checkbox"/> Premature death | <input type="checkbox"/> Pain |

Child 5 (Name):

- | | | | |
|--|--|--|-------------------------------------|
| <input type="checkbox"/> DIAGNOSED WITH FABRY DISEASE | <input type="checkbox"/> TESTED FOR FABRY DISEASE | | |
| <input type="checkbox"/> Heart issues | <input type="checkbox"/> Kidney/Dialysis | <input type="checkbox"/> Stroke | <input type="checkbox"/> Eye whorls |
| <input type="checkbox"/> Stomach/GI issues | <input type="checkbox"/> Little/No sweat | <input type="checkbox"/> Premature death | <input type="checkbox"/> Pain |

Your Siblings *(check all that apply)*

Sibling 1 (Name):

- | | | | |
|--|--|--|-------------------------------------|
| <input type="checkbox"/> DIAGNOSED WITH FABRY DISEASE | <input type="checkbox"/> TESTED FOR FABRY DISEASE | | |
| <input type="checkbox"/> Heart issues | <input type="checkbox"/> Kidney/Dialysis | <input type="checkbox"/> Stroke | <input type="checkbox"/> Eye whorls |
| <input type="checkbox"/> Stomach/GI issues | <input type="checkbox"/> Little/No sweat | <input type="checkbox"/> Premature death | <input type="checkbox"/> Pain |

Sibling 2 (Name):

- | | | | |
|--|--|--|-------------------------------------|
| <input type="checkbox"/> DIAGNOSED WITH FABRY DISEASE | <input type="checkbox"/> TESTED FOR FABRY DISEASE | | |
| <input type="checkbox"/> Heart issues | <input type="checkbox"/> Kidney/Dialysis | <input type="checkbox"/> Stroke | <input type="checkbox"/> Eye whorls |
| <input type="checkbox"/> Stomach/GI issues | <input type="checkbox"/> Little/No sweat | <input type="checkbox"/> Premature death | <input type="checkbox"/> Pain |

Sibling 3 (Name):

- | | | | |
|--|--|--|-------------------------------------|
| <input type="checkbox"/> DIAGNOSED WITH FABRY DISEASE | <input type="checkbox"/> TESTED FOR FABRY DISEASE | | |
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| <input type="checkbox"/> Stomach/GI issues | <input type="checkbox"/> Little/No sweat | <input type="checkbox"/> Premature death | <input type="checkbox"/> Pain |

Sibling 4 (Name):

- | | | | |
|--|--|--|-------------------------------------|
| <input type="checkbox"/> DIAGNOSED WITH FABRY DISEASE | <input type="checkbox"/> TESTED FOR FABRY DISEASE | | |
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| <input type="checkbox"/> Stomach/GI issues | <input type="checkbox"/> Little/No sweat | <input type="checkbox"/> Premature death | <input type="checkbox"/> Pain |

Sibling 5 (Name):

- | | | | |
|--|--|--|-------------------------------------|
| <input type="checkbox"/> DIAGNOSED WITH FABRY DISEASE | <input type="checkbox"/> TESTED FOR FABRY DISEASE | | |
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| <input type="checkbox"/> Stomach/GI issues | <input type="checkbox"/> Little/No sweat | <input type="checkbox"/> Premature death | <input type="checkbox"/> Pain |

Maternal Relatives *(check all that apply)*

Relative 1 (Name/Relation):

- | | | | |
|--|--|--|-------------------------------------|
| <input type="checkbox"/> DIAGNOSED WITH FABRY DISEASE | <input type="checkbox"/> TESTED FOR FABRY DISEASE | | |
| <input type="checkbox"/> Heart issues | <input type="checkbox"/> Kidney/Dialysis | <input type="checkbox"/> Stroke | <input type="checkbox"/> Eye whorls |
| <input type="checkbox"/> Stomach/GI issues | <input type="checkbox"/> Little/No sweat | <input type="checkbox"/> Premature death | <input type="checkbox"/> Pain |

Relative 2 (Name/Relation):

- | | | | |
|--|--|--|-------------------------------------|
| <input type="checkbox"/> DIAGNOSED WITH FABRY DISEASE | <input type="checkbox"/> TESTED FOR FABRY DISEASE | | |
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| <input type="checkbox"/> Stomach/GI issues | <input type="checkbox"/> Little/No sweat | <input type="checkbox"/> Premature death | <input type="checkbox"/> Pain |

Relative 3 (Name/Relation):

- | | | | |
|--|--|--|-------------------------------------|
| <input type="checkbox"/> DIAGNOSED WITH FABRY DISEASE | <input type="checkbox"/> TESTED FOR FABRY DISEASE | | |
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| <input type="checkbox"/> Stomach/GI issues | <input type="checkbox"/> Little/No sweat | <input type="checkbox"/> Premature death | <input type="checkbox"/> Pain |

Relative 4 (Name/Relation):

- | | | | |
|--|--|--|-------------------------------------|
| <input type="checkbox"/> DIAGNOSED WITH FABRY DISEASE | <input type="checkbox"/> TESTED FOR FABRY DISEASE | | |
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| <input type="checkbox"/> Stomach/GI issues | <input type="checkbox"/> Little/No sweat | <input type="checkbox"/> Premature death | <input type="checkbox"/> Pain |

Relative 5 (Name/Relation):

- | | | | |
|--|--|--|-------------------------------------|
| <input type="checkbox"/> DIAGNOSED WITH FABRY DISEASE | <input type="checkbox"/> TESTED FOR FABRY DISEASE | | |
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| <input type="checkbox"/> Stomach/GI issues | <input type="checkbox"/> Little/No sweat | <input type="checkbox"/> Premature death | <input type="checkbox"/> Pain |

Paternal Relatives *(check all that apply)*

Relative 1 (Name/Relation):

- | | | | |
|--|--|--|-------------------------------------|
| <input type="checkbox"/> DIAGNOSED WITH FABRY DISEASE | <input type="checkbox"/> TESTED FOR FABRY DISEASE | | |
| <input type="checkbox"/> Heart issues | <input type="checkbox"/> Kidney/Dialysis | <input type="checkbox"/> Stroke | <input type="checkbox"/> Eye whorls |
| <input type="checkbox"/> Stomach/GI issues | <input type="checkbox"/> Little/No sweat | <input type="checkbox"/> Premature death | <input type="checkbox"/> Pain |

Relative 2 (Name/Relation):

- | | | | |
|--|--|--|-------------------------------------|
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| <input type="checkbox"/> Stomach/GI issues | <input type="checkbox"/> Little/No sweat | <input type="checkbox"/> Premature death | <input type="checkbox"/> Pain |

Relative 4 (Name/Relation):

- | | | | |
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Relative 5 (Name/Relation):

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| <input type="checkbox"/> Stomach/GI issues | <input type="checkbox"/> Little/No sweat | <input type="checkbox"/> Premature death | <input type="checkbox"/> Pain |

SANOFI GENZYME OFFERS SUPPORT SERVICES FOR YOU AND YOUR FAMILY

For more than 30 years, Sanofi Genzyme has been committed to helping meet the needs of people who are living with rare disorders like Fabry disease. Our commitment extends to those who have Fabry disease and their families, as well as healthcare professionals. We offer a wide spectrum of services, all personalized and tailored to you through your Case Manager and Patient Education Liaison.

Patient Education Liaisons (PELs) can help:

- Educate and support you on Fabry disease management and inheritance
- Organize, support, and coordinate patient and/or family educational meetings
- Construct a medical family tree for your personal use
- Provide educational support about Fabry disease to community groups, employers and/or educators
- Provide support to certain healthcare providers/offices

GETTING STARTED IS EASY

Contact a CareConnectPSS Case Manager:
1-800-745-4447 (option 3)
Monday–Friday 8am–6pm EST

Connect with us online:

careconnectpss.com

SANOFI GENZYME 

50 Binney Street
Cambridge, MA 02142

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