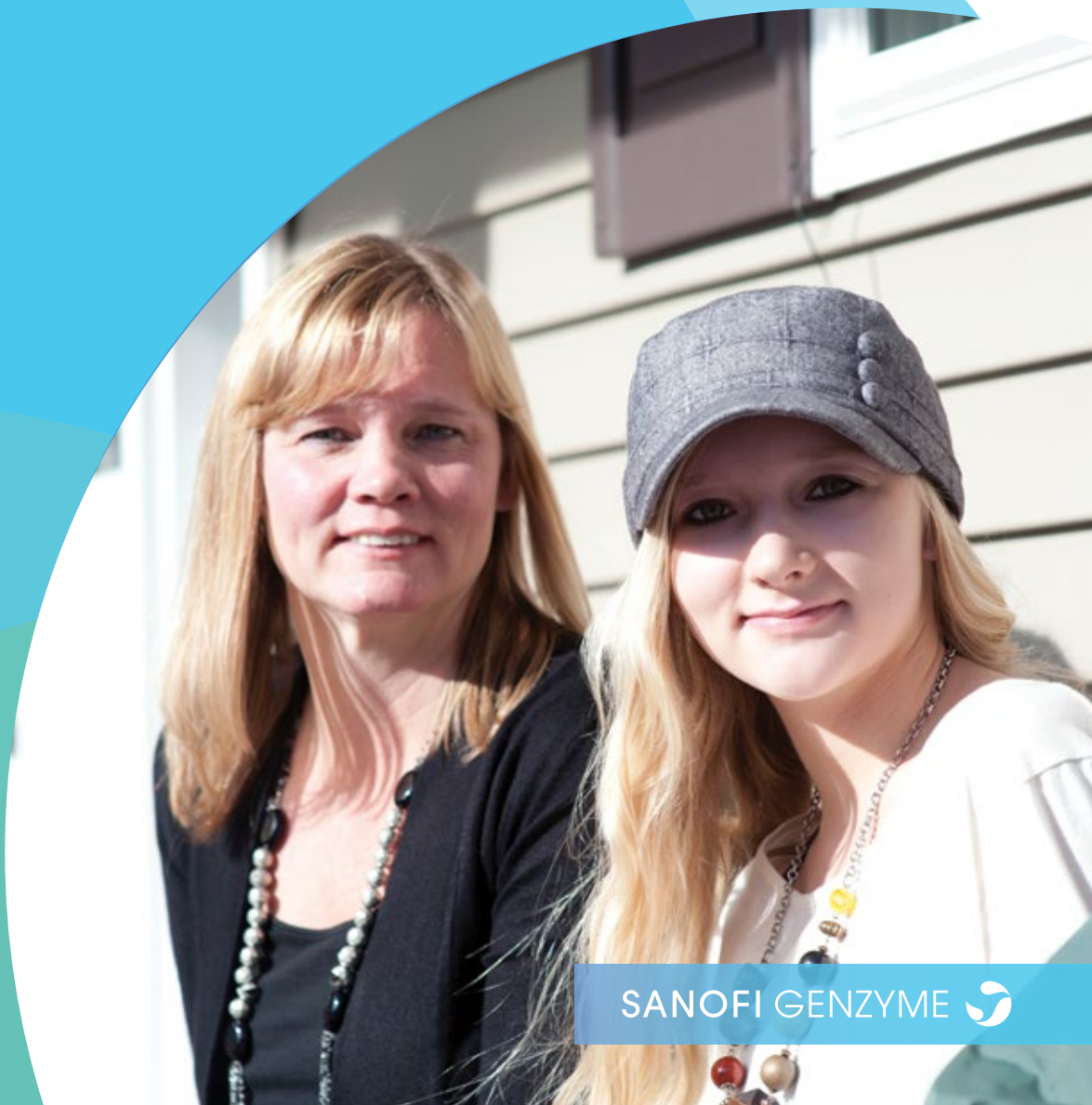
Monitoring Your Health

A Guide for Patients with Fabry Disease



Jade, Fabry patient
(with her mother, Lois)

SANOFI GENZYME

MONITORING YOUR HEALTH

If you have been diagnosed with Fabry disease, your doctor will likely want to see you regularly to monitor your health. Because Fabry disease is progressive - meaning it gets worse over time - it's important to track your health and let your doctor know if any new symptoms or changes have occurred.

Monitoring your health is recommended so that:

- You and your healthcare provider can track whether your test results are improving, staying stable or worsening over time
- If you are not currently experiencing symptoms, test results can help show whether the disease is progressing silently

Avery, Fabry patient

WAYS TO MONITOR FABRY DISEASE

Below are some common symptoms of Fabry disease, along with tests to monitor whether these symptoms are progressing. You should consult with your doctor about any specific questions you have about your health care.

Kidney Function

By early adulthood, many people with Fabry disease will have significant kidney problems, sometimes requiring dialysis.

- Glomerular Filtration Rate: A test to measure the level of kidney function and determine the stage of kidney disease.
- Tests for Albuminuria and Proteinuria: These tests measure protein in the urine. Excess protein in the urine is a sign of chronic kidney disease.
- Serum Creatinine and BUN (blood urea nitrogen): These tests measure the amount of certain waste products in the blood. Waste products are normally filtered out by the kidneys.
- Urine Protein Excretion: Another test to measure protein in the urine.

Heart Function

Many Fabry patients may experience serious heart problems. Tests for these include:

- Electrocardiogram (ECG or EKG): A test that measures electrical activity in the heart.
- Echocardiogram (ECHO): A test that uses sound waves to get a picture of the heart.
- 24-hour Holter Monitoring: A test that measures the heart's rhythms.
- Cardiac MRI: A test that uses a magnetic field and radio waves to create a detailed image of your heart.

Blood

Early signs of heart disease and other problems can show up in blood tests.

- Lipid panel: This test measures total cholesterol, HDL cholesterol, LDL cholesterol, and triglycerides. High cholesterol and high triglycerides are risk factors for heart disease.
- Plasma GL-3: This test shows the amount of GL-3 in your blood. Excess GL-3 is a sign of Fabry disease.

Hearing

Hearing tests are performed because many Fabry patients experience hearing loss or tinnitus, which is ringing in the ears.

Brain

Magnetic resonance imaging (MRI) is a technique that uses a magnetic field and radio waves to create detailed images of organs and tissues. A brain MRI looks at portions of your brain to detect problems in the central nervous system, another common symptom of Fabry disease.

Lung Function

A lung function test called spirometry measures how much air you inhale, how much you exhale and how quickly you exhale.

Eye

Most people with Fabry disease have a distinct pattern on their cornea called corneal whorling or corneal verticillata. It does not affect vision and is only visible through a simple eye exam called slit lamp ophthalmoscopy.

Quality of Life

Your healthcare provider can measure quality of life by asking you questions based on well-established surveys. Patients 18 and older may get the SF-36®, the Brief Pain Inventory (BPI), or both. Patients under 18 may get a set of surveys called PedsQL™ (Pediatric Quality of Life Assessment).

Monitoring Fabry Disease with My Doctor

Test	How often**	Test result at baseline Date: _____	Test date and result Date: _____ Improved Stable Worsened	Test date and result Date: _____ Improved Stable Worsened	Test date and result Date: _____ Improved Stable Worsened	Test date and result Date: _____ Improved Stable Worsened	Test date and result Date: _____ Improved Stable Worsened
SPECIALIZED							
Plasma GL-3	Every 3-6 months		☐ ☐ ☐	☐ ☐ ☐	☐ ☐ ☐	☐ ☐ ☐	☐ ☐ ☐
GENERAL							
General health*	Every 6 months		☐ ☐ ☐	☐ ☐ ☐	☐ ☐ ☐	☐ ☐ ☐	☐ ☐ ☐
Vital signs, height, weight	Every 6 months		☐ ☐ ☐	☐ ☐ ☐	☐ ☐ ☐	☐ ☐ ☐	☐ ☐ ☐
Quality of Life Survey (SF-36, BPI)	Every 6 months		☐ ☐ ☐	☐ ☐ ☐	☐ ☐ ☐	☐ ☐ ☐	☐ ☐ ☐
Enzyme activity and genotype	At baseline		_____	_____	_____	_____	_____
LABORATORY TESTS							
Kidney function tests							
Serum creatinine	Every 6 months		☐ ☐ ☐	☐ ☐ ☐	☐ ☐ ☐	☐ ☐ ☐	☐ ☐ ☐
BUN	Every 6 months		☐ ☐ ☐	☐ ☐ ☐	☐ ☐ ☐	☐ ☐ ☐	☐ ☐ ☐
Urine protein test	Every 6 months		☐ ☐ ☐	☐ ☐ ☐	☐ ☐ ☐	☐ ☐ ☐	☐ ☐ ☐
Blood test (lipid panel)	Every 12 months		☐ ☐ ☐	☐ ☐ ☐	☐ ☐ ☐	☐ ☐ ☐	☐ ☐ ☐
OTHER TESTS							
Hearing evaluation	Every 24-36 months		☐ ☐ ☐	☐ ☐ ☐	☐ ☐ ☐	☐ ☐ ☐	☐ ☐ ☐
Brain MRI	Every 24-36 months		☐ ☐ ☐	☐ ☐ ☐	☐ ☐ ☐	☐ ☐ ☐	☐ ☐ ☐
Electrocardiogram	Every 12 months		☐ ☐ ☐	☐ ☐ ☐	☐ ☐ ☐	☐ ☐ ☐	☐ ☐ ☐
Echocardiogram	Every 12 months		☐ ☐ ☐	☐ ☐ ☐	☐ ☐ ☐	☐ ☐ ☐	☐ ☐ ☐
24-Hour Holter monitor	Every 12 months		☐ ☐ ☐	☐ ☐ ☐	☐ ☐ ☐	☐ ☐ ☐	☐ ☐ ☐
Cardiac MRI	Every 12-24 months		☐ ☐ ☐	☐ ☐ ☐	☐ ☐ ☐	☐ ☐ ☐	☐ ☐ ☐
Lung function test (spirometry)	Every 24-36 months		☐ ☐ ☐	☐ ☐ ☐	☐ ☐ ☐	☐ ☐ ☐	☐ ☐ ☐
Slit lamp eye exam	At baseline		_____	_____	_____	_____	_____
My Tests (list any symptoms or tests that you and your doctor are tracking)							

* It is a good idea to also keep track of medications you are taking.

**Tests are performed when initially diagnosed with Fabry disease (baseline). The frequency of tests is derived from the Fabry Registry Schedule of Assessments, which is a global program organized and sponsored by Sanofi Genzyme. The tests may vary depending on your doctor's assessment and your individual needs.

JUST A PHONE CALL OR EMAIL AWAY

CareConnectPSS™ represents Sanofi Genzyme's more than 25-year commitment to supporting the rare disease community and is designed to support each patient's unique journey.

Whether your needs are large or small, your CareConnectPSS team will work closely with you and your health providers to give you the confidential and personalized support you need. To learn more about our range of support offerings, or to reach your CareConnectPSS Case Manager, please call 1-800-745-4447, and select Option 3, or email us at Info@CareConnectPSS.com.

For more information, visit us at careconnectpss.com

careconnect PSS™
Personalized Support Services

SANOFI GENZYME

50 Binney Street
Cambridge, MA 02142

SAUS.FD.17.04.1244h(1)