

## GLOSSARY

### Kidney:

**Measured GFR:** a calculation based on a blood test to see how well the kidneys are working

**Albuminuria and/or proteinuria:** urine tests to look for protein

**25 OH vitamin D:** a blood test to check for vitamin D levels

**Kidney biopsy:** using a needle, a doctor takes a tiny piece of the kidney to look at under a microscope

### Heart:

**Arrhythmia:** irregular heartbeat

**Bradycardia:** abnormally slow heart rate

**Cardiomyopathy:** disease of the heart muscle that makes it harder for your heart to pump blood to the rest of your body

**Blood pressure:** a measurement to check the pressure with which blood is pumped through blood vessels, using a blood pressure monitor

**Heart rhythm analysis:** tests to monitor the pace of each heart beat

**Electrocardiography (ECG) and echocardiography:** the first test records the electrical activity of the heart, while the other is an ultrasound of the heart

**48-h Holter monitoring:** a portable device to monitor the heart for 24 to 48 hours

**Cardiac MRI with gadolinium:** a test that scans the heart and forms an image. Gadolinium is added to the test to enhance the image (Note: consult with your healthcare provider about the use of gadolinium if you have signs, symptoms, or a past history of chronic kidney disease)

**Brain natriuretic peptide:** a blood test to check levels of certain proteins for heart health

### Brain:

**Brain MRI:** a test that creates images of the brain

**CT imaging:** a scan that forms images of the inside of the body

**Acute stroke:** a sudden interruption of blood flow to the brain

### Eyes:

**Ophthalmological screening:** different tests to assess eye health

### Nervous System:

**Pain evaluation and history:** an assessment of the type of pain you feel, how severe it is, and what it means to you

**Cold and heat intolerance, vibration test:** measurements to check the body's response to cold, heat, and vibrations

**Autonomic symptom evaluation:** an assessment done by a blood pressure test to check for low blood pressure.

Blood pressure is checked while lying down and standing

**Skin biopsy:** using a special tool, a doctor takes a tiny piece of the skin to look at under a microscope

### Ears:

**Audiometry:** tests to check hearing

### Lungs:

**Spirometry:** a test that uses a machine that you breathe into. It measures how well the lungs are working

### Stomach/GI:

**Endoscopic or radiographic evaluation:** looks at the intestines using an endoscope (tube with a light and camera on the end) or via imaging like an X-ray

### Overall Glycolipid Burden:

**Plasma and urinary sediment Lyso-GL-3, GL-3:** measures the levels of lipids (fatty substances) in blood and urine

**Biobanking:** a stored, large collection of biological samples, such as human tissue

### Bones:

**Bone dual-energy X-ray absorptiometry:** an X-ray scan that measures the density of your bones

## MY CARE TEAM

### Kidney:

**Name of my Nephrologist:** \_\_\_\_\_

**Phone Number:** \_\_\_\_\_ **Address:** \_\_\_\_\_

**Notes:** \_\_\_\_\_

### Heart:

**Name of my Cardiologist:** \_\_\_\_\_

**Phone Number:** \_\_\_\_\_ **Address:** \_\_\_\_\_

**Notes:** \_\_\_\_\_

### Brain:

**Name of my Neurologist:** \_\_\_\_\_

**Phone Number:** \_\_\_\_\_ **Address:** \_\_\_\_\_

**Notes:** \_\_\_\_\_

### Eyes:

**Name of my Ophthalmologist:** \_\_\_\_\_

**Phone Number:** \_\_\_\_\_ **Address:** \_\_\_\_\_

**Notes:** \_\_\_\_\_

### Ears:

**Name of my Audiologist:** \_\_\_\_\_

**Phone Number:** \_\_\_\_\_ **Address:** \_\_\_\_\_

**Notes:** \_\_\_\_\_

### Lungs:

**Name of my Pulmonologist:** \_\_\_\_\_

**Phone Number:** \_\_\_\_\_ **Address:** \_\_\_\_\_

**Notes:** \_\_\_\_\_

### Digestive System:

**Name of my Gastroenterologist:** \_\_\_\_\_

**Phone Number:** \_\_\_\_\_ **Address:** \_\_\_\_\_

**Notes:** \_\_\_\_\_

### Mental Health:

**Name of my Psychologist/Psychiatrist:** \_\_\_\_\_

**Phone Number:** \_\_\_\_\_ **Address:** \_\_\_\_\_

**Notes:** \_\_\_\_\_

### Other:

**Name of my Healthcare Provider:** \_\_\_\_\_

**Phone Number:** \_\_\_\_\_ **Address:** \_\_\_\_\_

**Notes:** \_\_\_\_\_



# My Fabry Tracker

*A helpful guide for tracking and monitoring your Fabry.*




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# Fabry: A whole-body disease


## Why monitoring matters


Some signs and symptoms of Fabry disease are very noticeable. Other changes that are happening in your body may not be as obvious. For this reason, it's important to work with your care team to monitor all the different parts of your body that may be affected by Fabry. Monitoring your Fabry may also help your healthcare provider determine which treatment(s) may be right for you.


TEST	MONITORING SCHEDULE					NOTES
	3 months	6 months	Annually	As clinically indicated	Other	
 <b>Kidney</b>						
Measured GFR	●	●	●			Moderate risk: every 6 months. High risk: every 3 months.
Albuminuria and/or proteinuria	●	●	●			Moderate risk: every 6 months. High risk: every 3 months.
25 OH vitamin D				●		Monitor in late fall/early winter.
Kidney biopsy				●		


TEST	MONITORING SCHEDULE					NOTES
	3 months	6 months	Annually	As clinically indicated	Other	
 <b>Heart</b>						
Blood pressure and cardiac rhythm					●	Monitor at every clinic visit.
ECG and echocardiography			●	●		
48-h Holter monitoring			●	●	●	More frequent monitoring may be necessary based on age and risk factors (ie, arrhythmia).
Cardiac MRI with gadolinium					●	Monitor every 2 years or when disease progression is evident.
Brain natriuretic peptide			●			Monitor annually for patients with cardiomyopathy or bradycardia.


TEST	MONITORING SCHEDULE					NOTES
	3 months	6 months	Annually	As clinically indicated	Other	
 <b>Nervous system</b>						
Pain evaluation and history			●			
Cold and heat intolerance, vibratory thresholds			●			For older patients: less frequent monitoring.
Autonomic symptom evaluation by orthostatic blood pressure			●			
Skin biopsy					●	


TEST	MONITORING SCHEDULE					NOTES
	3 months	6 months	Annually	As clinically indicated	Other	
 <b>Brain</b>						
Brain MRI				●	●	First assessment in men: older than 21 years old. First assessment in women: older than 30 years old. Monitor every 3 years.
CT imaging					●	Monitor in case of acute stroke.


TEST	MONITORING SCHEDULE					NOTES
	3 months	6 months	Annually	As clinically indicated	Other	
 <b>Ears</b>						
Audiometry				●		


TEST	MONITORING SCHEDULE					NOTES
	3 months	6 months	Annually	As clinically indicated	Other	
 <b>Lungs</b>						
Spirometry				●	●	Monitor every 2 years.

TEST	MONITORING SCHEDULE					NOTES
	3 months	6 months	Annually	As clinically indicated	Other	
 <b>GI</b>						
Endoscopic or radiographic evaluation				●		

TEST	MONITORING SCHEDULE					NOTES
	3 months	6 months	Annually	As clinically indicated	Other	
 <b>GL-3</b>						
Plasma and urinary sediment lyso-GL-3, GL-3					●	Currently, this is for research purposes only. Biobanking of samples is recommended, if possible.

TEST	MONITORING SCHEDULE					NOTES
	3 months	6 months	Annually	As clinically indicated	Other	
 <b>Bones</b>						
Bone dual-energy X-ray absorptiometry					●	

TEST	MONITORING SCHEDULE					NOTES
	3 months	6 months	Annually	As clinically indicated	Other	
 <b>Eyes</b>						
Ophthalmological screening				●		

TEST	MONITORING SCHEDULE					NOTES
	3 months	6 months	Annually	As clinically indicated	Other	
 <b>Mental Health</b>						
Monitor for anxiety and depression					●	Monitor at every clinic visit.

## Talking with your health care provider

Since each person living with Fabry is unique, it is very important to review this tracker with your doctors and specialists. They may recommend different tests and testing schedules based on your health needs. If you have any questions concerning these tests or your results, please talk with your healthcare provider.