Amicus assist™

My Fabry Tracker

A helpful guide for tracking and monitoring your Fabry.

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.

	MONITORING SCHEDULE					
TEST	*3 months*	*6 months*	*Annually*	*As clinically indicated*	*Other*	*NOTES*
Kidney						
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				●		
Heart						
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: 3 months	6 months	Annually	As clinically indicated	Other	NOTES
Nervous system						
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					●	
Brain						
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.
Ears						
Audiometry				●		
Lungs						
Spirometry				●	●	Monitor every 2 years.

TEST	MONITORING SCHEDULE: 3 months	6 months	Annually	As clinically indicated	Other	NOTES
GI						
Endoscopic or radiographic evaluation				●		
GL-3 — Overall glycolipid burden						
Plasma and urinary sediment lyso-GL-3, GL-3					●	Currently, this is for research purposes only. Biobanking of samples is recommended, if possible.
Bones						
Bone dual-energy X-ray absorptiometry					●	
Eyes						
Ophthalmological screening				●		
Mental Health						
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.

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: _____