

Genetic Cardiomyopathy Discussion Guide

Questions to Ask Your Doctor

Take this to your next cardiology or genetics appointment. There are two sets of questions, depending on whether you have been diagnosed with cardiomyopathy. If you are short on time, start with the **“Top 5 Questions.”**

What to bring with you to your appointment:

- › Trusted friend or loved one
- › Notepad/pen
- › Any test results from other doctors or health systems (or be able to access them on your phone)
- › List of medications, including all supplements
- › Other relevant health information, such as blood pressure readings, symptoms log, etc.
- › List of allergies
- › If you are not a native English speaker, call ahead to request a translator

Top 5 Questions

1. **Status:** “Do I have cardiomyopathy now, or am I currently a ‘healthy carrier’ at risk?”
2. **Function:** “What is my heart function (EF), and is it stable?”
“Are there any other medical conditions associated with this gene that I might be at risk of developing?”
3. **Monitoring:** “What is the specific plan for my next follow-up tests?”
4. **Family:** “How do I get my family members tested for this specific genetic variant?”
5. **Research:** “Are there any gene-specific clinical trials I should be aware of?”

Remember: You don't need to ask everything at once. Start with the basics—you can always ask more over time as you become more comfortable with your diagnosis.

Questions For Those with a Genetic Variant, *but NO Symptoms or Cardiomyopathy Diagnosis* Prevention, Monitoring, and Family.

➤ My Current Status

"I feel healthy—is my heart function currently in the normal range (Ejection Fraction)?"

"What is my specific risk level for developing cardiomyopathy in the future?"

➤ Testing & Monitoring

"What baseline tests do I need now (Echo, EKG, MRI) to capture my heart at its healthiest?"

"How often should we repeat these tests to catch any changes early?"

➤ Lifestyle & Protection

"Are there specific high-intensity exercises or lifestyle habits I should adjust to protect my heart muscle?"

"How can we optimize my blood pressure to reduce stress on my heart cells?"

➤ Family & Genetics

"Can you refer me to a Genetic Counselor to help map out testing for my children or siblings?"

"Can you provide me with a 'Family Letter' or specific genetic information to share with my relatives?"

Questions For Those with a Genetic Variant —AND— a *Cardiomyopathy Diagnosis* Treatment, Stabilization, and Innovation.

➤ Understanding My Condition

"What is my current Ejection Fraction (EF), and how has it changed since my last visit?"

"Does knowing that I have a genetic variant change my specific medication or treatment plan?"

➤ Specialized Care

"Can you refer me to a specialist who focuses on genetic cardiomyopathy?"

"Should I have a Cardiac MRI to look for 'fibrosis' (scarring) in the heart muscle?"

➤ Looking Ahead

"Is my specific variant eligible for any current gene-specific clinical trials or gene therapy research?"

"What are the specific 'Red Flag' symptoms that should prompt me to call 911 immediately?"

➤ Family Clarity

"Since we know the genetic cause, what is the best way to coordinate 'cascade testing' for my family members?"

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Genetic CardioMYopathy Awareness



Genetic Cardiomyopathy
Awareness Consortium

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