

Questions to Ask Your Care Team

Confirming a Duchenne Diagnosis

A diagnosis appointment can move quickly, especially when you are hearing unfamiliar medical terms. Use this guide to record the questions you want answered, note what is still pending, and make sure you leave with the reports and next steps your family needs.

BEFORE THE APPOINTMENT

Child's name:

Appointment date:

Clinician or clinic:
Person attending with
me:

QUESTIONS ABOUT THE DIAGNOSIS

☐	Has the diagnosis been genetically confirmed?
☐	What exact DMD gene change or variant was found?
☐	How did the laboratory classify the result?
☐	Did the testing include deletion and duplication analysis?
☐	Did the testing include sequencing for smaller gene changes?
☐	Does the genetic result fit my child's symptoms and clinical findings?
☐	Is any additional testing recommended?
☐	Are any test results or reports still pending?
☐	Could the result be consistent with Becker muscular dystrophy or another dystrophin-related condition?
☐	Should we meet with a genetic counselor?
☐	Should the child's mother, siblings, or other relatives be offered counseling or testing?
☐	Does this result affect treatment options?
☐	Does this result affect clinical-trial or research eligibility?
☐	Can you send us the complete genetic laboratory report?
☐	Can you give us a copy of the CK result and other relevant test results?
☐	Who should we contact if we have questions after this appointment?
☐	When should we schedule the next appointment?

QUESTIONS I WANT TO ADD

1. _____
2. _____
3. _____
4. _____

NOTES AND NEXT STEPS

Next appointment or action: _____

Person responsible for follow-up: _____

Expected date or timeframe: _____

Before you leave, ask for copies of the complete genetic laboratory report, CK result, and any other testing discussed during the appointment. You should not have to rely on memory from a difficult conversation.

You are allowed to ask, "Can you explain that again?"

DMD Pathways is an informational and navigation platform. This guide is for educational and appointment-preparation purposes only and is not medical advice, diagnosis, or treatment. Always consult a qualified healthcare professional regarding medical questions and treatment decisions.