Dear Parent, Patient, or Provider,

Welcome to Decode Duchenne, a genetic testing program that provides free genetic testing to patients who have been unable to access testing due to financial barriers. Decode Duchenne is administered by The Duchenne Registry and Parent Project Muscular Dystrophy. Decode Duchenne is sponsored by Sarepta Therapeutics and PTC Therapeutics.

To participate in Decode Duchenne, a person must meet four criteria:

☐ Have a confirmed or suspected diagnosis of Duchenne or Becker muscular dystrophy

☐ OR

☐ Be an asymptomatic female of an affected relative with a known causative mutation from previous DNA testing.

☐ Have never had genetic testing OR previous genetic testing has not confirmed a causative mutation in the DMD gene

☐ Have a financial barrier to receiving genetic testing

☐ Be a citizen or legal resident of the United States or Canada

Please read the attached documents carefully to participate in this program:

1. Process Outline: This overview describes the steps in the Decode Duchenne genetic testing process.

2. Application Form: This form must be completed by a participant’s doctor, nurse, or genetic counselor and submitted to Decode Duchenne to receive testing approval.

Our team of genetic counselors is always here to help. Contact us with any questions or concerns by telephone at 888-520-8675 option 1 or via email at coordinator@parentprojectmd.org.

Thank you for your interest in Decode Duchenne.

Sincerely,

Jen Ely, MS, CGC
Certified Genetic Counselor | Decode Duchenne Program Manager

Ann Martin, MS, CGC
Certified Genetic Counselor | Director, The Duchenne Registry
The Decode Duchenne Testing Process

Receiving genetic testing through the Decode Duchenne program is easy. Review the steps below:

1. **Check eligibility criteria**
   - You are eligible for testing if you have a known or suspected diagnosis of Duchenne or Becker muscular dystrophy and need genetic testing to identify the causative mutation OR if you are an asymptomatic female of an affected relative with a known causative mutation and you need carrier testing; you need financial help to get testing; and you are a citizen or legal resident of the United States or Canada.

2. **Register on the Duchenne Registry**
   - Register and learn more at www.duchenneregistry.org.
   - The Duchenne Registry is a patient registry that connects participants to current research, clinical trials, and valuable educational resources.
   - Participation in the patient registry enables you to save your genetic test results in your profile so that you can always access them.

3. **Submit the application form**
   - The application form must be completed by a healthcare provider.
   - Submit online at www.parentprojectmd.org/decode, via email coordinator@parentprojectmd.org or fax 404-935-0636.

4. **Receive approval, test requisition, and informed consent**
   - A Decode Duchenne team member will contact the provider listed on the application once it has been approved or if additional information is needed.
   - Once approved, the provider will be sent the participant’s test requisition, informed consent, and sample shipping instructions for PerkinElmer Genetics. A lab kit can also be provided.

5. **Complete the specimen collection**
   - The ordering physician should complete the parts of the test requisition not already filled in and have the patient sign the informed consent form.
   - The participant should have their blood (preferred specimen), saliva, or dried blood spot collected according to sample guidelines, and shipped directly to PerkinElmer Genetics.

6. **Receive results**
   - Results will take approximately 3 weeks.
   - The ordering provider and a Decode Duchenne genetic counselor will receive the report.
   - The participant’s healthcare team is responsible for delivering results to the participant.
   - A Decode Duchenne genetic counselor will upload a copy of the report to the participant's Duchenne Registry account (if registered).

**Get support at any time**
- Our certified genetic counselors are available to help providers and participants with any questions before, during, and after the genetic testing process.
- Contact us at coordinator@parentprojectmd.org or at 888-520-8675 option 1.
Application Form for Genetic Testing (Page 1 of 2)

This form must be completed by a healthcare provider who is involved in the care of the person diagnosed or suspected of having Duchenne or Becker muscular dystrophy, OR of the person needing carrier testing.

Please email the completed and signed form to coordinator@parentprojectmd.org or fax to 404-935-0636. Contact Jen Ely at 888-520-8675, option 1, with any questions.

Patient name: ____________________________ DOB: ____________ Gender: M / F

Patient address: ________________________________

I attest that my patient:

☐ Was denied coverage of genetic testing by his/her insurance company
☐ Was denied coverage of genetic testing by Medicaid/Medicare
☐ Cannot afford co-pay or deductible
☐ Does not have insurance
☐ Other: ________________________________

I attest that my patient:

☐ Has a suspected or confirmed diagnosis of Duchenne or Becker muscular dystrophy
☐ Is an asymptomatic female of an affected relative with a known causative mutation

Please check one of the following regarding your patient’s current testing status:

☐ My patient has never had genetic testing but has suspected diagnosis of Duchenne or Becker muscular dystrophy and/or has had a positive creatine kinase (CK) test
☐ My patient has had negative del/dup testing and needs gene sequencing
☐ My patient has had positive del/dup testing in the past, but needs repeat analysis. The mutation found in the past was ________________________________.
☐ My patient is an asymptomatic female and needs carrier testing. A copy of the positive genetic report of the known family member with Duchenne or Becker muscular dystrophy must be included and how they are related to the patient.
☐ Other: ________________________________

Have you used Decode Duchenne in the past? ___ Yes, I previously used Decode

No. If no, how did you hear about the program?

☐ Another clinician at my hospital/clinic previously used Decode
☐ PPMD and/or The DuchenneConnect Registry
☐ Another advocacy organization
☐ Conference booth/networking
☐ Sarepta or PTC representative
☐ ChildMuscleWeakness.org
☐ Online search engine
☐ Direct mailing from PPMD/Decode Duchenne
☐ Email from PPMD/Decode Duchenne
☐ Other
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Do you need a lab kit?  Yes / No
If yes, how many?  _____ Blood (preferred);  _____ Saliva;  _____ DBS Card
(PerkinElmer lab kit(s) will be shipped to address below.)

Is this patient currently in clinic or coming into clinic today?  Yes / No
(If you circle Yes we will send the requisition today, assuming we receive application between 8-5 ET M-F.)

Signature of Healthcare Provider:  ____________________________________________
Name/Title:  ____________________________________________
Institution:  ____________________________________________
Street Address:  ____________________________________________
City, State, Zipcode:  ____________________________________________
Phone:  __________________________ Fax:  __________________________
Email (for communication):  __________________________

De-identified data from the Decode Duchenne program may be shared with industry sponsors, including Sarepta and PTC Therapeutics. This de-identified data may be used for diagnostic and therapeutic disease research, such as understanding the incidence of certain dystrophin gene mutations, evaluating and improving the diagnosis of Duchenne/Becker, and developing novel mutation-specific therapeutic strategies.