

Dear Parent/Patient,

Thank you for your interest in Decode Duchenne, a new and innovative genetic testing program of the DuchenneConnect Registry and Parent Project Muscular Dystrophy. We are excited to bring genetic testing to patients who have been unable to access genetic testing in the past due to financial barriers. Decode Duchenne is sponsored by Sarepta Therapeutics.

**Attached you will find two important forms:**

1. An Outline of the Steps involved for Genetic Testing through the Decode Duchenne program.
2. An Application Form for Genetic Testing that **MUST BE COMPLETED** by your or your child's doctor, nurse or genetic counselor.

**Please read these forms carefully and FOLLOW ALL STEPS in the outline.**

If you have any questions or concerns, please contact the DuchenneConnect Coordinator, Ann Martin, MS, CGC via email ([coordinator@duchenneconnect.org](mailto:coordinator@duchenneconnect.org)) or phone (201-937-1408), Monday - Friday 8am - 5pm EST.

Thank you again for your interest in Decode Duchenne.

Sincerely,

Ann Martin, MS, CGC  
Certified Genetic Counselor  
DuchenneConnect Coordinator

***To participate in Decode Duchenne, you must:***

- Have a confirmed or suspected diagnosis of Duchenne or Becker muscular dystrophy based on clinical symptoms, as assessed by your treating physician, and have a positive creatine kinase (CK) test.
- Not have had genetic testing previously, or must require additional genetic testing to identify a causative mutation.
- Be a citizen or legal resident of the United States.

***If you meet ALL of the above criteria, please follow these steps to participate in the Decode Duchenne Genetic Testing Program:***

1. **Register on DuchenneConnect** ([www.duchenneconnect.org](http://www.duchenneconnect.org)). If you/your child are already registered, please make sure your account is up-to-date.
2. Have your/your child's healthcare provider (doctor, nurse or genetic counselor) complete and sign the Decode Duchenne **Application Form for Genetic Testing**.
3. **Please email or fax the form** to the DuchenneConnect Coordinator (below).

***Once Steps 1, 2 and 3 are completed, the DuchenneConnect Coordinator will send you the Emory Genetics Laboratory requisition form and instructions for blood draw and shipment of the sample to Emory. \*All testing must be completed at Emory Genetics Laboratory for participation in Decode Duchenne.\****

4. Once you have received the Emory documents, please call your/your child's doctor's office to schedule a blood draw. **You must take the Emory documents with you to the blood draw.**
5. Emory will process the blood sample. This may take up to **six (6) weeks** depending on the type of analysis needed.
6. Emory will send the report to the healthcare provider listed on the requisition form and to the DuchenneConnect Coordinator.
7. **Your/your child's healthcare provider will contact you with the results.** If you have not been contacted with your results and six (6) weeks have passed since the blood draw, please call your doctor's office.
8. The DuchenneConnect Coordinator will attach the genetic test report to the your/your child's DuchenneConnect account.

**Questions?** Please contact the DuchenneConnect Coordinator, Ann Martin, MS, CGC via email ([coordinator@duchenneconnect.org](mailto:coordinator@duchenneconnect.org)) or phone (201-937-1408).

**Application Form for Genetic Testing**

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. If available, please attach a copy of the denial letter from the insurance company, Medicaid or Medicare which states denial of coverage or only partial coverage of genetic testing.

Please email the completed and signed form to [coordinator@duchenneconnect.org](mailto:coordinator@duchenneconnect.org) or fax to 404-935-0636. If you have questions, please call Ann Martin at 201-937-1408.

I attest that my patient, \_\_\_\_\_, DOB \_\_\_\_\_:

- A. Was denied coverage of genetic testing by his/her insurance company
- B. Was denied coverage of genetic testing by Medicaid/Medicare
- C. Does not have any health insurance

If you answered A or B above, what was the reason for denial: \_\_\_\_\_

**Please check one of the following regarding your patient:**

- My patient has never had any genetic testing but has had a positive creatine kinase (CK) test.
- My patient needs repeat deletion/duplication analysis because the del/dup testing done in the past did not analyze all 79 exons.
- My patient needs dystrophin gene sequencing because recent del/dup analysis (via MLPA or arrayCGH) was negative.
- Other: \_\_\_\_\_

**Signature of Healthcare Provider:** \_\_\_\_\_

**Clinical Title:** \_\_\_\_\_

**Print Name:** \_\_\_\_\_

**Institution:** \_\_\_\_\_

**Email:** \_\_\_\_\_

**Phone:** \_\_\_\_\_