DuchenneConnect

• Online self-report registry and resource for individuals with Duchenne or Becker, as well as carrier females
• Established by PPMD in 2007, in collaboration with the NIH, CDC and Emory Genetics
• 4,000+ registrants

DuchenneConnect.org
International Registry

DuchenneConnect continues to grow, now representing over 100 countries.
Goal of DuchenneConnect

To educate and connect the entire Duchenne and Becker community, including individuals with Duchenne and Becker, their families, healthcare providers and researchers.
What We Do

Education
Website, newsletters, email blasts, social media, webinars

Recruitment
In 2017, recruited for 8 clinical trials and 11 research studies

Genetic Testing
Decode Duchenne genetic testing program

Advance Research
In 2017, provided data to 9 institutions (5 industry)
Clinical Trials

Read our family-friendly FAQs on clinical trials.

Click here to register now!

Decode Duchenne

Free genetic testing, interpretation and counseling for individuals with Duchenne or Becker muscular dystrophy. Decode Duchenne is administered by DuchenneConnect and PPMD and is funded by Sarepta Therapeutics and PTC Therapeutics.

Find a Clinical Trial

Easily search our family-friendly summaries of clinical trials and research studies.

PCORnet

DuchenneConnect is a member of PCORnet, the National Patient-Centered Clinical Research Network, an innovative initiative of the Patient-Centered Outcomes Research Institute (PCORI).

Duchenne Deletion Tool

Use this educational tool to help you understand if your child may be a candidate for an exon skipping therapy. This tool is only for individuals with a deletion of one or more exons in the Duchenne gene.
Ann Test 1

**Medical Surveys**
- Bone/Orthopedic Module
- Breathing/Respiratory Module
- GI/GU Module
- Heart Module
- Behavior & Learning Module
- Pain Interference - Adults
- Insurance Module
- Clinical Trials & Registry Participation Module
- Genetic Testing & Family History Module
- Corticosteroid Module
- Diagnosis Module
- Muscle Function Module

**Testing Results**
- Genetic Results (1)
- Cardiac Testing Results (1)
- Clinical Notes or Records (1)

**Healthcare Providers**
- Brenda Wong - Neurology
- Linda Cripe - Cardiology

**Family Members**
- Ann Test 1
- John Martin
- Mark Martin

**Invitations**
- Invite Others
  Invite friends or extended family members with Duchenne or Becker to join.

**Growth Measurements**
- Height
  2014-06-16 - 170.00 centimeters
- Weight
  2014-06-16 - 61.00 kilograms
Partnerships with other networks:
TREAT-NMD

• Member of TREAT-NMD International Neuromuscular Registry
• 8 key data fields are shared with global registry to advance research
• Data shared is always de-identified
DuchenneConnect in PCORnet

20 Patient-Powered Research Networks (PPRNs) + 13 Clinical Data Research Networks (CDRNs) = PCORnet

A national infrastructure for people-centered clinical research
Duchenne Regulatory Science Consortium

Pooling data from registries, trials, natural history studies, other academic researchers to develop a disease progression model for Duchenne
Data Makes a Difference – Encourage Your Patients to Register!

www.duchenneconnect.org

coordinator@duchenneconnect.org

888-520-8675
Free genetic testing, interpretation, & counseling for people with Duchenne or Becker muscular dystrophy.
Criteria for Free Testing:

☑ Symptomatic/suspected diagnosis of Duchenne or Becker
☑ Any financial barrier
☑ Legal resident of US or Canada

Available for...

➢ First time testing, regardless of age
➢ Repeat testing for those who need it

All testing performed at:

EGL Genetics | Eurofins Clinical Diagnostics
Over 800 applications and over 600 patients tested through the Decode Duchenne program!