# Duchenne and Becker Muscular Dystrophy

## Web Resources

Web resources for financial and family support, and research.

<table>
<thead>
<tr>
<th>General</th>
<th>Muscular Dystrophy Association (MDA)</th>
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<td>mdausa.org</td>
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<td>Find information on conditions, education resources, and summer camp and equipment assistance. The MDA works to fight neuromuscular diseases through research, medical and support service programs, and professional and public education. Seattle Children’s is an MDA care center.</td>
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<tr>
<th>MDA Young Adult Programs</th>
<th>mda.org/young-adults</th>
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<tbody>
<tr>
<td></td>
<td>An informational web site for teens and young adults with neuromuscular disease. Find information on college, careers, employment, and personal care attendants (PCAs).</td>
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<th>Parent Project Muscular Dystrophy (PPMD)</th>
<th>parentprojectmd.org</th>
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<td>Find DMD care guidelines, educational webinars and conference presentations as well as therapy recommendations. This organization focuses on developing treatment options by funding research, improving care through education, connecting community members and impacting legislation. Seattle Children’s is a PPMD certified care center.</td>
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<th>Duchenne Connect</th>
<th>duchenneconnect.org</th>
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<td>Website and registry that brings together patients and families and connects them with research, clinical care and clinical trials.</td>
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<th>Cure Duchenne</th>
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<td>Organization raises awareness and funds to find a cure for Duchenne muscular dystrophy. This website contains information and videos on various care topics for DMD.</td>
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**To Learn More**

- Rehabilitation Medicine
  206-987-2114
- Occupational & Physical Therapy
  206-987-2113
- Ask your child’s healthcare provider
- seattlechildrens.org

**Free Interpreter Services**

- In the hospital, ask your nurse.
- From outside the hospital, call the toll-free Family Interpreting Line, 1-866-583-1527. Tell the interpreter the name or extension you need.
Duchenne and Becker Muscular Dystrophy Web Resources

Research

clinicaltrials.gov
Find out about research projects that are available in the United States.

Parent Project Muscular Dystrophy
Parentprojectmd.org/research, go to Explore at the bottom of the page and click on Clinical Trials
This page contains a table of research trials that are currently enrolling new patients. Each trial has a question and answer page with information for parents and families.

Seattle Children’s Neuromuscular Research
www.seattlechildrens.org/research
Click on the link “Participate in Research” to find out more information about research projects happening at Seattle Children’s or contact our research coordinators directly at muscleresearch@seattlechildrens.org.

Financial Support

Social Security Administration
ssa.gov
800-772-1213
Supplemental Security Income provides benefits to children with ongoing medical conditions and limited income and resources.

United Healthcare Children’s Foundation
uhccf.org
Provides grants for medical services not covered by commercial insurance health plans.

Parent and Caregiver Support

Family to Family Health Information Center (F2F HIC)
familyvoicesofwashington.com
F2F HIC provides help and information on finding health insurance for your child, Medicaid issues and how to pay for medical bills.

Medicaid Personal Care, Developmental Disabilities Administration
dshs.wa.gov/ddd/services.shtml
360-725-3413
Provides caregiver support at home for those with Medicaid and who meet the criteria.

Parent Training and Information (PTI)
wapave.org
Helps parents understand and advocate for their child in the special education system including how to take part in the IEP team, understanding your child’s rights and finding resources.
### Medical Equipment

**Durable Medical Equipment (DME) Guide**  
cureduchenne.org/durable-medical-equipment-guide  
Helps parents understand the different types of medical equipment that may be available for your child. The site has links to manufacturer’s websites for more specific information on models or brands.

### Employment and Vocational Resources

**Division of Vocational Rehabilitation**  
dshs.wa.gov/DVR  
800-637-5627  
Helps people with disabilities participate in their communities and become employed.

**University of Washington DO-IT program**  
washington.edu/doit  
Empowers youth with disabilities through technology and education. The Do-IT Scholars program prepares high school students with disabilities for success in college. Students who wish to participate should apply in January of their sophomore year.

### Recreation and Travel

**Outdoors for All**  
outdoorsforall.org  
Volunteer organization that promotes recreation for persons of all abilities. Programs include a “Learn to Ride a Bike”, adapted bicycle rentals, winter sports and other activities.

**Seattle Adaptive Sports**  
seattleadaptivesports.org/home  
This organization promotes various sport activities in wheelchairs. Programs include a power wheelchair soccer team.

**City or Neighborhood Parks and Recreation**  
seattle.gov/parks/find (Seattle)  
metroparkstacoma.org (Tacoma)  
Your local parks and recreation department may offer many recreational opportunities including swimming, sports and social events.

**CurbFree with Cory Lee Travel Blog**  
curbfreewithcorylee.com  
Cory shares his experiences with world travel in his wheelchair and provides useful travel trips.
WheelchairTravel.org
Wheelchairtravel.org
An accessible travel blog detailing people’s experiences traveling throughout the world in a wheelchair. Also includes resources and information for accessible traveling.