Duchenne and Becker Muscular Dystrophy Web Resources

**General**

**Muscular Dystrophy Association (MDA)**  
www.mdausa.org  
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.

**MDA Transitions Center**  
transitions.mda.org  
An informational web site for teens and young adults with neuromuscular disease. Find information on college, careers, employment, and mobile apps and accessories. This web site encourages participation by young teens and adults through blogs and a collaborative-wiki.

**Parent Project Muscular Dystrophy (PPMD)**  
www.parentprojectmd.org  
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.

**Duchenne Connect**  
www.duchenneconnect.org  
Website and registry that brings together patients and families and connects them with research, clinical care and clinical trials.

**Cure Duchenne**  
www.cureduchenne.org  
Organization raises awareness and funds to find a cure for Duchenne muscular dystrophy. Find videos on therapy topics through their partner Duchenne Therapy Network.

**Duchenne Therapy Network**  
www.duchennetherapynetwork.com
Research
clinicaltrials.gov
Find out about research projects that are available in the United States.

Seattle Children’s Neuromuscular Research
www.seattlechildrens.org/research
muscleresearch@seattlechildrens.org
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.

Financial Support
Social Security Administration
www.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
www.uhccf.org
Provides grants for medical services not covered by commercial insurance health plans.

Parent and Caregiver Support
Center for Children with Special Needs
www.cshcn.org
Provides information and resources on caring for a child with special needs including organizing medical records, finding support and school resources.

Family to Family Health Information Center (F2FHIC)
www.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
www.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)
www.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.
To Learn More

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

Employment and Vocational Resources

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

University of Washington DO-IT program
www.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

Outdoors for All
www.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
www.seattleadapitivesports.org/home
This organization promotes various sport activities in wheelchairs. Programs include a power wheelchair soccer team.

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