

Duchenne and Becker Muscular Dystrophy Web Resources

Web resources for financial and family support, and research.

General

Muscular Dystrophy Association (MDA)

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 Young Adult Programs

mda.org/young-adults

An informational web site for teens and young adults with neuromuscular disease. Find information on college, careers, employment, and personal care attendants (PCAs).

Parent Project Muscular Dystrophy (PPMD)

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

duchenneconnect.org

Website and registry that brings together patients and families and connects them with research, clinical care and clinical trials.

Cure Duchenne

cureduchenne.org

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.

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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.



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 (F2FHIC)

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.