**Muscular Dystrophy**

Muscular dystrophy literally means the wasting away or atrophy of muscles.

The muscular dystrophies (MD) refer to the group of genetic diseases characterized by progressive weakness and degeneration of the skeletal muscles that control movement. There are many forms of muscular dystrophy, some noticeable at birth known as congenital muscular dystrophy while other forms develop in adolescence (BECKER MD). Regardless of the exact timing of onset, some muscular dystrophies lead to mobility impairment or even paralysis.

The three most common types of MD are: Duchenne, facioscapulohumeral, and myotonic. These three types differ in terms of pattern of inheritance, age of onset, rate of progression, and distribution of weakness.

**Duchenne MD**

Duchenne MD primarily affects boys and is the result of mutations in the gene that regulates dystrophin – a protein involved in maintaining the integrity of muscle fiber. Onset is between 3-5 years and progresses rapidly. Most boys become unable to walk at 12, and by 20 have to use a respirator to breathe.

**Facioscapulohumeral MD**

Facioscapulohumeral MD appears in adolescence and causes progressive weakness in facial muscles and certain muscles in the arms and legs. It progresses slowly and can vary in symptoms from mild to disabling.

**Myotonic MD**

Myotonic MD varies in the age of onset and is characterized by myotonia (prolonged muscle spasm) in the fingers and facial muscles: a floppy-footed, high-stepping gait; cataracts; cardiac abnormalities; and endocrine disturbances. Individuals with myotonic MD have long faces and drooping eyelids; men have frontal baldness.
Is there any treatment?

There is no specific treatment for any of the various forms of MD. Physical therapy is often practiced to prevent painful muscle contractures. And / or certain prescribed drugs may be used for pain management as well as for arresting muscular deterioration within some forms of MD. Orthopedic appliances are used for support while corrective orthopedic surgery may be required to improve the quality of life for others. In some cases, respiratory therapy may be needed, as noted before. Finally, cardiac abnormalities may require a pacemaker.

Sources:

National Institute of Neurological Disorders and Stroke, National Institutes of Health

Websites

http://www.mdausa.org/
Muscular Dystrophy Association
National Headquarters
222 S. Riverside Plaza, Suite 1500
Chicago, IL 60606
Phone: 800-572-1717
MDA is dedicated to curing muscular dystrophy, ALS and related diseases by funding worldwide research. The Association also provides comprehensive medical and support services, and professional and public health education. MDA has more than 200 offices across the U.S., sponsors some 200 hospital-affiliated clinics, and supports more than 330 research projects around the world.

www.cdc.gov/ncbddd/duchenne
Centers for Disease Control: Muscular Dystrophy
The CDC sponsors MD STARnet, the Muscular Dystrophy Surveillance Tracking and Research Network, a program set up in several states to identify all individuals who have Duchenne/Becker Muscular Dystrophy.

http://www.cureduchenne.org/
CureDuchenne
1400 Quail Street, Suite 110
Newport Beach, CA 92660
Phone: 949-872-2552
Email: info@cureducheene.org
CureDuchenne’s goal is to identify research with the most likelihood of making it to clinical trials and then provide the financial bridge that will take it from the lab and into human trials.
Duchenne Connect
This site provides news and a registry for Duchenne MD.

Find-a-Cure for Children with Duchenne, Inc.
E-mail: findacure@comcast.net
Find-a-Cure funds research to find a cure for Duchenne muscular dystrophy.

Hereditary Neuropathy Foundation (HNF)
432 Park Avenue South, 4th Floor
New York, NY 10016
Phone: 212-722-8396 or 855-435-7268 (Toll free)
E-mail: info@hnf-cure.org
HNF is a non-profit organization which raises awareness, funds scientific research, and educates the medical community as well as the general public about Charcot-Marie-Tooth disease (CMT).

KidsHealth: The Meaning of Muscular Dystrophy
This page has information on muscular dystrophy written for children.

Medline Plus: Muscular Dystrophy
This page has information on muscular dystrophy including diagnosis, treatment, and coping.

Medline Plus: Spinal Muscular Atrophy
This page has information on muscular dystrophy including diagnosis and symptoms.

Muscular Dystrophy Family Fund
PO Box 776
Carmel, IN 46082
Phone: 317-615-9140
MDFF exists to provide resources, services, and adaptive equipment to enable patients with muscular dystrophy and their family members to live independent and productive lives.

National Institute of Neurological Disorders and Stroke (NINDS): Muscular Dystrophy Information Page
This page has information on muscular dystrophy including treatment, prognosis, research, and links to other resources.
Parent Project Muscular Dystrophy (PPMD)
401 Hackensack Avenue, 9th Floor
Hackensack, NJ 07601
Phone: 201-250-8440, 800-714-5437 (Toll-free)
Email: info@parentprojectmd.org
PPMD is the largest nonprofit organization in the U.S. focused entirely on Duchenne. The organization takes a comprehensive approach by funding research, raising awareness, promoting advocacy, connecting the community, and broadening treatment options.

Respiratory Physician List for Muscular Dystrophy Patients
This page lists physicians with an interest in the respiratory care of patients with muscular dystrophy and neuromuscular weakness. Physicians are listed by state and country. The page was last updated on July 12, 2005.

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LENDING LIBRARY

The following books and videos are available for free loan from the PRC library. For more information, please visit the online catalog at:
http://www1.youseemore.com/ReevePRC/default.asp

Books


• Bobatoon, Star. I Hate Muscular Dystrophy: Loving a Child with a Life-Altering Disease. www.Blackcurrantpress.com, 2011. Bobatoon’s son Hurricane or “Cane” was diagnosed with DMD.


• Degnan, Cyndie. His Strength Made Perfect: Michael’s Story. Bloomington, Ind.: Crossbooks, 2012. Degnan’s son Michael was diagnosed with DMD at the age of four.


• Gerhardt, Mo. Perspective from an Electric Chair. Bloomington, Ind.: AuthorHouse, 2011.
Biography of Gerhardt who has Duchenne Muscular Dystrophy.


The author married a woman who had 3 sons with MD who lived until their twenties.

- Thomas, Gloria. **With a Little Help From His Friends.** UK: The Michael Thomas Book Fund, 1999. A mother’s biography of her son, Michael Thomas, who had Duchenne MD.


- Winheld, Josh. **Worth the Ride: My Journey with Duchenne Muscular Dystrophy.** Little Treasure Books, 2008. Winheld was 29 when he wrote his autobiography. He earned a degree from Temple University.


### Fiction


- Olson, John B. **Adrenaline.** Minneapolis, MN: Bethany House, 2003. James Parker has MD and is trying to find a cure. Desperation takes him beyond the limits of medical ethics.

### Children’s Books
• Abramovitz, Melissa. **Muscular Dystrophy (Diseases & Disorders)**. Detroit, MI: Lucent Books/Gale, 2008.

• Brady, Bill and Laurie. **A Charm for Jo**. Hollidaysburg, PA: Jason and Nordic Publishers, 2005. Juvenile fiction about a young girl who goes to a new school and adjusts to it as her classmates adjust to her MD.


• Siegel, Irwin M. **Hey! I’m Here, Too!** Tucson, AZ: Muscular Dystrophy Association, 1989. Written for siblings of boys with Duchenne Muscular Dystrophy.

**Videos**


• **Beyond the Chair: The Story of One Man’s Extraordinary Journey**. Intention Media, 2011. DVD (91 minutes) Andrew Shelley leads a successful life as an engineer and bachelor. He has muscular dystrophy and is a wheelchair user. He decides to take a trip around the world despite the challenges his MD will cause.
• **Giving a Face to Duchenne Muscular Dystrophy: Understanding the Disease Guidelines for Care and Management.** Parent Project Muscular Dystrophy, 2003. Two disc DVD.

• **Living and Dying with Muscular Dystrophy.** Princeton, NJ: Films for the Humanities and Sciences, 2007. DVD
  ABC News Nightline program on a young man with Duchenne muscular dystrophy. Paralleling the celebrated documentary Darius Goes West, the program describes a cross-country adventure undertaken by this wheelchair user and his friends.

• **Muscular Dystrophy…The Doctor Is In.** Princeton, NJ: Films for the Humanities and Sciences, 1990.

• **Rory O'Shea Was Here.** Universal. 2005 (105 minutes)
  Drama. The two lead characters are wheelchair users (one with CP and the other with Duchenne muscular dystrophy). They live together with the help of an aide.

• **Soop On Wheels.** New York: Filmakers Library, 1998. (52 minutes)
  Documentary on Everett Soop, a Blackfoot, living on the Blood Indian Reserve in southern Alberta.

• **White Cane and Wheels.** University of Southern California, 2004. Distributed by Fanlight Productions. (26 minutes) DVD
  Steve and Carmen are an independent couple. Steve has muscular dystrophy and Carmen is blind.

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