



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

Muscular Dystrophy Association

<http://www.mdausa.org/>

Muscular Dystrophy Family Foundation

<http://www.mdff.org/>

Medline Plus: Muscular Dystrophy

<http://www.nlm.nih.gov/medlineplus/muscular dystrophy.html>

Medline Plus: Spinal Muscular Atrophy

<http://www.nlm.nih.gov/medlineplus/spinalmuscularatrophy.html>

NINDS Muscular Dystrophy Information Page

http://www.ninds.nih.gov/health_and_medical/disorders/md.htm

Disaboom: Muscular Dystrophy

<http://www.disaboom.com/muscular-dystrophy>

Parent Project: Muscular Dystrophy—Leading the Duchenne Muscular Dystrophy Community

www.parentprojectmd.org

Cure Duchenne

<http://www.cureduchenne.org/>

Duchenne Connect

<https://www.duchenneconnect.org/>

Provides news and a registry for Duchenne MD.

Find a Cure for Children with Duchenne, Inc.

<http://www.findacure.com/>

Respiratory Physician List for Muscular Dystrophy Patients

<http://www.pitt.edu/~finder/respdocMD.html>

Kids Health: The Meaning of Muscular Dystrophy

http://kidshealth.org/kid/health_problems/bone/muscular_dystrophy.html

Hereditary Neuropathy Foundation: Fighting to Cure Charcot-Marie Tooth

<http://www.hnf-cure.org/>

Chat Rooms

Yahoo's Duchenne Muscular Dystrophy

http://health.groups.yahoo.com/group/Duchenne_Muscular_Dystrophy/

Yahoo's Muscular Dystrophy Discussion Groups

http://health.dir.groups.yahoo.com/dir/Health_Wellness/Support/Diseases_and_Conditions/Muscular_Dystrophy?show_groups=1

The following books and videos are available for free loan from the PRC library. For more information, please see www.paralysis.org and click the Lending Library tab.

Books

- Bayle, Susan. **Our Man Sam**. Scottville, MI: Susan Bayle, 1998.
- Banks, Denedria Renee. **Melodies of My Life: A Disabled Girl's Journey to Womanhood**. New York: iUniverse, 2005. Charcot-Marie-Tooth biography.
- Bergman, Thomas. **Precious Time: Children Living With Muscular Dystrophy**. Milwaukee, WI: Gareth Stevens Publishing, 1996.
- Cohen, Richard M. **Strong at the Broken Places: Voices of Illness, a Chorus of Hope**. New York: HarperCollins, 2008.
One chapter is about a man with Duchenne MD.
- Cohen, Terry Scott and Barry M. Cohen. **Disabled & Challenged: Reach for Your Dreams!** Clearwater, Fla.: WishingUwell Publishing, 2005.
- Daly, Ida with Hazel Flagler Begeman. **Adventure in a Wheelchair**. Philadelphia: Whitmore Publishing Co., 1973. Biography

- Davidson, John. **Jesse's Journey: A Canadian Story**. Surrey, B.C. Canada: Timberholme Books Ltd, 2001.
- Duncan, Sorcha. **Behind the Cane**. Richmond, Va.: Dragon Rider Press, 2006. Poetry. Duncan has MD and the proceeds go to Muscular Dystrophy Association.
- Eldredge, Patricia A. **His Cup Runneth Over**. San Jose, Calif.: Writer's Showcase, 2002.
- Eveloff, Scott E. **Both Sides of the White Coat**. New York, NY: People With Disabilities Press, 2000.
- Fox, Geoffrey J. **Tomorrow's Never Today**. Baltimore: PublishAmerica, 2004. Poetry from an author with MD.
- Franks, Hugh. **Will to Live**. Boston, MA: Routledge & Kegan Paul Ltd., 1979. Biography.
- Green, Maurus. **The Vanishing Root: Eddie McCaffrey's Story**. London: New City, 1994.
- Haskins, Joan Horsley. **A Boy With Magic**. Author, 2004. jjhaskins33@msn.com
Fictional account of a young boy with muscular dystrophy who gets a service dog named Magic.
- Hartocollis, Anemona. **Seven Days of Possibilities: One Teacher, 24 Kids, and the Music That Changed Their Lives Forever**. New York: Public Affairs, 2004. A biography about Johanna Grussner, a Bronx music teacher who has muscular dystrophy. She is a Finnish native who takes her class to visit her native country.
- Johnson, Harriet McBryde. **Too Late to Die Young: Nearly True Tales from a Life**. New York, NY: Henry Holt and Company, LLC, 2005.
- Likens, Arthur Dale. **Our Mansion on Anglin' Road**. Mustang, Okla.: Tate Publishing, 2007.
Carl's oldest brother has muscular dystrophy and is a wheelchair user. Fiction.
- Long, Ed. **India, Wheelchair Journey**. San Diego: Ed Long Publications, 1995. Long's account of his travel through India as a wheelchair user.
- Mills, A.J. **The Will to Live: The Battle of a Young Boy Against Muscular Dystrophy**. Alexandria, Va.: Humor Books.
- Misheck, Barb. **A Wing and a Prayer: An Artist's Journey with Muscular Dystrophy**. Baltimore: PublishAmerica, 2007.

- Muscular Dystrophy Association. **Journey of Love: A Parent's Guide to Duchenne Muscular Dystrophy**. Tucson, AZ: MDA, 1998.
- **Muscular Dystrophy Sourcebook**. Joyce Brennfleck Shannon, editor. Detroit, MI: Omnigraphics, 2004.
- **Occupational Therapy and Duchenne Muscular Dystrophy**. Kate Stone, et al. editors. New York: John Wiley & Sons, 2007.
- **The Official Patient's Sourcebook on Muscular Dystrophy**. San Diego, CA: Icon Healthcare, 2002.
http://www.icongrouponline.com/health/Muscular_Dystrophy.html
- O'Hagan, Christine Kehl. **The Book of Kehls**. New York: St. Martin's Press, 2005.
A five-generation family history of Duchenne muscular dystrophy.
- Petty, Jerry. **I Know He Cares For Me: Battling with Muscular Dystrophy and Trusting God**. Charlotte, N.C.: Chosen Word Publishing, 2005.
- Pratt, Bryan. **Look Beyond This Cover: The Bryan Pratt Autobiography**. Nashville, TN: Columbia Publications, 2000.
- Siegel, Irwin M. **Muscular Dystrophy in Children: A Guide for Families**. New York, NY: Demos Medical Publishing, 1999.
- Smith, Greg. **On A Roll: Reflections From America's Wheelchair Dude With The Winning Attitude**. Ocean Springs, MS: On A Roll Communications, 2005.
- Stagg, Patricia. **Sunshine on My Shoulder: A Loving Unforeseen Spiritual Journey**. Enumclaw, Wash.: Pleasant Word, 2003. A biography of her son Tim who has Charcot-Marie-Tooth disease.
- Stepanek, Jeni. **Messenger: The Legacy of Mattie J.T. Stepanek and Heartsongs**. New York: Dutton, 2009. A biography of her late son, Mattie, by a mother who also has MD.
- Stepanek, Mattie J.T. **Celebrate Through Heartsongs**. New York, NY: Hyperion, 2002.
- Stepanek, Mattie J.T. **Heartsongs**. New York, NY: Hyperion, 2001, 2002.
- Stepanek, Mattie J.T. **Hope Through Heartsongs**. New York, NY: Hyperion, 2002.

- Stepanek, Mattie J.T. with Jimmy Carter. **Just Peace: A Message of Hope.** Kansas City: Andrews McMeel Publishing, 2006.
- Stepanek, Mattie J.T. **Loving Through Heartsongs.** New York, NY: Hyperion, 2003.
- Stepanek, Mattie J.T. **Reflections of a Peacemaker: A Portrait Through Heartsongs.** New York, NY: Hyperion, 2002.
- Terpstra, John. **The Boys: Or, Waiting for the Electrician's Daughter.** Kentville, Nova Scotia: Gasperau Printers, 2005. 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 biography of Michael Thomas who had Duchenne MD by his mother.
- Weisman, Mary-Lou. **Intensive Care: A Family Love Story.** Lincoln, Neb.: Authors Guild BackinPrint, 2000.
- Wilfong, Rachel. **Rise Up & Walk! A Journey to Healing.** Enumclaw, WA: Winepress Publishing, 1999. Wilfong was healed of MD after 15 years in a wheelchair and attributes it to her faith.
- Wolfson, Penny. **Moonrise.** New York, NY: St. Martin's Press, 2003. Biography.

Fiction

- Knowles, Anne. **Under the Shadow.** Cambridge: Harper & Row Publishers, 1983. Fifteen-year old Cathy helps her friend Mark, who has muscular dystrophy, find a sense of freedom when she gets a horse for him to ride.
- 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: Lucent Books/Gale, 2008.

- Brady, Bill and Laurie. **A Charm for Jo**. Hollidaysburg, Penn.: 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.
- Briggs-Bunting, Jane. **Llama on the Lam**. Oxford, MI: Black River Trading Co., 2001.
Fiction.
- Burnett, Gail Lemley. **Muscular Dystrophy**. Berkeley Heights, NJ: Enslow Publishers, 2000. Revised ed. Health Watch series for children.
- Foland, Constance M. **A Song for Jeffrey**. Middleton, WI: Pleasant Company Publications, 1999.
Fiction for preteen girls.
- Farrell, Mame. **Marrying Malcolm Murgatroyd**. Farrar Straus Giroux, 1998.
Fiction
- Osofsky, Audrey. **My Buddy**. New York, NY: Henry Hold and Company, 1992.
A boy and his service dog.

Videos

- **Bearing Witness : Luke Melchior**. Boston, MA: Fanlight Productions, 2003. 51 minutes. Documentary
- **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 & 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 & Sciences, 1990.
- **Rory O'Shea Was Here**. Universal. 2005 105 min. The two lead characters are wheelchair users (one with CP and the other has Duchenne muscular dystrophy). They live together with the help of an aide. Drama

- **Soop On Wheels.** New York, NY: Filmmakers 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)
Steve and Carmen are an independent couple. Steve has muscular dystrophy and Carmen is blind.

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