



For Strength,
Independence & Life



Programs and
Services to Help
You and Your
Family

Muscular Dystrophy Association
mda.org



“When I was diagnosed with muscular dystrophy, we didn’t know where to turn. But the Muscular Dystrophy Association was really there for me and my family. They walked us through what the disease was, what we could expect, how we should work together as a team to tackle this disease and make sure that it didn’t impair me from achieving my dreams.”

Vance, limb-girdle muscular dystrophy

MDA Programs and Services

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When I was diagnosed with spinal muscular atrophy at 15 months old, my parents had to face the hard truth that my life was going to be different, we were going to face many challenges, and we would need help. Thankfully, we were able to turn to MDA for support.

Our local MDA representative shared with us the many resources MDA provides for people with neuromuscular diseases, including their comprehensive Care Centers, summer camps for kids and cutting-edge medical research. Little did I know that this support would truly change my life.

At my MDA Care Center in Colorado, the team of physicians, therapists and nurses work tirelessly to maintain every aspect of my care and health. I've gained an amazing network of mentors and advocates there who I now consider family. Likewise, attending MDA Summer Camp had a tremendous impact in shaping the adult I am today. It was here I learned I could be an independent, career-driven adult able to live life my way, unrestricted by the limitations others place on me.

In this booklet, you'll find detailed information about all the services MDA offers and how you can connect with your local MDA team and find out about accessing critical resources and support. MDA has been the backbone to my life in so many ways. I hope you'll let them be there for you too as we live our lives to the fullest.

Joe Akmakjian
MDA National Goodwill Ambassador

The Muscular Dystrophy Association is Here to Help

MDA is leading the fight to free individuals – and the families who love them – from the harm of muscular dystrophy, ALS and related neuromuscular diseases that take away physical strength, independence and life. Together with our supporters, we’re helping kids and adults live longer and grow stronger. Here’s how we do this:



Finding research breakthroughs across diseases

MDA takes a big-picture perspective across neuromuscular diseases to uncover breakthroughs that will accelerate treatments and cures. The power in this research approach is that knowledge and information from one disease often can yield progress in others to speed urgently needed answers for families.



Caring for kids and adults from day one

MDA provides early diagnosis, highly specialized care and access to promising clinical trials at MDA Care Centers in top hospitals and health care facilities across the United States and Puerto Rico.



Empowering families with services and support

From support groups and educational seminars to assistance with durable medical equipment and giving kids with muscular dystrophy the best week of the year at MDA Summer Camp, MDA empowers families in hometowns across America with help and support they need today.

MDA is the gateway to information, resources and specialized health care for individuals and families living with neuromuscular diseases. At local offices around the country, MDA's compassionate and knowledgeable staff provides support and guidance.

This booklet provides basic information about MDA services and programs. For information specific to you, contact your local MDA representative or the MDA Resource Center at **800-572-1717** or **ResourceCenter@mdausa.org**.

Turn to MDA with questions about:

- Specialized health care and referrals
- Research advances impacting your disease
- Equipment assistance
- Explaining your disease to family members and others
- Connecting with individuals in your area who have a similar diagnosis
- Informational brochures and publications
- Outreach activities including support groups, educational seminars and family gatherings
- Support and resources for caregivers
- Educating you and your family during flu season
- Presentations to your child's school
- Information on community-based resources
- MDA's efforts to advocate for public policies and research advancements that impact individuals with neuromuscular diseases
- How you can get involved to make a difference in your local community

Accessing MDA services

After contacting your local MDA office, the next step to access MDA services is to attend an MDA Care Center to confirm your diagnosis of one of the neuromuscular diseases covered by MDA (see page 29 for a complete list).

If the disease diagnosed is not covered by MDA, referrals will be made to an appropriate health or community agency.



“To us, MDA means inspiration and encouragement. On the days when spinal muscular atrophy has us feeling down, MDA motivates us to keep fighting for progress toward a cure. They uplift us by providing support not only to our daughter but to our whole family.”

Kara, mother of a child with spinal muscular atrophy

Caring for you from day one

Your MDA team

MDA local offices are your headquarters for access to specialized health care at MDA Care Centers, as well as for local support groups, MDA Summer Camp, resource referrals and more. Staff at your local MDA office can provide information, support and guidance.

In fact, MDA is just a phone call away when you have non-medical questions about living with a neuromuscular disease. Medical questions should be directed to the MDA Care Center team, and MDA staff can provide that contact information if needed.

In most areas, your primary contact at MDA will be the Family Care Specialist (FCS), who can connect you with all appropriate MDA services and provide information about federal, state and local resources that may be helpful.

The MDA Care Center

MDA is here to help connect families with information, resources and access to top health professionals skilled in the diagnosis and medical management of neuromuscular conditions.

MDA provides care for kids and adults from day one at our nationwide network of MDA Care Centers. These state-of-the-art Care Centers, located at top hospitals and medical institutions, bring health care specialists from a variety of disciplines together so families receive the care they need at one time, in one place. MDA Care Centers receive tens of thousands of visits each year while also serving at the forefront of research and treatment by hosting clinical trials for the latest promising therapies.

Local MDA staff can direct you to the closest MDA Care Center, or you can find a local MDA

Care Center online by going to mda.org and entering your location in the “Find MDA in Your Community” box. You also can call the MDA Resource Center at **800-572-1717** or email ResourceCenter@mdausa.org.

MDA also funds MDA ALS Care Centers across the country. These locations feature medical teams with particular expertise in the disease and often serve as the site of ALS-focused research and clinical trials.

The Care Center team

MDA Care Centers utilize a multidisciplinary team approach, meaning individuals can see knowledgeable health care specialists from a variety of disciplines, all at one location. A grant from MDA to the institution helps support this multidisciplinary team approach to care.

The core team of specialists at every Care Center comprises: a physician (neurologist or psychiatrist), social worker, physical therapist and Care Center coordinator (nurse, nurse practitioner, genetic counselor or other provider). Additional specialists are required to attend sessions or be available for consultation. These include: cardiologists, dietitians, endocrinologists, occupational therapists, orthopedists, pulmonologists and speech-language pathologists.

The institution will bill your insurance for the visit. If you do not have insurance, the social worker at the MDA Care Center will let you know about financial assistance programs available at the institution and help connect you with local resources.

Your MDA specialist is a central figure in the Care Center program. He or she is available to answer questions, provide MDA educational materials, coordinate any MDA services you may require and assist with community resource referrals.



“Getting our daughter’s diagnosis when she was 2 years old was scary, shocking and isolating. Right off the bat, we knew MDA was on our team and would be there to support us.

MDA was one of the first things our neurologist and genetic counselor mentioned to us. To have an organization there to provide a community and be a resource for us was, and continues to be, a huge asset for our entire family.”

Becky, mother of a child who has congenital muscular dystrophy



Disease identification

The first step in medical care is determining the nature of the disease. The MDA Care Center team can perform diagnostic examinations and recommend pertinent laboratory tests.

Some of these tests may be extensive, but in most instances they can be done on an outpatient basis. Information about genetic-based diagnostic testing is available at the MDA Care Center.

Following clinical examination and analysis of the laboratory tests, many neuromuscular diseases can be quickly and accurately identified. Some neuromuscular conditions, however, can be more difficult to diagnose. In these cases, the physician will make what is called a “differential diagnosis,” listing two or more diseases that have similar symptoms.

A definitive diagnosis may require waiting until the disease has progressed to a stage that is unique to that disease.

With the majority of neuromuscular diseases, the first noticeable symptom is usually a persistent weakness in one or more muscles.

Muscles can become weak for many reasons. The first question the physician will seek to answer in trying to establish a diagnosis is

whether muscle function is abnormal because there is a disease of muscle itself, or whether muscle function is abnormal because of a disorder that has developed in other tissue (e.g., nerve). The following three pages describe the most common diagnostic and laboratory procedures used to determine why muscle function is abnormal and arrive at a definitive diagnosis.

Tests used to determine diagnosis

Neuromuscular diseases can present in a variety of ways and at different ages. Prior to receiving a confirmed diagnosis, you'll likely undergo an array of tests to ensure that as much information as possible is obtained and other diseases are ruled out. Many treatment options are dependent upon obtaining a specific diagnosis.

Among the various types of diagnostic tools your medical team may use are the following:

Clinical examination

The clinical examination of someone suspected of having a neuromuscular disease focuses on muscle appearance and strength. Muscles are examined with special attention given to those of the arms, legs, shoulders and hips. A few neuromuscular diseases affect facial muscles, and these too are examined.

Determining which muscles are not weak is as important as determining which muscles are weak. Each neuromuscular disease typically shows a specific pattern of muscle involvement. A final diagnosis is based in large part on the pattern of muscle involvement detected during the clinical examination.

Family history

Many neuromuscular diseases are genetic in origin. Knowledge of other affected family members can help to establish and/or confirm a diagnosis. However, it's possible to have a genetic disease even without a family history of that disease.

Nerve conduction studies and electromyogram

These two tests often are performed at the same evaluation. The nerve conduction studies measure the ability of nerves to conduct impulses to muscle; this is an important test when evaluating for disorders such as Charcot-Marie-Tooth disease. An electromyogram (EMG) measures electrical activity of muscle. Muscle of someone with a neuromuscular disease may have an electrical activity characteristically different from that of normal muscle.

Serum enzyme tests

Serum enzyme tests measure the amount of muscle proteins present in the blood. When muscle tissue is healthy, these enzymes, particularly creatine kinase (CK), remain in muscle and the amount present in blood is relatively low.

Many, but not all, neuromuscular diseases that cause muscle damage lead to a significant increase in the muscle CK and other enzyme levels found in the blood. Thus, serum enzyme tests can be important aids in the diagnosis of neuromuscular diseases.

The value of these tests is often greatest at the early stages of the disease. At the earliest disease stage, muscle mass is relatively great and changes in serum enzyme levels may occur even before symptoms such as weakness become apparent. In some neuromuscular diseases, muscle enzyme levels fluctuate with disease activity.

At later disease stages, however, muscle mass may be so reduced that serum enzyme levels may even appear normal.

Genetic tests

A small amount of blood can be used to extract DNA from blood cells. This is extremely valuable for detecting genetic mutations that can cause specific neuromuscular diseases. A confirmed genetic diagnosis is often needed to be eligible to participate in a clinical trial and to determine whether a person can benefit from a treatment (such as Exondys 51 for Duchenne muscular dystrophy) that targets a specific genetic mutation.

Muscle biopsy

In this procedure, muscle tissue is surgically removed for microscopic and/or biochemical analysis. For some neuromuscular diseases, a final diagnosis depends on the analysis of a muscle biopsy. The amount of muscle removed is roughly equivalent in size to the tip of a little finger. In some conditions, such as the inflammatory myopathies and central core disease, the muscle tissue has a characteristic appearance under the microscope. Muscle tissue can be analyzed for abnormalities in a number of proteins within muscle cells.

Managing neuromuscular disease

Upon diagnosis, the MDA Care Center team may recommend a number of measures to medically manage neuromuscular disorders.

Periodic re-evaluations

Follow-up visits are provided at MDA Care Centers. Ongoing medical management can include therapies and measures for controlling symptoms, and medical interventions to assist individuals in maintaining the highest possible quality of life.

Therapy

An MDA Care Center physician may recommend that you consult with a physical, occupational, respiratory and/or speech therapist to assist you in managing symptoms of your neuromuscular disease and to maintain independence.

Physical therapy:

Physical therapy can keep still-healthy muscles functioning, help you maintain independence and prevent the onset of painful muscle contractures.

Occupational therapy: Occupational therapy enables people to make maximum use of their physical capabilities through the use of strategies and techniques, specially designed implements and daily living aids in the home and work environments.

Respiratory therapy: Respiratory therapy provides instruction in the use of prescribed respiratory equipment designed to augment or increase vital lung capacity.

Speech therapy: At a speech therapy consultation, the muscles responsible for speech and swallowing are evaluated. Through such an evaluation, a speech-language pathologist can determine if exercise, use of an augmentative communication device and/or modifications to meals are appropriate.



Social services

Social services are a vital aspect of the MDA Care Center program. MDA local offices and Care Centers may provide additional resources for families seeking to identify alternate sources of payment for medical services and equipment needs.

Social workers also may assist with connecting you to other community resources and providing emotional support for you and your family.

Genetic counseling

Genetic counselors can assist families by:

- obtaining and interpreting a genetic (DNA) or other appropriate test;
- obtaining a diagnosis for a genetic condition;
- determining whether parents of an affected child are carriers of the disorder;
- assessing the risk of passing on the disease to future children;
- determining whether other family members may be at risk; and
- exploring resources for payment of genetic testing.

Flu inoculations

Influenza is particularly hazardous to people whose respiratory muscles have been weakened by neuromuscular diseases. Contact your Care Center team to find out how to obtain a flu shot. To learn more about how to protect yourself and your family during influenza season, visit MDA's Flu Season Resource Center at mda.org/flu-seasonsupport.

Empowering you with support and services

MDA support services help kids and adults with neuromuscular diseases, their families and caregivers address the challenges that accompany these conditions.

Read the next several pages to learn about how MDA can help support your family. Additional support services and local resources are also provided online at mda.org.



"MDA has been a huge answer in helping my family and me navigate a difficult medical condition. They have provided many educational events and support groups that have greatly helped me understand my disability, gain resources in the community and network with other individuals and doctors so I know I am not alone."

Nikki, mitochondrial myopathy

MDA Resource Center

The national MDA Resource Center connects families and individuals affected by neuromuscular disease with trained MDA resource specialists who provide one-on-one, personalized counsel and answers about disease information, support services, community resources and more.

MDA's Resource Center is available to anyone affected by muscular dystrophy, ALS and related neuromuscular diseases. Resource specialists are available to assist you at **800-572-1717** or **ResourceCenter@mdausa.org**, Monday through Friday from 8 a.m. to 5:30 p.m. Central time.

MDA Summer Camp

MDA Summer Camp provides a life-changing experience for thousands of kids with neuromuscular diseases – at no cost to their parents. Kids, ages 6-17, dream about MDA camp year-round, and they almost all agree “it’s the best week of the year.” They love camp because it’s a place where they have the freedom to be kids with others who are just like them. Kids enjoy a week of barrier-free fun while creating lifelong friendships, building self-confidence and developing independence. It’s also a one-of-a-kind opportunity to share interests, learn more about themselves and find strength among friends.



“MDA Summer Camp is a place where you can live unlimited and be who you want to be. My friends at MDA Summer Camp are like my brothers and sisters. We laugh, we play, we work together and share stories.”

Latondra, MDA camper who has congenital muscular dystrophy

Young adult programs

MDA is committed to supporting young adults living with neuromuscular conditions as they move from high school to higher education and employment and pursue their independent living goals. Our peer-led initiative provides services and supports for young adults to surpass limits and unleash their fullest potential. This includes an interactive website, opportunities for one-on-one coaching sessions with MDA’s national director of young adult and community engagement, resource referral and educational materials, and more. Young adults are invited to learn more at mda.org/young-adults, or reach out with questions via email at youngadults@mdausa.org.

Equipment assistance

MDA assists individuals with obtaining medical equipment through its national equipment inventory program and referrals to community resources.

MDA's equipment program is available to anyone affected by the diseases in MDA's program for whom medical equipment has been prescribed through an MDA Care Center or by another medical professional.

To the extent feasible and when available, MDA provides new or gently used wheelchairs in good condition along with other durable medical equipment when medically prescribed due to an individual's neuromuscular disease. In addition to wheelchairs, we may be able to provide hospital beds, walkers and canes, communication devices and similar items.

Through its offices in communities across the country, MDA gratefully accepts donations of new or gently used medical equipment for distribution through its equipment program.



"MDA has been a pillar of support for my family since our diagnosis. Having four children with special needs is a difficult journey, but for me, I know nothing different. This is my 'normal.' I feel that MDA works tirelessly to give my kids the best opportunity to feel 'normal,' to get the care they need, and to not feel alone with their disease."

Liz, mother of four children
with myotonic dystrophy

MDA is able to make minor repairs to equipment donated to MDA for this purpose.

Many federal, state and local resources exist to assist individuals with equipment purchases. Local MDA offices maintain an extensive database of resources available in your area. For help with navigating the process of obtaining prescribed equipment, talk to your local MDA representative or contact the MDA Resource Center at **800-572-1717** or **ResourceCenter@mdausa.org**.

Support groups

MDA stands alongside our families, implementing vital initiatives to assist and empower the kids and adults we serve. In hometowns across America, MDA offers support groups – including many that are disease-specific and others that are topic-focused, such as groups for caregivers, parents and young adults. In the support group setting, you and/or your loved ones can share everything from tears and laughter, to medical and financial tips, to travel stories and recipes. More importantly, you'll find a sense of fellowship and a personal connection that strengthens everyone involved.

The families you meet at MDA support groups are living this experience with you. Lean on them, learn from others, and call them when you need to talk or need help. You'll find others leaning on, and learning from, you too. Your local MDA staff can let you know about the types of support groups offered in your area, as well as provide up-to-date meeting schedules and locations.

Education

MDA helps families stay informed about the latest in research, clinical trials, health care information, community resources and helpful daily living strategies through an array of educational speakers and seminars in hometowns across America. Your local MDA staff can let you know about the types of educational events that are offered in your area, as well as scheduling information.

MDA website (mda.org)

This site houses resources and in-depth information, including:

- Contact information for all MDA Care Centers and local offices
- Information about MDA services, programs, resources and spokespeople
- Information about each disease in MDA's program, explaining the underlying biology, symptoms, interventions, inheritance patterns, current research and other relevant information
- News updates on research advances and health care issues
- Information about clinical trials and MDA research grants
- Personal narratives and first-person accounts from our families, researchers and supporters on MDA's blog, Strongly
- Information for young adults living with neuromuscular disease through MDA's young adult programs
- Advocacy information about pending legislation relevant to the MDA community
- Tools to help you get involved in the fight against neuromuscular disease

Quest Magazine (mda.org/quest)

MDA's quarterly flagship publication is free to individuals and families registered with MDA. The award-winning Quest Magazine is the leading source of research, clinical care and daily living information for individuals with neuromuscular diseases, their families, friends and caregivers. Each issue contains articles about research breakthroughs and clinical trials, medical care, health and wellness, and personal profiles of individuals and families living with neuromuscular diseases. Its articles explore daily living issues, including parenting, caregiving, independent living, helpful products and strategies, and legislation of importance to the neuromuscular disease community. The digital magazine offers everything in the print magazine, including a downloadable, printable PDF for each issue, web-exclusive content and article archives.

Other MDA publications

Visit MDA's disease pages (mda.org/disease/list) for a concise, informative overview of each of the diseases in our program. Other publications include detailed guidebooks for caregivers, parents and teachers, and booklets about coping with medical and daily living challenges. All publications are free to those MDA serves, and can be downloaded online or obtained through your local MDA office.

Ways to get involved in your community

Advocacy

MDA is dedicated to doing everything in our power to advocate for policies and programs that support the neuromuscular disease community and empower individuals to live independent and fulfilling lives.

That is why we are inviting you to join MDA in advocating for policies that advance biomedical research, ensure that safe and effective treatments are developed and delivered as quickly as possible, improve access to care and services, and maximize opportunities for people with disabilities to live independently and achieve their life goals.

Whether you are living with a neuromuscular disease, or love someone who is. Whether you are a researcher, a health care provider, a teacher or a community leader. We need your help. MDA advocates are actively engaged in every state across the nation and in almost every U.S. congressional district. With your help, we will continue to make a positive impact.

Your involvement is key. Every MDA advocate is essential to progress, and we hope that you will join us in making a difference today.

Getting involved with MDA's advocacy program is easy. With three simple steps, you can help impact public policy. Simply sign up, take action, and spread the word.



- 1. Sign up.** Become an MDA advocate today by registering at mda.org/get-involved/mda-advocacy. When you sign up, you will receive email updates and up-to-the-minute news on policy issues impacting the MDA community.
- 2. Take action.** MDA advocates receive action alerts that contain information regarding important policy initiatives where every voice is needed to help make a difference. Action alerts provide MDA advocates the opportunity to easily contact their elected officials using online tools that provide talking points about important legislation and automatically match the MDA advocate sending the message with the contact information for their elected officials.

MDA's Policy & Advocacy Team, located in Washington D.C., is also available as a resource to assist you in engaging your members of Congress in person. We invite you to reach out to our team at advocacy@mdausa.org at any time with questions about MDA's initiatives and for more information about how you can get involved.

- 3. Spread the word.** Take a moment to share Action alerts, advocacy emails and information about MDA's advocacy initiatives with your friends, family and colleagues. You also can follow us on Twitter at [@MDAadvocacy](https://twitter.com/MDAadvocacy).



"I'm so glad we found MDA, since they have always been there to support me and my family. Today, I probably wouldn't be attending college and pursuing my education goals if not for the confidence I gained from MDA programs and events."

Anuar, Duchenne muscular dystrophy

Volunteer opportunities

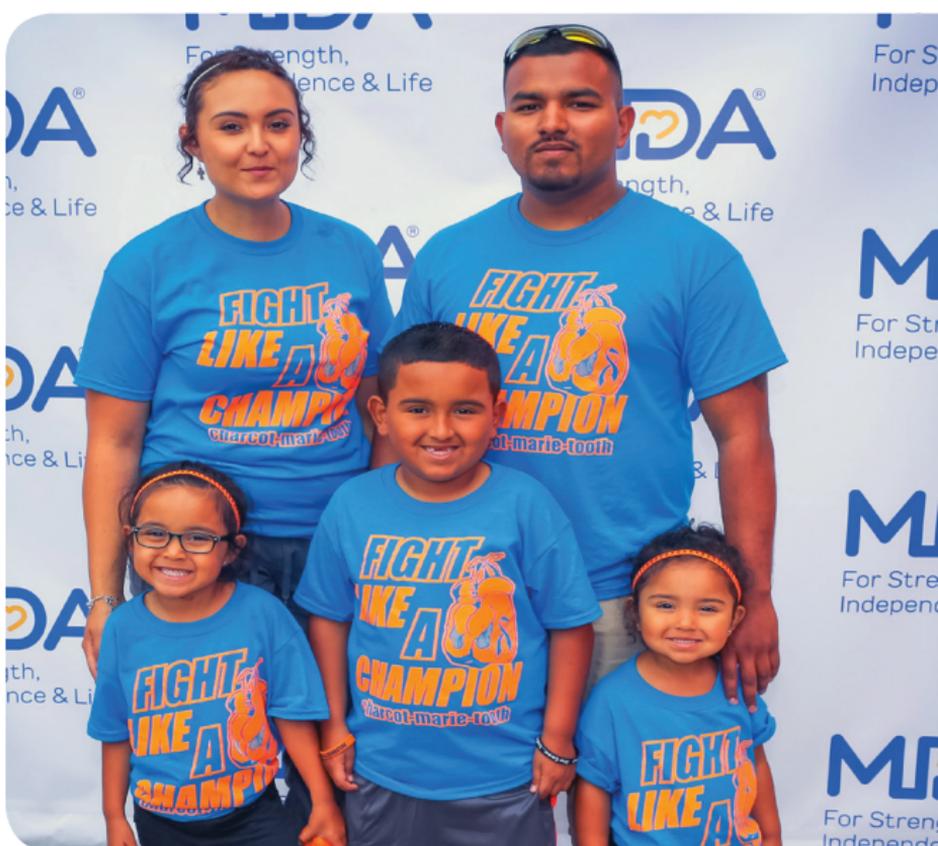
Volunteers are the driving force that enables MDA to support families in hometowns across America. Together, we are able to make experiences like MDA Summer Camp, support groups, seminars, special events and many other initiatives possible for families who are counting on us.

Here are just a few ways you can make a difference:

- **Office Volunteer:** Join us in your local MDA office to work on various projects, including making phone calls, data entry, auction procurement, supply assistance and more. Specialized HIPAA training is required and provided. Volunteers must be at least 18 years old.

- **Day of Event Volunteers:** Help us make MDA special events — such as Muscle Walk, Team Momentum, Lock-Up, galas and golf tournaments — successful. Time commitment varies depending on event and time of year.
- **Community Outreach Volunteer:** Share MDA in your community through MDA Summer Camp volunteer recruitment presentations, reaching out to and visiting retail partners who fundraise for MDA, supporting health and job fairs, and other opportunities. Time commitment varies throughout the year.
- **Summer Camp Volunteer:** Apply to spend a life-changing week at MDA Summer Camp. Volunteer counselors must be at least 16 years old (18 at some camps) and will provide campers with around-the-clock care and companionship. Training is required and provided.

To learn more, contact your local MDA representative or visit mda.org/get-involved.



For all the latest updates about the diseases in MDA's program, innovative research and care, ways to volunteer and more, visit mda.org/email and sign up to receive email from MDA – and be sure to follow us on our social channels.

 facebook.com/MDAnational

 [@MDAnews](https://twitter.com/MDAnews)

 [@MDAnews](https://www.instagram.com/MDAnews)



"I know no matter how much money I raise to run with MDA Team Momentum or Muscle Walk, every cent will be used for a good cause. Maybe it will be one of the dollars I raise that contributes to the ah-ha moment of an effective treatment or maybe it will be money that pays for a child to experience one of the greatest weeks of their life at MDA Summer Camp. No matter what it is, I know that I am making a positive impact in not only my son's life but all those living with neuromuscular diseases."

Josh, MDA Team Momentum and Muscle Walk participant, and father of a child who has Duchenne muscular dystrophy

Diseases in MDA's Program

Muscular dystrophies

Myotonic dystrophy

Duchenne muscular dystrophy

Becker muscular dystrophy

Limb-girdle muscular dystrophy

Facioscapulohumeral
muscular dystrophy

Congenital muscular dystrophy

Oculopharyngeal muscular dystrophy

Emery-Dreifuss muscular dystrophy

Diseases of peripheral nerves

Charcot-Marie-Tooth disease

Dejerine-Sottas disease

Endocrine myopathies

Hyperthyroid myopathy

Hypothyroid myopathy

Motor neuron diseases

Amyotrophic lateral sclerosis (ALS)

Spinal muscular dystrophy

Spinal-bulbar muscular atrophy

Inflammatory myopathies

Polymyositis

Dermatomyositis

Inclusion-body myositis

Mitochondrial diseases

Mitochondrial myopathies

Friedreich's ataxia

Other myopathies

Congenital myopathies

Core myopathies

Distal myopathies

Nemaline myopathies

Myotubular myopathy

Centronuclear myopathies

Myofibrillar myopathy



"My life collapsed. We were inconsolable. I had been healthy and active all my life. I ran regularly and finished nine half marathons after age 48. And I had no family history of the disease. Why was this happening to me?"

[MDA] came to me with open arms, soothing voices and offers to help walk this walk with me and my family."

Joan, ALS

Metabolic diseases of muscle

Phosphorylase deficiency (McArdle disease)
Acid maltase deficiency (Pompe disease)
Phosphofructokinase deficiency (Tarui disease)
Debrancher enzyme deficiency
(Cori or Forbes disease)
Carnitine deficiency
Carnitine palmityl transferase deficiency
Phosphoglycerate kinase deficiency
Phosphoglycerate mutase deficiency
Lactate dehydrogenase deficiency
Myoadenylate deaminase deficiency

Diseases of the neuromuscular junction

Myasthenia gravis
Lambert-Eaton (myasthenic) syndrome
Congenital myasthenic syndromes

Ion channel muscle diseases

Myotonia congenita
Paramyotonia congenita
Periodic paralysis

For detailed information about the diseases in MDA's program, please visit the online disease directory at mda.org/disease/list.



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Independence & Life

Muscular Dystrophy Association

 mda.org

 800-572-1717

 mda@mdausa.org

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