



MDA[®]

Fact Sheet

What is MDA?

Founded in 1950, the Muscular Dystrophy Association today is one of the world's leading nonprofit health organizations, funding research, health care and support services covering more than 40 neuromuscular diseases affecting more than 1 million Americans.

Active in local communities around the country, MDA is dedicated to finding treatments and cures for neuromuscular diseases, and to supporting the individuals and families affected by these diseases.

What does MDA cover?

The majority of diseases under MDA's umbrella are caused by genetic factors. All result in progressive muscle weakness. Symptoms can range from mild muscle weakness to complete paralysis of all voluntary muscles, including those used for breathing and swallowing. Among these diseases, the age of onset varies from birth to adulthood, and life span after diagnosis can be as short as a year or as long as several decades.

Detailed information about each of the neuromuscular diseases in MDA's program can be found at mda.org.

What does MDA do?

Worldwide research: MDA annually funds some 300 research projects around the world. Thanks to MDA-funded research:

- disease-causing genetic mutations have been identified for most of the diseases in its program;
- clinical trials of potential therapies are under way in Duchenne and Becker muscular dystrophies, spinal muscular atrophy, ALS and other diseases;
- the largest drug discovery project for ALS to date is being conducted at the ALS Therapy Development Institute;

- optimal care guidelines have been developed for several rare conditions; and
- a lifesaving enzyme replacement therapy has been developed for Pompe disease.

Health care and support services:

MDA's comprehensive services program helps individuals and their families meet the challenges imposed by chronic, progressive muscle diseases through:

- a national network of some 200 medical clinics staffed by experts in neuromuscular diseases, including 41 clinics designated as MDA/ALS centers;
- local support groups and events for individuals and families;
- assistance locating, obtaining and repairing needed durable medical equipment; and
- online opportunities to connect, share and learn through online communities, care coordination tools and webinars.

Summer camps: Each year, thousands of youngsters ages 6-17 attend a free week-long accessible summer camp session where they get to be "just kids."

Public and professional health education:

Online and in print, MDA offers a vast library of information about research, clinical trials, health care and daily living strategies. MDA also regularly convenes international scientific meetings and conferences for researchers and MDA clinic directors.

Advocacy: MDA represents the needs of the neuromuscular disease community in matters of public policy and research advancement, and facilitates involvement in these areas by the people it serves.

Community programs: Public awareness programs such as the MDA Art Collection and Personal Achievement Award demonstrate that disability is no barrier to creativity and service.



MDA's website, mda.org, is constantly updated with the latest research news and information about the diseases in its program. Follow MDA on Facebook, Twitter and YouTube.



mda.org • als.mda.org • (800) 572-1717
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Who supports MDA?

Designated a "Top-Rated Charity" by the American Institute of Philanthropy, MDA is the first nonprofit to receive a Lifetime Achievement Award from the American Medical Association "for significant and lasting contributions to the health and welfare of humanity." MDA spends 77 cents of every dollar on its research and services programs.

MDA's programs are supported nationally and in local communities by businesses, associations, organizations, and the care and dedication of countless individual volunteers.

MDA's Purpose and Programs

The Muscular Dystrophy Association fights neuromuscular diseases through an unparalleled worldwide research effort. The following diseases are included in MDA's program:

Muscular Dystrophies

Myotonic dystrophy (*Steinert disease*)
Duchenne muscular dystrophy
Becker muscular dystrophy
Limb-girdle muscular dystrophy
Facioscapulohumeral muscular dystrophy
Congenital muscular dystrophy
Oculopharyngeal muscular dystrophy
Distal muscular dystrophy
Emery-Dreifuss muscular dystrophy

Motor Neuron Diseases

Amyotrophic lateral sclerosis (*ALS*)
Infantile progressive spinal muscular atrophy
(*Type 1, Werdnig-Hoffmann disease*)
Intermediate spinal muscular atrophy
(*Type 2*)
Juvenile spinal muscular atrophy
(*Type 3, Kugelberg-Welander disease*)
Adult spinal muscular atrophy (*Type 4*)
Spinal-bulbar muscular atrophy
(*Kennedy disease*)

Inflammatory Myopathies

Polymyositis
Dermatomyositis
Inclusion-body myositis

Diseases of Neuromuscular Junction

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

Diseases of Peripheral Nerve

Charcot-Marie-Tooth disease
Friedreich's ataxia
Dejerine-Sottas disease

Metabolic Diseases of Muscle

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

Myopathies Due to Endocrine Abnormalities

Hyperthyroid myopathy
Hypothyroid myopathy

Other Myopathies

Myotonia congenita
Paramyotonia congenita
Central core disease
Nemaline myopathy
Myotubular myopathy
Periodic paralysis