
Neuromuscular Diseases

Muscular Dystrophy Association

www.mda.org

Voluntary health agency that fosters neuromuscular disease research and provides patient care funded almost entirely by individual private contributors. MDA addresses the muscular dystrophies, spinal muscular atrophy, ALS, Charcot-Marie-Tooth disease, myasthenia gravis, Friedreich's ataxia, metabolic diseases of muscle, and inflammatory diseases of muscle, for a total of more than 40 neuromuscular diseases.

AMYOTROPHIC LATERAL SCLEROSIS

ALS Therapy Development Institute

www.als.net

Nonprofit biotechnology company dedicated to discovering and developing treatments for ALS. The organization focuses on a concentrated drug discovery program for ALS and collaborates with companies and academic researchers to perform advanced investigations.

The ALS Association

www.alsa.org

Nonprofit voluntary health organization dedicated solely to the fight against amyotrophic lateral sclerosis. Funds research and sponsors advocacy programs, a network of chapters, and certified centers and clinics located nationwide.

Les Turner ALS Foundation

www.lesturnerals.org

Advances scientific research into the causes, treatments and prevention of ALS, provides people living with ALS, their families and caregivers exceptional clinical care and support services, and increases awareness and education of ALS.

Project ALS

www.projectals.org

Nonprofit organization that raises awareness and funds toward treatments and a cure for amyotrophic lateral sclerosis.

PRIZE4LIFE

www.prize4life.org

Nonprofit organization dedicated to the discovery of treatments and a cure for ALS.

MUSCULAR DYSTROPHIES

Cure CMD (Congenital Muscular Dystrophy)

<http://curecmd.org/>

Nonprofit group whose mission is to bring research, treatments and, in the future, a cure for the congenital muscular dystrophies. Works globally with dedicated parent, government, and research advocates funds high potential research and clinical trials, with success being determined by clinical applications that improve the lives of those afflicted with CMDs.

Fibromuscular Dysplasia Society of America (FMDSA)

www.fmdsa.com

A public health charity working toward better diagnosis and treatment of fibromuscular dysplasia by building awareness, funding research, providing patient support, and educating patients and the healthcare community.

FSH Society (Facioscapulohumeral Dystrophy)

www.fshsociety.org

Helps patients and families through education and outreach via a newsletter, website, conferences and social media funds scientific research leading to treatments, guided by a world-class Scientific Advisory Board and advocates for increased government and industry funding for research and to encourage drug trials.

Jain Foundation

www.jain-foundation.org

Seeks to expedite development of a cure or therapy for Limb-girdle muscular dystrophy type 2B (LGMD2B) and Miyoshi Myopathy. Maintains a patient registry, funds and monitors research and progress, provides financial support to accelerate clinical trials, and encourages scientific collaboration.

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www.curecalpain3.org/

Coalition to Cure Calpain 3 (C3) Coalition to Cure Calpain 3 provides support for promising research into finding treatments or a cure for limb-girdle muscular dystrophy, type 2A/Calpainopathy (LGMD2A).

The Myositis Association

www.myositis.org

Works to improve the lives of those affected by inflammatory myopathies. Seeks out persons with inflammatory myopathies, provides a support network, acts as a resource for patients and the medical community, advocates for patients, and promotes research into the causes and treatment of these disorders.

Myotonic Dystrophy Foundation

www.myotonic.org

Enhances the quality of life of people living with myotonic dystrophy and advances research focused on treatments and a cure. The world's largest patient organization focused solely on myotonic dystrophy.

Parent Project Muscular Dystrophy

www.endduchenne.org

Dedicated to ending Duchenne muscular dystrophy through accelerated research and advocacy. Demands optimal care for all young men and educates the global community.

MYASTHENIA GRAVIS

Myasthenia Gravis Foundation of America, Inc

www.myasthenia.org

Works to facilitate the timely diagnosis and optimal care of individuals affected by myasthenia gravis and closely related disorders and to improve their lives through programs of patient services, public information, medical research, professional education, advocacy, and patient care.

NEUROPATHIES

American Diabetes Association

www.diabetes.org

Nonprofit health organization providing diabetes research, advocacy services, and information, including the complications of diabetes, such as diabetic neuropathy.

Charcot-Marie-Tooth Association (CMTA)

www.charcot-marie-tooth.org

Provides education and support to persons with Charcot-Marie-Tooth disorders, their families, and the health professionals who treat them.

Hereditary Neuropathy Foundation

www.hnf-cure.org

Nonprofit organization that raises awareness, funds innovative research, and offers medical information and emotional support for those with Charcot-Marie-Tooth disorder and their families and caregivers.

The Foundation for Peripheral Neuropathy

www.foundationforpn.org

Nonprofit organization whose mission is to dramatically improve the lives of people living with peripheral neuropathy.

PARALYSIS

Christopher and Dana Reeve Foundation

www.christopherreeve.org

The Christopher & Dana Reeve Foundation is dedicated to curing spinal cord injury by funding innovative research and improving the quality of life for people living with paralysis through grants, information and advocacy.

Miami Project to Cure Paralysis

www.themiamiproject.org

Supports research and related programs in the area of spinal cord injury.

Spastic Paraplegia Foundation, Inc.

www.sp-foundation.org

Volunteer nonprofit organization dedicated to finding cures for hereditary spastic paraparesis and primary lateral sclerosis. See also Genetic Alliance, page 41, and National Ataxia Foundation, page 8.

The Spinal Cord Society

www.scsus.org/

International advocacy organization that supports research, publishes a newsletter, and sponsors an international network of chapters.

Neuromuscular Diseases

SPASMODIC DYSPHONIA

National Spasmodic Dysphonia Association

www.dysphonia.org

Works to advance medical research into the causes of and treatments for spasmodic dysphonia, promotes physician and public awareness of the disorder, and sponsors support groups for patients and their families.

SPINAL MUSCLE ATROPHIES

Cure SMA

www.curesma.org

Provide funding for SMA research through our comprehensive research model leading providers of family support and patient services.

Fight SMA

www.fightsma.org

National nonprofit organization committed to accelerating a cure for spinal muscular atrophy.

Kennedy's Disease Association

www.kennedysdisease.org

Nonprofit resource that offers support and information about spinal bulbar muscular atrophy, or Kennedy's disease. Works to increase awareness and to raise funds in support of research. Sponsors support groups.

Spinal Muscular Atrophy Foundation

www.smafoundation.org

Nonprofit foundation dedicated to accelerating the development of a treatment or cure for SMA.