

I WANT TO

LEARN MORE ABOUT NEUROMUSCULAR DISEASE

MDA Disease Fact Sheets and Resources

Overviews of some of the most common neuromuscular diseases and other educational resources
mda.org/education

MDA Disease Webpages

Summaries of many of the diseases MDA covers
mda.org/disease/list

MDA Engage Disease Symposia

Recorded and upcoming educational events that each focus on one disease
mda.org/care/mda-engage/disease-symposia

Quest Diseases A-Z

Quest content, including personal stories and research updates, related to specific diseases
MDAQuest.org/diseases-a-z

NIH Genetic and Rare Disease Information Center

Searchable database of rare and genetic diseases from the National Institutes of Health (NIH)
RareDiseases.info.nih.gov

NORD Rare Disease Database

Overviews of thousands of rare diseases from the National Organization for Rare Disorders (NORD)
RareDiseases.org/rare-disease-information

NORD Rare Disease Video Library

Educational videos about many rare diseases
RareDiseases.org/rare-disease-video-library

+MORE EDUCATION

MDA Engage is a community education program bringing accessible knowledge and resources to the neuromuscular disease community. Watch seminars and webinars covering a variety of topics — from research updates to nutrition and parenting tips — live or on-demand. Visit mda.org/engage.

UNDERSTAND GENETIC INHERITANCE

MDA Education Materials

See Disease Specific Resources and General Neuromuscular Disease Resources for fact sheets about genetics and inheritance patterns
mda.org/education

Quest Feature: Family Inheritance

How genetic neuromuscular disease is passed from one generation to another
MDAQuest.org/family-inheritance

LEARN ABOUT GENETIC TESTING

MDA Education Materials

See Disease Specific Resources and General Neuromuscular Disease Resources for fact sheets about genetics and genetic testing
mda.org/education

Quest Feature: The Importance of Genetic Testing

The advantages of getting a genetic diagnosis and how to get started
MDAQuest.org/importance-genetic-testing

UNDERSTAND GENE THERAPY

Quest Feature: Targeting Genes

How gene-targeted therapies for neuromuscular diseases work
MDAQuest.org/targeting-genes

Quest Feature: Express Delivery

How viral vectors are used in gene-targeted therapies for neuromuscular diseases
MDAQuest.org/express-delivery

ASGCT Gene Therapy 101

Explanations and videos from the American Society of Gene and Cell Therapy
PatientEducation.asgct.org/gene-therapy-101

I WANT TO

READ ABOUT RESEARCH

Quest Blog

Covers breaking news on treatments, and research and clinical trial updates
[MDAQuest.org/blog](https://mdaquest.org/blog)

MDA Grants at a Glance

Research projects funded through MDA's grants program
mda.org/gaag

BioNews

Online health news service with five disease-specific publications covering neuromuscular diseases
[ALSNewsToday.com](https://alsnews.com)
[FriedreichsAtaxiaNews.com](https://friedreichsataxia.com)
[MuscularDystrophyNews.com](https://muscular-dystrophy.com)
[MyastheniaGravisNews.com](https://myasthenia.com)
[SMANewsToday.com](https://smadaily.com)

ANCAN: A Layperson's Guide to Reading Medical Research

Strategies to help you understand research articles from the Answer Cancer Foundation
[AnCan.org/special-presentation-a-laypersons-guide-to-reading-medical-research](https://an-cancer.org/special-presentation-a-laypersons-guide-to-reading-medical-research)

FIND CLINICAL TRIALS

MDA Clinical Trials Finder

The Trial Finder tool helps sort through available neuromuscular disease clinical trials
mda.org/clinical-trials

MDA Clinical Trial Updates

List of open clinical trials for neuromuscular diseases
mda.org/clinical-trial-updates

ClinicalTrials.gov

A database of clinical studies around the world from the US National Library of Medicine
[ClinicalTrials.gov](https://clinicaltrials.gov)

Trials Today

A quick way to search the thousands of studies available on ClinicalTrials.gov
[TrialsToday.org](https://trials-today.org)

FIND A DISEASE REGISTRY

MDA MOVR Data Hub

Collects data on multiple neuromuscular diseases to help researchers build clinical trials and understand treatment outcomes
mda.org/MOVR

National ALS Registry

Collects information from individuals with amyotrophic lateral sclerosis (ALS) to help researchers learn more about the disease and its risk factors
cdc.gov/als

NIH List of Registries

List of disease registries available nationally
nih.gov/health-information/nih-clinical-research-trials-you/list-registries



Image: iStock.com/Aleksei Naumov

+MORE RESOURCES

The MDA Resource Center answers questions and can assist with finding services and programs for people in the neuromuscular disease community. Resource Center staff are available Monday through Friday, 9 am to 5 pm CT. Call **833-ASK-MDA1 (1-833-275-6321)** or email ResourceCenter@mdaUSA.org.