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, research and clinical trial updates
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
FriedreichsAtaxiaNews.com
MuscularDystrophyNews.com
MyastheniaGravisNews.com
SMANewsToday.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

🔍 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

Trials Today
A quick way to search the thousands of studies available on ClinicalTrials.gov
TrialsToday.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

← 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.