

Leading the Way with MDA



MDA Mission

Muscular Dystrophy Association is the **#1** voluntary health organization in the United States for people living with muscular dystrophy, ALS, and related neuromuscular diseases.

For over **70 years**, MDA has led the way in accelerating research, advancing care, and advocating for the support of MDA families.



MDA's mission is to empower the people we serve to live longer, more independent lives.



MDA Care Center Network

MDA leads the way in caring for people living with muscular dystrophy, ALS, and related neuromuscular diseases, with the largest nationwide network of multidisciplinary MDA Care Centers.

At MDA, we are committed to ensuring that the MDA Care Center Network operates with a multidisciplinary approach which brings together the expertise of professionals from a wide range of disciplines in **one** location to provide coordinated, patient centered care.

What is equally important is that the MDA Care Center team is connected to the latest clinical trials and FDA-approved treatments.



Locations ● Care Center ● Multiple Care Centers ● Care Affiliate



150

Locations in the
MDA care center
Network

\$6M+



MDA Care
Center Network
investment



2,000

Clinicians and
scientists trained
since 1950

60,000+



Individuals living
with NMD receiving
care each year



MDA Care Center Network

Multidisciplinary Care Team

Physician	Physical Therapist	Coordinator	Cardiologist	Dietician/Nutritionist
Endocrinologist	Gastroenterologist	Genetic counselor or Geneticist	Neurologist	Neuropsychologist
Occupational Therapist	Orthopedist	Orthotist	Palliative care professional	Physiatrist/PMR
Pulmonologist	Research Coordinator	Respiratory Therapist	Social Worker	Speech-Language Pathologist



MOVR

MDA's neuroMuscular Observational Research Data Hub

From the very beginning, MDA's founders knew that muscular dystrophy could not be diagnosed properly or cured without new knowledge that could only come from research. That remains true today, and the entire field of NMD medicine looks to MDA for leadership in this area.

Custom Technology Platform

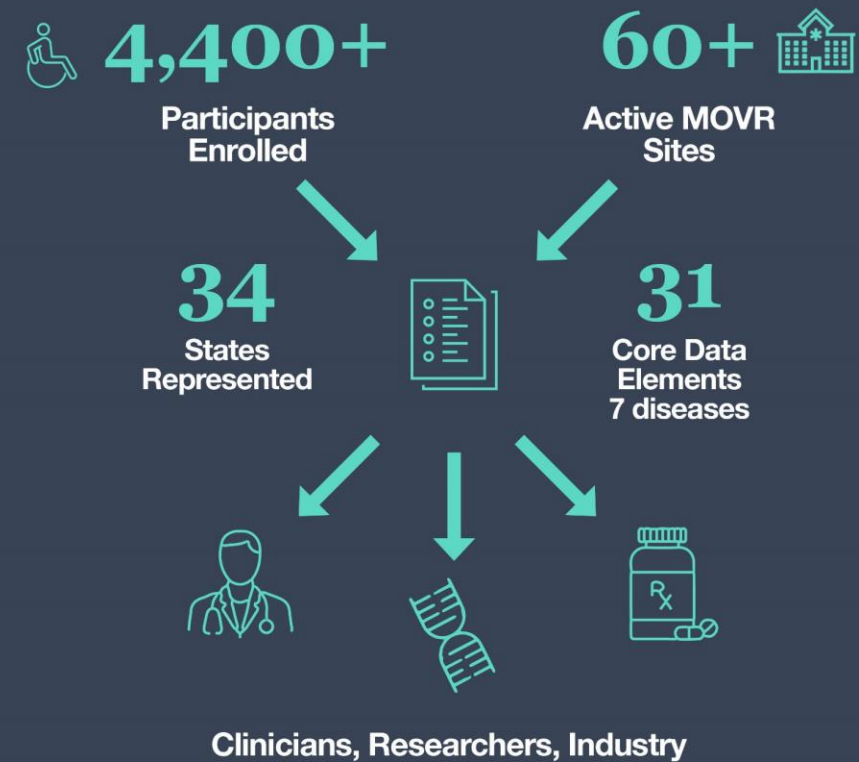
- Compliant with HIPAA and FAIR data principles
- Ability to interface with other registries and datasets
- Data use policies to ensure appropriate protections of participant privacy

Clinic-Entered Data Powered by MDA Care Centers

- GCP and ICH-compliance training and education of site personnel
- Clinical Trial Manager to monitor and ensure compliance and provide feedback on quality of data entry
- IRB review and approval of study protocol and informed consent forms
- Research Advisory Committee and Publications Committee

Reporting and Visualization Tools for Robust Data Analysis

- Custom MOVR Visualization and Reporting Platform (VRP) that allows users to easily manipulate datasets into cohorts and projects
- Extensive data dictionary



How industry CEOs describe MOVR

“Essential tool”

“Innovative”

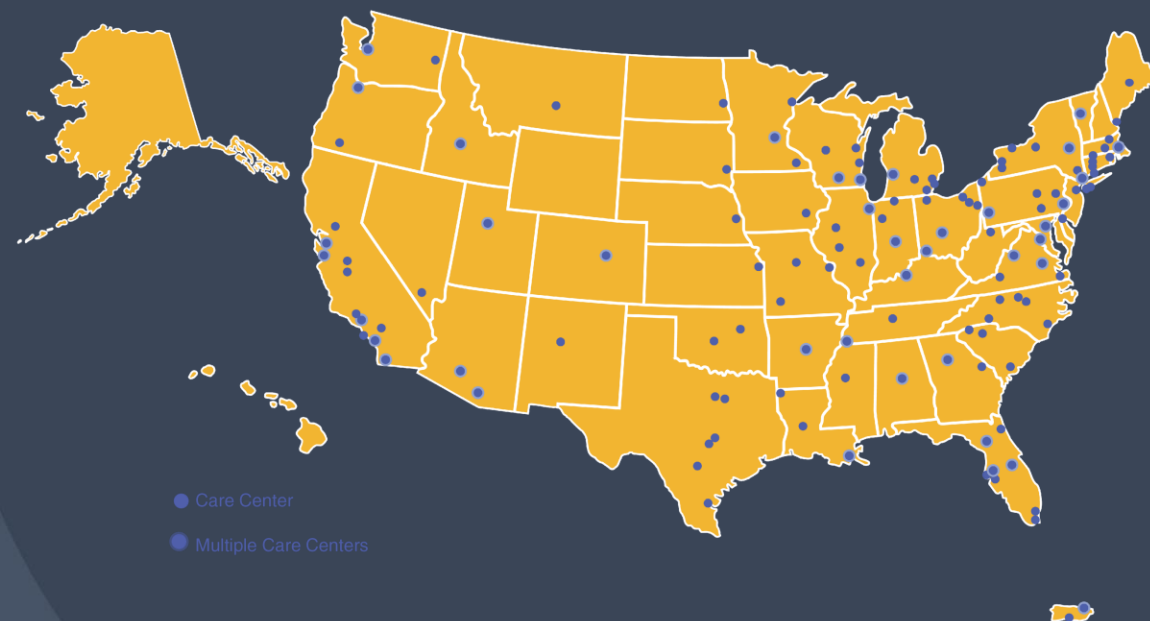
“First of its kind”

“Better access”



MDA/ALS Care Centers

End ALS
with MDA[®]



MDA's Advocacy Efforts to Increase Access to Care

- MDA advocates to increase access to anything that can improve our community's health and wellbeing
- Key priorities for the ALS community:
 - Medicare coverage of multidisciplinary care
 - Home-and-community based services
- But other areas of importance include:
 - Better coverage of medical devices
 - Telehealth
 - And more

Work Requirements, Medicare and HCBS: Fighting to Step Forward, Not Back

COMMENTARY

June 28, 2023 by Joel Cartner, Director of Access Policy, Muscular Dystrophy Association

There is much to reflect on about the recent events in Washington surrounding the debt ceiling crisis. In the end, both sides agreed to a plan and the country escaped default.

But what should not go unnoticed in that discussion is what *almost* happened.

Up until the 11th hour, Republican negotiators put work requirements for Medicaid in some form firmly on the table.



RESNA Blog

CMS Expands Medicare Coverage of Power Seat Elevation

Date: Wednesday, May 24, 2023

Category: General



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