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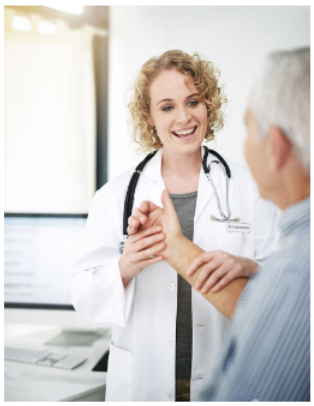

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MOVR Data Hub (neuroMuscular ObserVational Research)

MDA's MOVR Data Hub™ (neuroMuscular ObserVational Research) is improving the ability of researchers and healthcare providers to enhance the care and management of individuals living with neuromuscular disease, and to aid in the development of clinical trials for promising new treatments.

Unprecedented times set the stage for MOVR

Genetic and therapeutic advances are transforming the landscape of neuromuscular medicine, with breakthroughs in neuromuscular disease research and care happening at a much faster pace than ever before. As more therapies become available, they will begin to shift in makeup from purely supportive treatments to those that modify disease at the molecular level.

In order to make upcoming therapies available to all individuals affected by neuromuscular diseases, there are challenges that must be overcome.

- Researchers must better understand the relationship between health outcomes and genes, and between health outcomes and medical interventions (such as drugs, surgeries, medical devices).
- Doctors must be able to quickly match their patients to clinical trials, to approved therapies and to personalized care.
- Patients at all ages and stages of disease need to a platform to be 'seen' and 'counted' by the medical and scientific communities as they are working to develop drugs and improve care.

MDA's MOVR data hub (neuro**M**uscular **O**bser**V**ational **R**esearch) aims to overcome these barriers. The MOVR data hub gathers medical and genetic data through MDA's network of Care Centers from patients who agree to share their anonymized information. This large dataset will provide researchers with insights into how drugs and other treatments affect outcomes, how clinical trials could be better designed, and how neuromuscular disease affects people the same or differently. It will also ensure that doctors can quickly identify patients who may benefit from new therapies or who may want to participate in a clinical trial.

What is a registry?

A registry is a database of information that enables health care professionals to track or measure a number of health-related or quality-of-life outcomes in individuals with a specific disease or condition. Disease registries can improve quality of life, medical care and treatment for individuals and families living with neuromuscular disease.

What is a data hub?

A data hub is builds on the classic registry model, adding data from patient reported outcomes, as well as from technological tools including smart phones, apps and wearables.

What is MOVR?

MOVR is a unified national patient data hub for neuromuscular diseases that collects comprehensive clinical data and accurate genetic diagnostic information from individuals seen at MDA Care Centers. MOVR traces its origins to the MDA U.S. Neuromuscular Disease Registry, launched in 2013 to better understand how neuromuscular diseases develop and progress, and to identify which treatments lead to the best health outcomes.

Four diseases — amyotrophic lateral sclerosis (ALS), spinal muscular atrophy (SMA), Duchenne muscular dystrophy (DMD) and Becker muscular dystrophy (BMD) — are included in the data hub, which collects patient

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Four diseases — amyotrophic lateral sclerosis (ALS), spinal muscular atrophy (SMA), Duchenne muscular dystrophy (DMD) and Becker muscular dystrophy (BMD) — are included in the data hub, which collects patient information at more than 25 MDA Care Centers across the United States. However, MDA is working to expand the number of covered diseases and double the number of sites collecting data from 25 to 50.

Through a partnership with IQVIA, a leading global provider of information and innovative technology solutions, MOVR is evolving to meet the goal of managing and integrating data from various sources.

Listen to a podcast interview about MOVR.

What is MOVR expected to accomplish?

Two major areas of focus for MOVR will be clinical care and drug development, with specific emphasis on benchmarking quality of care, safety and effectiveness of new treatments, natural history of disease, and correlation between genotype (genetic makeup) and phenotype (disease characteristics).

The MOVR data hub will expand on the idea of a traditional patient registry by combining clinical and genetic data with patient reported outcomes collected through smartphones, incorporating activity data from wearable devices, and the potential to include additional innovative technologies. The powerful combination of these real-world data sources will enable clinicians to establish which interventions are tied to the best clinical outcomes and advance the standard of care.

> *MDA is uniquely positioned to establish a neuromuscular disease data hub. We are the only organization in the neuromuscular disease field that supports multiple neuromuscular diseases and maintains a nationwide network of more than 150 MDA Care Centers that provide multidisciplinary care to more than 40,000 individuals each year.*

Why does MOVR include four diseases right now?

The four diseases currently included in MOVR (ALS, SMA, DMD and BMD) were chosen for the registry pilot project because there were multiple experimental therapies in development for them, and clinical and research specialists in national working groups had already identified and standardized much of the information that is important to collect in clinical trials. In addition, formal “standards of care” for individuals with these diseases had already been defined, which provided a unique opportunity to demonstrate how the registry could be used to measure the implementation of these care standards and their impact on individual health outcomes.

Plans include the addition of three more diseases by the end of 2018.

How is data entered into MOVR?

MOVR data are collected by medical professionals at the care center site, ensuring complete and accurate capture of highly detailed medical information. Extensive medical data is collected, including medical and laboratory test results, prescriptions for drugs and medical devices, surgeries and other interventions. This level of detail and accuracy is necessary in order to draw conclusions from the data.

How will my data be used, and how will my private information be protected?

The MOVR data hub platform is built on a foundation of comprehensive data privacy and security principles that must be adopted and enforced by all parties within IQVIA, MDA and all participating sites. All data is saved in a secure database and de-identified — meaning all identifying (personal) information connected to each individual enrolled in MOVR is protected and can’t be connected to the clinical data shared with researchers. State-of-the-art security measures protect patient privacy, yet also provide for dynamic aggregation of data for research purposes and the ability for researchers to reach out to clinicians about trials and advances that may benefit individual patients of theirs.

Participate in MOVR

Participation in MOVR is voluntary, and all participants (or legal guardians) must sign a consent form to participate.

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An independent committee called an Institutional Review Board (IRB) protects the rights and welfare of participants involved in MOVR and ensures all research using MOVR data is held to the highest ethical standards.

To learn more about MOVR and to find out if your local MDA Care Center currently participates in this initiative, contact at mdamovr@mdausa.org.

Use of MOVR data to support research

MDA invites researchers to use MOVR data to accelerate improvements in drug development and health services research. Requests for access to de-identified data are welcomed from academic investigators, clinicians and industry. Publication and presentation of results from the analyses of MOVR data are encouraged. Email mdamovr@mdausa.org to receive a Request for Data Access Form and the Data and Publication Guidelines.

Highlights of the MDA U.S. Neuromuscular Disease Registry (2013-2016)

The first report from the pilot phase of the registry is available for download and contains a list of MDA Care Centers and demographics for the patient population that participated in the pilot phase. The report also contains disease-specific data including information about diagnosis, genetics, treatments, surgeries, nutrition, ventilation, assistive devices, and clinical trial participation.

Download the digital version of the Registry Highlights Report.

Muscular Dystrophy Association National Office
222 S. Riverside Plaza, Suite 1500
Chicago, Illinois 60606
800-572-1717 | ResourceCenter@mdausa.org

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