MOVR Data Hub™

(neuroMuscular ObserVational Research): Information for Clinical Providers

MDA's Data Hub Is Expanding

Thank you to every provider and institution that is making MOVR a success. As part of the continued drive to understand, treat and ultimately cure neuromuscular diseases, MDA is pleased to report on the expansion of the **MOVR (neuroMuscular ObserVational Research) Data Hub**, a patient registry that gathers and tracks longitudinal clinical data on patients who have granted consent and signed on to participate.

MOVR traces its origins to the MDA U.S. Neuromuscular Disease Registry (USNDR), launched in 2013, which established a longitudinal clinical data set to help enhance the understanding of multiple neuromuscular disorders. A highlights report about the registry was published after the USNDR study concluded in 2018, and is available to review on **mda.org**. The USNDR data set has been rolled directly into the MOVR Data Hub.

Since the initial program rollout in October 2018, the number of MOVR data collection sites has been steadily increasing. Patient enthusiasm has also been growing. For example, at one MDA Care Center, 100% of the patients who learned about MOVR consented to participate. In 2019, the data hub added three diseases to its collection inventory, in addition to the four diseases originally in MOVR.

What diseases are included in MOVR?

Seven diseases are now being tracked in the data hub:

- ALS (amyotrophic lateral sclerosis)
- BMD (Becker muscular dystrophy)
- DMD (Duchenne muscular dystrophy)
- SMA (spinal muscular atrophy)
- FSHD (facioscapulohumeral muscular dystrophy)
- LGMD (limb-girdle muscular dystrophy)
- Pompe disease or acid maltase deficiency (AMD)

Additional diseases will continue to be added to the database over time with direction from MDA's steering committee of NMD Key Opinion Leaders.

What are the benefits to patients?

For individuals with neuromuscular disease, participating in MOVR is the first time they can contribute to the largest repository of NMD longitudinal patient data shared across leading academic medical centers, enabling comparison of the practices that correlate most closely with better patient outcomes. Those learnings can in turn lead to improvements in individual patient care.

In addition, patients participating in MOVR are actively contributing to research targeting the development of new therapies for and across neuromuscular diseases.

What are the key aims of MOVR?

1. Optimize health outcomes
   - Support development and refinement of standards of care
   - Provide insights for quality improvement
   - Inform clinical best practices

2. Drive understanding of neuromuscular disease
   - Characterize genotype-phenotype correlation
   - Wed patient perspectives with genetic and clinical data sets
   - Collect insights on pre-symptomatic infants identified via newborn screening
   - Better characterize the patient experience
   - Track natural history of disease
   - Gather and assimilate data gathered outside of a clinical trial (also known as real world data [RWD])
   - Appreciate how therapies are changing the course of disease

3. Accelerate therapy development
   - Identify potential participants for clinical trials
   - Identify clinical trial feasibility and design

To learn more about becoming a MOVR site, email **MDAMOVR@mdausa.org**. For additional information, visit the **MOVR website**.