



MOVR DATA HUB

NEUROMUSCULAR OBSERVATIONAL RESEARCH



What is the MOVR Data Hub™?

The MOVR Data Hub is a collection of data including hospital/clinic visits. The collection of these data—sometimes called a database—enables tracking and measuring of health-related or quality-of-life outcomes which provide researchers and clinicians a better understanding of the diseases and the therapies used to treat them.

Why is this important?

As someone with a neuromuscular condition, you can be our research partner. By being in MOVR, your information is combined, in a safe and confidential way, with others living with the same disease. Having a larger set of data helps researchers better understand:

- How doctors can better identify patients who may benefit from new therapies or who may want to participate in a clinical trial
- How neuromuscular diseases affect people the same or differently
- How drugs and other treatments affect health outcomes
- How to improve and standardize care
- How clinical trials could be better designed



What information is collected?

The data hub collects a wide range of clinical data from individuals seen in MDA Care Centers including diagnostic tests, clinical measures and treatments. The clinical data is entered by a clinician.

Going forward, Patient Reported Outcomes (PROs) will capture the experiences, symptoms, and accomplishments that patients encounter as part of their diagnosis or because of treatment. PROs are typically surveys or scales completed by patients themselves. MOVR will also collect PRO information through technology such as smartphone apps.

The combination of clinical data and patient experience data will enhance our understanding of therapies and their effects.





What diseases will be included in the Data hub?

As of July 2019, the following diseases are included in the Data Hub:

- Amyotrophic lateral sclerosis (ALS)
- Becker muscular dystrophy (BMD)
- Duchenne muscular dystrophy (DMD)
- Spinal muscular atrophy (SMA)
- Facioscapulohumeral muscular dystrophy (FSHD)
- Limb-girdle muscular dystrophy (LGMD)
- Acid maltase deficiency (AMD, Pompe disease)

Additional diseases will continue to be added over time.



How can I participate?

Simply let your clinician or MDA staff member know you are interested in participation.

Participation in the data hub is voluntary. An independent committee called an Institutional Review Board (IRB) protects the rights and welfare of participants involved in the data hub and ensures all research conducted is held to the highest ethical standards. Data from the data hub used for research purposes is de-identified, meaning that the identity of the individuals enrolled in the data hub is protected and not able to be connected to the clinical data.



We invite you to join us as a research partner and transform the lives of people affected by neuromuscular disease. Please ask your MDA Care Specialist about MOVR and whether your Care Center is currently involved. Click here for more information on the MDA website.



*Designated a Top-Rated Charity by the American Institute of Philanthropy, MDA is the first nonprofit to receive a **Lifetime Achievement Award from the American Medical Association** for "significant and lasting contributions to the health and welfare of humanity."*



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