MOVR Data Hub™ (neuroMuscular ObserVational Research): Information for Clinical Providers

What is MOVR?

The MOVR (neuroMuscular ObserVational Research) Data Hub is a patient registry established by the Muscular Dystrophy Association (MDA) that gathers and tracks longitudinal clinical data and will wed that information with genetic and real world data. MOVR is overseen by an IRB and all patients participating in MOVR must first be consented. MOVR also follows clinical data collection practices, including the use of Clinical Research Associates (CRAs) and formal training processes, provided by MDA, to ensure the highest quality data is gathered.

What are the aims of MOVR?
MOVR is intended and designed to meet the following aims:
- Optimize Health Outcomes
- Accelerate Therapy Development
- Drive Understanding of Disease

Who manages the MOVR Data Hub technology platform and is the patient data safe there?
MDA has partnered with IQVIA, a leading global provider of healthcare and innovative technology solutions, to create a safe place to manage and integrate patient data from various sources — including our network of MDA Care Centers.

IQVIA™ — The Human Data Science Company™ — is dedicated to helping its customers improve health outcomes around the world by mobilizing unparalleled data, technology, expertise, and analytics through services and offerings focused on improving human health. IQVIA has been supporting USDNR since 2013 and is releasing MOVR on the new IQVIA Registry Platform (IRP).

What diseases are included in the MOVR Data Hub?
Four diseases — Amyotrophic lateral sclerosis (ALS), Becker muscular dystrophy (BMD), Duchenne muscular dystrophy (DMD), and Spinal muscular atrophy (SMA) — are currently included in the data hub. Three additional diseases — Facioscapulohumeral muscular dystrophy (FSHD), Limb-girdle muscular dystrophy (LGMD), and Pompe disease will be added soon.

Where is the MOVR Data Hub collecting data?
MOVR is being used at multiple MDA Care Centers across the country. If you would like to learn more about becoming a MOVR site or would like to know about currently active sites, please reach out to **MDAMOVR@mdausa.org**.

Why is collecting this data important?
The patient data stored in MOVR will help researchers better understand:
- the natural history and disease progression
- how diseases affect people the same or differently
- how to improve and standardize care for patients with neuromuscular disease
- how drugs and other treatments affect health outcomes
- how clinical trials could be better designed to bring new therapies to patients sooner

How are data collected?
MOVR data are collected by healthcare professionals at the Care Center, ensuring complete and accurate capture of detailed medical information. Medical data is collected, including medical and laboratory test results, prescription drug usage, medical devices, surgeries and other interventions. All data is stored in a secure database and de-identified — meaning all identifying (personal) information is protected and can't be connected to the clinical data shared with researchers.

How can I learn more about MOVR or find out how I can become a MOVR site?
For more information, please visit the MDA's website, **MDA.org** and look for the MOVR Data Hub under the Innovations in Science section. You can also reach out to the MDA MOVR team directly at **MDAMOVR@mdausa.org**.

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