

MOVR Makes an Impact on Multiple Levels

For 10 years, MDA's Neuromuscular Observational Research (MOVR) Data Hub has been collecting information on several neuromuscular diseases from MDA Care Centers. More than 5,000 patients have participated. This ever-growing trove of data helps clinicians and researchers in the neuromuscular space, influencing and informing the creation of new clinical trials and increasing the speed at which new drugs are developed. This is a remarkable accomplishment in a field where there was once little data.

In addition to the shortage of data on neuromuscular diseases, much of the existing data came from patient registries focused on one disease, and the databases were siloed. Addressing these issues is exactly what MOVR was designed to do, according to Jessica Waits, Director of Clinical Operations for MOVR. "MOVR captures multiple diseases in one registry," she says. "We're really making an impact creating bridges across diseases."

Andre Paredes, MOVR's Director of Research Analytics, says the diverse data is rapidly expanding the understanding and treatment of neuromuscular diseases. "The types of questions researchers can ask are now larger, and the ways that industry can work with the patient population in rare diseases is now available as a result of MOVR," he says.

For researchers and clinicians, MOVR allows for a streamlined view of the neuromuscular disease community within a single platform. "Clinicians get access to their data directly, so whether they are working on a presentation, a publication, or research on one of the diseases MOVR captures data on, they can hone in on that using the MOVR platform," Jessica says.

Patients also benefit from MOVR by being matched more quickly to clinical trials. In addition, Andre believes that participating in MOVR promotes a sense of community among patients and families, who understand that the data collected may help lead to the development of therapies. "It gives them a sense that they're giving to something bigger than themselves," he says.

MOVR Resources:

- Find an overview of MOVR and links to information for clinicians, researchers, MOVR sites, and more [here](#).
- Learn about MOVR's Visualization Reporting Platform and how to join MOVR [here](#).
- Find MOVR publications and presentations [here](#).