

MONTHLY Feature

MOVR Data Hub Makes an Impact

New executive director understands the value of data and collaboration



MDA's neuroMuscular ObserVational Research (MOVR) Data Hub is the first data hub that will aggregate clinical, genetic, and patient-reported data for multiple NMDs, making it a valuable tool for clinicians and researchers looking to improve care and develop therapies.

In the past year, MDA has worked to position MOVR to make an even bigger impact in the NMD research community.

New leadership

One key to optimizing MOVR is leadership that understands the value of data and collaboration. In November, Rayne Rodgers, MPH, became executive director of

MOVR. Rayne comes to the position with a deep commitment to patient advocacy and years of experience in biopharmaceutical drug development and clinical trials.

"I have a strong understanding of clinical trial development, clinical trial implementation, data standards, data integrity — many of the things that industry looks for to base value around data," Rayne says. She also has experience launching patient registries and in portal development.

As head of MOVR, Rayne is responsible for MOVR operations, strategy, performance, and partnerships. She leads a cross-functional team that works with the MDA Care Center Network and participating sites, as

Sites participating in MOVR are compensated for start-up and for their time inputting data.

well as business partners, advisory committees, and MDA’s research team. Rayne’s addition complements the already strong MDA MOVR team.

“Thanks to the work of everyone at MDA, MOVR is a state-of-the-art technology platform capturing data across seven neuromuscular diseases from 34 care center sites,” she says. “I’m thrilled to be guiding it forward.”

“Rayne comes to us with significant experience in patient registry management in an industry setting and familiarity with clinical operations and patient advocacy,” says Sharon Hesterlee, MDA’s EVP and chief research officer. “She also brings an incredible enthusiasm for MOVR and its potential and will be working in the next months to flesh out the vision for the MOVR’s next phase.”

The state of MOVR

Over the past year, MDA has continued to build state-of-the-art technology to optimize MOVR for sharing and data analysis. Here are some highlights:

- Custom Visualization and Reporting Platform (VRP): This advanced visualization dashboard gives clinicians and researchers the ability to easily manipulate datasets into projects with advanced data governance.
- CDISC SDTM implementation: All data in MOVR, including legacy data, has been transformed to CDISC SDTM, the FDA submission data standard. This allows researchers and industry partners that are developing drugs the opportunity to use the MOVR data to supplement regulatory submissions for drug approvals.
- Global Unique Identifier (GUID) implementation: GUID ensures appropriate protection for participant privacy while allowing for the matching of participants across disease registries and datasets for more accurate analyses.
- Electronic health record (EHR) integration enabled: Bringing medical history and prior treatment data in from EHR makes data collection more efficient and accurate.

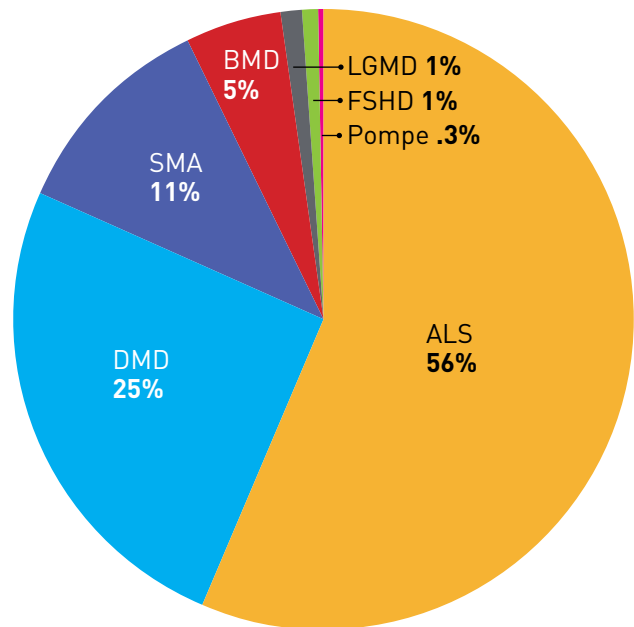
In addition, MDA has put in place the Research Advisory Committee, Data Use Committee, and Publication Committee to provide support and guidance. “We are aligning what we’re doing with the data with experts in clinical research and technology,” Rayne says.

Sites participating in MOVR are compensated for start-up and for their time inputting data. “But the real value is, we offer them immediate access to their site-level data as well as the opportunity to request free access to the de-identified aggregate dataset through the Data Use Committee,” Rayne says.

Looking forward

In the coming year, the MOVR team plans quarterly publications. The first will be a descriptive paper, followed by publications on the three disease areas with most participants in the registry.

Percent of patients in each disease area in MOVR



Another focus in 2021 will be building partnerships with other organizations with accredited data sources, as well as in the biopharmaceutical industry. “We’re increasing our ties with industry when it comes to drug and therapy development,” Rayne says. “We’re also getting a lot of feedback from industry that MOVR is a way to help guide clinical trial protocol development.”