

Dystrophy association, Quintiles make patient registry

09 October 2013 | News | By BioSpectrum Bureau



Singapore: Quintiles and Muscular Dystrophy Association (MDA) have formed a partnership to develop and implement the US Neuromuscular Disease Registry, a patient registry that will play an important role in determining effective treatments for people with muscular dystrophy and related muscle diseases.

Quintiles was awarded the project based on its depth of experience in post-marketing research, multi-stakeholder strategy, and systems-oriented approach to registry design and development.

MDA will use the registry to study the natural history of muscular dystrophy and related muscle diseases, collect information on practice patterns, inform care guidelines and improve quality of care for patients. The registry is currently available at 25 medical clinics within the organization's national network, with plans to expand to their full network of 200 clinics by 2015.

"Patient registries are an increasingly important component of real-world evidence development for understanding the cause of disease and identifying effective treatments," said Mr Richard Gliklich, president, Quintiles Outcome, the real-world and late phase division of Quintiles. "In designing the US Neuromuscular Disease Registry, our goal is to create a research and collaboration platform that will enable physicians, patients, caregivers and others involved in MDA's mission to collaborate to advance new treatments for patients."

"We are making remarkable progress in researching new lifesaving treatments and cures for neuromuscular diseases as we move from bench to bedside in clinical trials," said Mr Valerie Cwik, executive VP and chief medical and scientific officer, MDA. "We are committed to changing and saving the lives of the individuals and families we serve, and the U.S. Neuromuscular Disease Registry brings us one step closer to answering critical clinical and research questions that will improve quality of care."