FSHD Society signs agreement to expand the FSHD Clinical Trial Research Network

Additional support will expand the international network by up to four additional sites to enable well-powered clinical outcome studies for facioscapulohumeral muscular dystrophy

LEXINGTON, Mass. (PRWEB) August 27, 2019 -- The FSHD Society announced today that it has signed a memorandum of understanding to enter into a three-year agreement to enable the expansion of the international facioscapulohumeral muscular dystrophy (FSHD) Clinical Trial Research Network (CTRN).

FSHD is a hereditary muscle-damaging condition that affects an estimated one out of 8,000 people, or nearly one million men, women, and children worldwide. There is currently no drug to treat or cure FSHD.

The CTRN was formed to create an infrastructure of clinics with expertise in FSHD to hasten therapeutic development by ensuring site training of key personnel, streamlining regulatory oversight and data capture, validating novel clinical outcome measures, and refining clinical trial strategies.

Currently the network hosts the Clinical Trial Readiness to Solve Barriers to Drug Development in FSHD study (ReSolve), an 18-month observational study following 220 individuals with FSHD. The network was initially financed with seed funding from the FSHD Society, as well as other non-profits, and has since been awarded $1.2MM in support from the Muscular Dystrophy Association.

The current CTRN encompasses a total of 11 sites, with 8 sites in the United States and 3 sites in Europe. The central coordinating center is housed at the University of Kansas Medical Center, and the data and statistical coordinating center at the University of Rochester Medical Center. Under the new agreement, the FSHD Society will provide KUMC with additional infrastructure support and allow it to expand the CTRN by up to four additional sites.

“With the prospect of a growing number of FSHD clinical trials on the horizon, it will be critical for the CTRN to have the capacity and bandwidth to not only carry out the existing research studies but also successfully recruit and participate in clinical trials” said Mark Stone, President and CEO of the FSHD Society.

Jeffrey Statland, MD, associate professor of neurology and co-director of the CTRN, added “We are grateful to the FSHD Society and like-minded organizations that have made it possible for the network to form and carry out studies to help bridge the gaps in clinical trial readiness. The additional sites will ensure that the CTRN will be able to meet the goal of trial preparedness, and ensure well-trained FSHD clinical centers.”

About the CTRN (www.kumc.edu/fshd/about-the-fshd-ctrn.html)
The Facioscapulohumeral Muscular Dystrophy Clinical Trial Research Network (FSHD CTRN) is a consortium of eleven academic research centers (8 in the United States, and 3 in Europe) with expertise in FSHD clinical research, or in conducting neuromuscular clinical trials. These centers leverage existing clinical trials infrastructure: including clinical investigators, research coordinators, study evaluators, and institutional resources like Clinical and Translational Science Research Awards (CTSA) and local Research Institutes for clinical trial budget and contracting, and Clinical Research Centers, which provide subsidized clinical research space and facilities.
About the FSHD Society (www.fshsociety.org)
The FSHD Society is the world’s largest research-focused patient organization for facioscapulohumeral muscular dystrophy (FSHD), one of the most prevalent forms of muscular dystrophy. The Society has catalyzed major advancements and is accelerating the development of treatments and a cure to end the pain, disability, and suffering endured by one million people worldwide who live with FSHD. The FSHD Society has transformed the landscape for FSHD research and is committed to making sure that no one faces this disease alone. The Society offers a community of support, news, and information through its website at https://www.fshsociety.org.
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