Many “Firsts” for the 26th Annual FSHD International Research Congress

The world’s premier conference on the rare muscle disease sets attendance records as it convenes for the first time in Europe

LEXINGTON, Mass. (PRWEB) June 19, 2019 -- The FSH Society announced the opening today of its 26th annual International Research Congress (IRC) in Marseille, France. The conference is widely seen as the premier global platform for the discussion and dissemination of state-of-the-art research on facioscapulohumeral muscular dystrophy (FSHD). Nearly 200 researchers, clinicians, industry representatives and patient advocates are attending.

Researchers who have networked at this yearly gathering since 1994 have helped to drive fundamental discoveries, with a broad consensus on a “central hypothesis” of the genetic basis of FSHD, development of cellular and animal models, identification of therapeutic targets, and a flowering of ideas for treating FSHD. The field is nearing the completion of a Phase 2 clinical trial of a myostatin inhibitor, and the first disease-modifying therapy for FSHD is expected to go into a Phase 2 trial later this year.

Many aspects of this year’s conference signal the rapid maturation of the field. The Congress is being held for the first time in Europe, to reflect the major contributions of European centers of excellence in FSHD. To keep pace with the expansion of FSHD research, this meeting has been extended from one day to two full days.

The program committee made special efforts to attract clinical researchers, as advancement of drug development brings greater urgency to improving the understanding of the clinical features of FSHD, genotype-phenotype correlations, natural history, and evaluation of disease progression. As a result, the number of attendees and scientific presentations has grown by 50 percent.

“With the recent advances in FSHD studies now including large sets of data, greater availability of biomaterials from multiple large research initiatives, and the rapid approach of more clinical trials,” the program committee noted, “the FSHD International Research Congress serves a more important role than ever: to ensure dissemination of the latest ideas and discussion of the field’s needs and priorities, combined with collaboration and coordination, to speed up progress toward delivering effective treatments to our patients and families.”

About the FSH Society
The FSH 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 FSH 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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