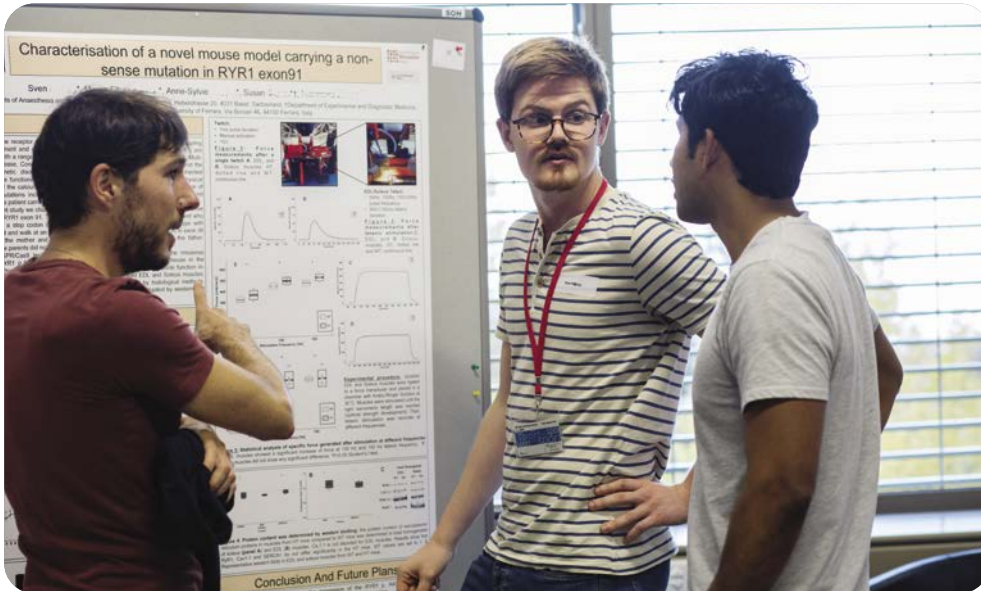


Swiss Biotech Success Stories award winner 2024

A Swiss foundation supporting R&D for the treatment of neuromuscular diseases since 1985



Imagine that you are the parents of two sons who have difficulties running and playing football with their friends. After seeing many doctors, both children are diagnosed with a genetic, progressive neuromuscular disease. Medical understanding of this disease is rudimentary; there are many variants, no available therapies and the prognosis is often fatal.

This is what happened to Jacques and Monique Rognon in the early 80s. After an initial period of despair and helplessness, they decided to promote research on neuromuscular diseases. In 1985, together with two patient organizations, they created the "Fondation Suisse de Recherche sur les Maladies Musculaires" (FSRMM) and from then on devoted all their energy to fundraising.

Since its inception, FSRMM has raised in excess of CHF 30 million and funded more than 200 research projects at Swiss universities and hospitals. These projects range from basic research to clinical applications, with a particular focus on supporting young researchers to establish their own neuromuscular research projects. FSRMM also contributes to patient registries, supports seven Swiss reference centers that care for the patients and help their parents, sponsors the European Neuromuscular Centre, a forum that brings scientists together to discuss specific neuromuscular diseases, and organizes a biannual, three-day meeting for Swiss researchers. Finally, FSRMM has provided seed funding to two startup companies. Clinical trials are underway and the first compounds have now been approved in the US and Europe.



“Over the last 40 years, remarkable progress has been made in the understanding of rare diseases and neuromuscular diseases in particular. FSRMM occupies a prominent position in this niche area in Switzerland. As a private complement to public research funding, its objective remains unchanged: to advance research and give hope to those affected.”

Alain Pfulg, President of the FSRMM