



A Case Study of Joining FSHD Europe as a New Member Organisation

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FSHD Europe is growing and looking for new members to join. FSHD Finland joined in 2024 and gave a good example that others could follow. We interviewed Lauri Pirinen and Lora Chun on how they managed to do this.

How was the beginning of your journey?

Actually, the beginning was tough. We started from scratch one and a half years ago. It was hard to reach out to patients or search for help, and personally I was even about to give up when no one responded, says Lauri Pirinen. As contrast to that, the welcome to the international FSHD community was very warm. The people behind FSHD Europe seemed to be very open-hearted ever since from the beginning and they offered many kinds of support. Thanks to their advice, we had success in engaging with patients later.

How was it to set up an organisation and join FSHD Europe?

It was not possible to act within our muscular dystrophy association, so we decided to start our own organisation. There were several reasons including to be convincing, to be able to get grants etc. According to the Finnish law there must be at least three founders of an organisation who become board members. Writing statutes was relatively easy as there were templates available, and the organisation registration process included inspection of the statutes by a lawyer. Eventually, our application was approved. After the registration we needed to write privacy policy for member database according to GDPR, and other tasks that running an organisation requires as opening a bank account etc. We told FSHD Europe that we had started an official organisation and they were interested in it. They welcomed us to join when we feel fit to join after getting started on a national level. We still have work to do to get really started but this felt the right time to join.

What were the biggest challenges?

The biggest challenge was how to connect with other patients and, how to motivate people to be the founders of the organisation. Group messages didn't seem to work. Instead, personal messages and organising a patient meeting worked clearly better. Overall, it requires a lot of work to motivate patients to become members, says Lora Chun. Difficulties in patient engagement are a universal problem since many people from other countries have said they have similar problems too.

What was the easiest part?

Joining FSHD Europe was very easy. We just filled in a form and sent it by email, and the process was very straightforward. Also, before this our muscular dystrophy association forwarded a message to their members who have an FSHD diagnosis that we are reaching out to them which was beneficial.

What do you think are the reasons to join FSHD Europe?

First, being integrated to a larger federation, and thereby, being able to collaborate smoothly. Speaking with one voice, and thus, having a larger impact. As it is a rare disease there are not a lot of patients or expertise in a single country.

What do you think FSHD Europe can offer to new beginners?

FSHD Europe already has two guides available, one for starting a FSHD patient organisation and one to create and manage a website (you find them here). The guide offers clear steps, and it can be further enhanced. Being connected to FSHD Europe for getting answers to even the simplest questions and being connected to peers who are also starting an organisation is crucial.

What would you say to those who are in the same situation as you were one and a half years ago?

It takes time and effort, but it is possible. A lot of progress can happen in a short period of time.