

FSHD Europe

Patient Representative for FSHD

We are looking for FSHD patients from across Europe to join us in international advocacy efforts. Help us represent the community in important areas such as EMA (European Medicines Agency), Health Technology Assessments (HTA), and patient education.

Are you someone with lived experience of FSHD, or are you closely involved with FSHD and neuromuscular conditions in general? Can you look beyond your own situation and take other people's experiences into account? If so, the role of patient representative might be a great fit for you.

You will contribute to discussions from the patient perspective at the European level, focusing on research, care, and policy around FSHD.

You don't need to be a researcher or doctor, what matters is a critical mindset. Can you judge whether a study is relevant to patients? Whether the burden is acceptable, privacy is respected, and costs are covered? As a patient, you are uniquely placed to assess what truly works in real life.

Who can become a patient representative?

- Minimal 18 years old
- Lived experience (patient, parent, or caregiver)
- Member of a national patient organization
- Sufficient English communication skills

What you bring:

- Lived experience with FSHD or close involvement, and a willingness to understand other perspectives
- Ability to translate individual experiences into the bigger picture
- Optional: interested in taking a training course in patient representation

What to expect:

- Regular online meetings
- Opportunities for personal growth and development
- Networking opportunities

If you're interested in joining the FSHD Patient Advisory Council, please contact us today! Email: Ria.deHaas@fshd-europe.info

FSHD Europe

Member patient advisory council

Are you living with FSHD? Your voice matters! We are inviting individuals affected by FSHD to join the **FSHD Europe Patient Advisory Council (PAC)** and help shape the future of treatments and care for this rare disease.

As a PAC member, you will have the opportunity to directly engage with pharmaceutical companies, researchers, and healthcare professionals. Your insights, experiences, and opinions will be crucial in guiding the development of new therapies and ensuring that patient needs are at the forefront of clinical research.

The council will meet periodically, and your participation will include sharing feedback, providing input on study designs, and discussing potential treatments in development.

We are looking for individuals who are passionate about improving the lives of people with FSHD. Whether you're newly diagnosed or have been living with FSHD for some time, your unique perspective is invaluable.

Who can become a PAC Member?

- Minimal 18 years old
- Lived experience (patient, parent, or caregiver)
- Member of a national patient organization
- Sufficient English communication skills
- Reflect both personal and community perspectives
- Willing to sign a Non-Disclosure Agreement (NDA)
- Able to review materials ahead of time
- Commit to scheduled meetings

What to expect:

- Increased understanding of the practice of clinical trials
- Increased understanding of FSHD disease pathologies and therapy targets
- Contribution to FSHD Europe
- Networking opportunities
- Meaningful volunteer work / CV building

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FSHD Europe

Communication Expert

Are you passionate about supporting the FSHD community? FSHD Europe, the leading European patient organization, is looking for a young, dynamic communications expert to join our team as a volunteer!

We're seeking someone between the ages of 18 - 40 who is highly experienced in social media and online communications. If you have a deep understanding of how to engage communities and raise awareness, we want you to help us amplify our message and connect with FSHD patients across Europe.

This is a remote volunteer position requiring 4-8 hours a week. Fluency in English is important, as it will be our main working language. Your role will involve managing social media channels, creating engaging content, and helping raise awareness about FSHD while supporting our advocacy efforts.

What to expect:

- Participating in online meetings with the management team
- Contributing to the communication strategy
- Writing news items for the website, newsletter, and social media
- An open-minded team that is eager to learn from you
- Bring in your own ideas!

If you're enthusiastic about making a difference for the FSHD community, working online, and being part of an exciting, impactful, developing organization, we'd love to hear from you!

Ready to make a change? Please contact us today!

Email: Ria.deHaas@fshd-europe.info