



Guide to Starting a FSHD Patient Organization

FSHD Europe is the voice for people living with facio-scapulo-humeral dystrophy (FSHD)

Our mission is to improve the quality of life for all patients and their families, and facilitate the easy diagnosis of FSHD, and enable all patients have access to the best treatment. FSHD Europe unites and amplifies the voice of FSHD patients across Europe, raising awareness and interest among all stakeholders, including researchers, clinicians, pharmaceutical companies, regulators, payors, and national patient organizations.

Our **objectives** are:

- To find a cure for FSHD through successful cooperation.
- To promote awareness, understanding, and knowledge of FSHD.
- To stimulate, promote, and share knowledge and experiences in the field of care, welfare, support, and diagnostics of individuals struck by FSHD and their families.
- To stimulate, facilitate, and financially or otherwise support research into the causes of FSHD to find a cure or medicine for FSHD.
- To raise funds to finance scientific research into FSHD as such and into support activities in the broadest sense of the word.
- To work towards the attainment of the Association's goals in collaboration with national and international FSHD and other organizations, whether private or governmental, that have any involvement with muscular disorders.
- To protect the interests of people suffering from FSHD and their families, in the broadest sense of the word.

This guide is based on a content originally created by the Axial Spondyloarthritis International Federation (ASIF). FSHD Europe is grateful for ASIF's generosity in sharing its resources.

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Introduction

Almost every patient organization starts out because someone wants to make important change happen for those affected by a particular health condition.

Patient organizations connect people with shared experiences, provide education and awareness, stimulate research and optimal care, or tackle policy issues to improve diagnosis and treatment. They can help people better manage their health and support them in their engagement with healthcare professionals.

There are many things to consider when establishing a patient organisation, and it can be difficult to know where to start. This guide has been created to support your ambition to set up an FSHD patient organization.

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Finding your community

Building a community takes time and commitment. Your FSHD community will be crucial to the success of your organisation.

Find your community and tell them about wanting to start a patient group. Your community is likely to start off as a small group of people, either living with FSHD or connected in some way to the disease. It could be a small Facebook Group to start with. Connecting with, and growing your relationships with your community, including patients, neurologists and other healthcare professionals is an important first step to establishing a community base.

To do this:

- You can use social media to connect with patients and caregivers; try finding relevant groups. There may be FSHD related groups already established in your country.
- You can write emails to specialist healthcare professionals, asking them to let their patients know you are establishing a patient group and passing on your contact details (you can produce a simple electronic flyer for them).
- It is helpful to connect with healthcare professionals and ask them to be involved in your community. They have a unique perspective, can help to guide your work, and will help to build credibility.

Setting up the organisation

Continue to build your community and talk to them before you establish your goals. The first gathering of patients and caregivers, whether virtual or in person, is usually passionate and exhilarating — especially if the attendees have never met other people living with the same disease. This is a critical opportunity to ensure you have a good understanding of the needs of your community, which will help you identify the goals of your organisation.

Identify your team. Why do it alone? You can grow and reach more people as a team and people will have different sets of skills and expertise that can complement each other. As you establish your group, seek out individuals who are passionate about changing the lives of people with FSHD.

Name your group. You can decide on the name of your organisation with your team or community. Once this is decided, the name can usually be registered as a non-profit organisation with the government in your country.

Build your database of members. As people ask to be involved with your group, start to build a list of who they are, their contact details and what their interest is (for example, patient, parent, or healthcare professional). Having this information is crucial to be able to communicate with your members. When you start applying for funding, having a database of members is important. You should ask for their permission to keep this information and ensure you are complying with local data protection laws.

Ask FSHD Europe to connect you with other patient groups that can help with advice and sharing their experience.

Your organisation's identity

Some of the most important parts of establishing your group's identity include your name, logo, vision, and mission, as well as your online presence (website and social Media).

- **Logo.** A logo can be a helpful identifier of your group. It can be used on your organisation's social media channels, website, and materials to help build familiarity with the organisation.
- **Tagline.** This is usually one line that describes your vision or mission — something that tells people what you are all about. For example, "To connect and support people living with FSHD".
- **Website.** There are many free or low-cost website platforms, like WordPress. This can be basic at first and grow over time.
- **Materials.** A one-page leaflet (electronic or printed) is an effective way to introduce people to your organisation.
- **Social media.** Decide which social media channels will be most effective for your organisation – start with one if your resources are limited. Consider creating a private group for members to talk openly.

Creating a leadership team

Is it really needed?

A leadership team plays a key role in guiding your organisation.

It also provides a group of individuals with different skills and experiences to share roles and responsibilities and, therefore, make better decisions for the organisation. Your team might be very small to start with and grow, as you find you need additional experience, expertise, or capacity.

There are no rigid rules about who the team should be made up of, you might want to consider:

- Chair or President: This person leads the team and meetings; and ensures everyone gets chance to have input
- Treasurer: If your association will be managing funds (donations, grants, membership fees etc.), it is good governance to have someone who oversees the organisation's finances
- Patients
- Healthcare professionals

Engaging healthcare professionals

The value of clinical experts

The expertise of healthcare providers who specialise in FSHD or neuromuscular diseases is a valuable resource. Their role could be to validate that the information you are providing patients is accurate or to use their experience to help the organisation make decisions.

Building strong relationships with disease experts will help establish your organisation among the medical community, while also helping you to reach patients.

Ways to involve healthcare professionals:

- Invite a medical expert to join your leadership team, or to be a medical advisor.
- Invite medical experts to share new research and disease developments at events, in your newsletter, website or social media.
- You can ask them to share your social media posts.

Healthcare professionals to engage

There are many healthcare professionals that your organisation may work with, from fields including – but not limited to – neurologists, geneticists, rehabilitation doctor, physiotherapist, and psychologists.

Governance

What is it?

A set of guidelines and regulations that says how your organisation will be run and outlines its structure. This gives an organisation direction and a purpose and provides a framework and a strong foundation. Again, this can be basic at first and grow over time.

What is included?

- Vision, mission, and purpose
- Team roles (including responsibilities)
- Team structure
- How decisions are taken
- Board effectiveness
- Risk and financial planning
- Compliance with legislation
- Accountability, openness
- Equality and diversity

Funding the organisation

Running a successful patient organisation costs money. There could be office expenses, fees to design and host a website, or costs associated with printing flyers and brochures.

As the organisation becomes more established, you may also have salary costs or the costs of running specific projects.

Funding can come from:

- Donations
- Membership fees
- Funds from pharmaceutical companies
- Grants for non-profit organisations
- Fundraising

It is important to check local regulations on the funding of non-profit organisations.

Stay connected with your community

Build a database. Include your members, volunteers, and supporters (healthcare professionals, pharmaceutical industry contacts) to make it easy to find their information.

Post on social media. Sharing posts and information from other organisations (such as FSHD Europe, the World FSHD Alliance and FSHD Society) is a wonderful way to stay connected without always having to create new content.

Write a newsletter. This can be a simple pdf that you attach to an email or consider a platform such as MailChimp that offers free or low-cost plans that make it easy to create and send newsletters.

Update content. Your website and newsletters are suitable places to provide links to recent FSHD news and interviews with medical experts, researchers and patients.

Increase subscribers. Encourage people to sign up for your newsletter by adding a sign-up link on your website and posting about it on social media.

Share campaigns. Sharing campaigns from FSHD (World FSHD Day on June 20th) or other relevant organisations is an effective way to engage with your community.

Meetings and conferences

There are many ways to connect with patients, caregivers, and healthcare professionals, either in-person or virtually.

- Support groups – patients only
- Webinars – invite speakers
- Information sessions – invite speakers
- Attending conferences – having a booth for your organisation, speaking or presenting a poster at a conference can be a great way to connect with new individuals.
- Events on awareness days like World FSHD Day June 20th
- Podcasts can also be a great way to share information with your community

It is useful to record virtual events for those that cannot attend. It can also be a good reference point later to help build a library of resources. You can consider setting up your own YouTube channel.

Education and engagement

A key strength of a patient organisation is its ability to keep its community engaged and educated.

The information available on your website, in newsletters and on social media, is important. Ensuring its current and accurate helps to establish trust and credibility.

Some ideas to generate content:

- Interviews with doctors and other healthcare professionals
- Patient/ caregiver stories
- 'Explainer' type stories that look at relevant lifestyle issues
- Reporting on articles from other organisations
- Profiles of leading researchers

We're here to help

We understand how daunting setting up your own organisation can be. FSHD Europe was founded in 2010 by people living with FSHD and their close relatives who saw the value of collaboration across Europe. We currently have ten member organisations who support people with FSHD in different European countries. We recognise that every country has different contexts and challenges, with national organisations at different stages. We may not always have the answers, but we are committed to supporting our European FSHD community and will do all we can to help you. We believe in our capacity to do this.

Please reach out to us if you need help.

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