



Guide to Create and Manage a Website

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.

Content

Website considerations	4
Content Management System (CMS)	5
Domains and hosting	6
Designing your website	7
Brand and accessibility	8
Creating a strong website	9
Website design	10
Best practices to engage users	11
Launching and managing your website	12
Tracking your website's performance	13
Some commonly used website terms	14
We're here to help	14

Website considerations

There are many things that contribute to a perfect website – but small charitable organisations don't necessarily need a perfect website – they often need something [simple, but effective](#), that meets their basic requirements and can grow with them.

When starting, the process can be daunting, take significant time and be expensive. This guide highlights things to consider, but not all need to be done immediately.

Your budget will determine many things about your website. For example, will you build the website yourself or get a developer to create it for you? Websites can be relatively easy to create; however, seeking advice from an expert is often worth the investment as they may ask you things that you haven't considered. They can also help create a structure that will allow your website to grow as your organisation grows.

[Quality content is vital](#) – if the information is not correct and relevant, people will not return to your site. Consider how often you can update the information – if your resources are limited, include content that will not become out of date too quickly.

Ensure that you [regularly check your website](#) – links and images sometimes break, and information gets out-dated.

Content Management System (CMS)

- CMS is the software that allows you to create, manage and modify content on a website, without specialist knowledge in coding.
- There are lots of CMS platforms available, with WordPress being the most popular. It offers a free, easy to use, reliable and secure system, with many plug-ins that allow you to create contact forms and accept online donations etc.
- Security, especially if taking donations or collecting contact information, is vital. Whatever system you use, it is important to ensure that it is secure.
- Make sure the collection of any personal information complies with local privacy laws.
- With many people accessing websites on phones and tablets, it's important for them to be responsive. Today, most CMSs will incorporate mobile optimisation into the design, but it is always worth checking.

Domains and hosting

A **domain name** is a unique easy to remember address, for example 'fshd-europe.info'. Choose one that is short, simple and relates to your organisation's name. You can search to find names that are available.

- Most charities choose to use '.org' or '.info' or country specific, this can help to convey a sense of trust.
- There are many companies that sell domain names and offer different subscription options.

A **website host** is a company that stores your website files and data and allows your site to be online. The web hosting provider is responsible for sending your website content to your visitor.

- There are many website hosting plans available – it is important to ensure the company has a user-friendly control panel to manage your hosting account, provides regular backups of your site, offers fast loading speeds and guarantees maximum uptime (you don't want your website to be offline).
- Check the add-ons and renewal fees when considering the pricing plans. Choose a company with good 24/7 customer service that can assist you with any issues, and who you can easily contact if you have technical problems.

It is worth considering buying your domain name and hosting from the same company as this can reduce complications. You may want to ask another patient organisation for a recommendation.

Designing your website

Your website will represent your organisation and will be one of the first places people go to find out about you. What do you want them to know? What information do you want to share with them? Think about what you want your website to be and do?

Consider drafting a brief for your website, including:

- **Critical features** – who you are and what you do, contact information, donation facility, social media links, information about FSHD and your activities.
- **Important features** – requirements that are important but are less time critical, for example event calendar.
- **Less important features** – items that can be added to the website after launch, for example links to other relevant organisations.

Brand and accessibility

Your website should reinforce your brand.

As well as including your logo and colour palette, your website should use a consistent tone of voice (professional, friendly, welcoming etc.) so that visitors recognise your organisation.

The [Web Content Accessibility Guidelines \(WCAG\)](#) are an internationally recognised set of recommendations.

[Follow accessibility guidelines to ensure everyone can access your website.](#) Does your CMS support accessibility? Have you used headings correctly to organise your content, used alt text for all images, given links unique and descriptive names, ensured forms are accessible, and considered the used of high contrast colours?

Creating a strong website

Your website represents you. It's your chance to tell visitors who and what you are, your mission, and share valuable information about FSHD.

- Your home page should include your organisation's name, logo, and the key information you want to share, for example what your organisation does – keep it simple and visually appealing.
- Your content should be sectioned into pages and with clearly marked menu items at the top of the home page to allow users to find the information they are looking for easily.
- Calls to action and contact information should also be easy to find.
- Use images and colour to break up text, invite users in and keep them interested.
- Try to include information and use language that your audience can relate to. If it's too scientific they may lose interest.

Website design

On average, **you have 15 seconds to capture someone's attention** the first time they visit your website, so you need to be ready...

- Use attractive banners and images that catch the eye and communicate a message.
- Catchy, short headlines and lots of sub-heads in long content pieces help the reader to stay interested and follow the story.
- Include relevant links to similar content throughout your website. Consider taking visitors on a journey, when they get to the bottom of an article, where you can point them next to?
- Include links to other resources so that your site can act as information hub (always open these links in a new window so you don't lose them from your site).
- Tools such as Canva provide an easy way to create images and banners for websites, social media, and other resources; Canva has free offering for charities. Websites such as Unsplash provide free stock images that can improve the look of your website.

Best practices to engage users

- Tell patient and caregiver stories
- Research, statistics, and expert reports provide value, but also help to position your organisation as connected and knowledgeable.
- Lists, such as, 'Top five reasons to exercise' are easy to read and are likely to keep someone on your page longer.
- Add new content as often as possible to keep your site fresh.
- Combine different content formats like videos and podcasts to keep your site interesting.
- Include logos of other organisations (such as FSHD Europe and FSHD Society) to show your organisation is part of a global group and add credibility.

Launching and managing your website

Checklist for launching your website

- Ensure all dummy content has been deleted and placeholder images replaced.
- Check your contact details.
- Test any forms.
- Set up web analytics.
- Finalise legal pages, for example Privacy Policy.
- Secure your website – you might choose to use a security plug-in.
- Activate automatic updates for any plug-ins.
- Create a backup policy – either in-house or via your web hosting company.
- Test, test and test again!
- Once your website is live, invite a couple of people to visit your site and test the links, contact form, pages etc. before you tell people your website is live.

Let your community know your website is live!

- Social media is a key tool in launching your site and continuing to drive traffic there. Posts and tweets can link to your website to allow people to read a full article or find out more. Include links to your social media accounts on your website.
- Ask your contacts to share your launch posts about your website.
- Include an article about your website in your newsletter. You may choose to publish short articles in your electronic newsletter, which link through to full articles on the website; this will regularly drive traffic to your website.
- Include your website address – and social media handles – on your email footer and in any printed material or presentations you give.
- If you have a relationship with any healthcare practitioners, let them know you have a website and encourage them to let their patients know.

Future considerations

Consider [Search Engine Optimisation \(SEO\)](#). This is the process of improving your site to increase its visibility when people search for something related to your organisation – there are many websites and companies offering advice.

[Google Ad Grants](#) offer not for profit organisations grants for ad space on Google.

Tracking your website's performance

Keeping track of how many people visit your website, what content they are most interested in, and how long they stay on a page can be helpful.

This information can be used to ensure the content and services you are offering are of value.

Google Analytics is a popular web analytic tool, which offers a basic free service as well as charging for advanced features. You may want to talk to a web developer about setting analytics up on your website.

Some commonly used website terms

Alt Text – is the descriptive text attached to images on your website. It can be recognised by screen readers and will show when images are hovered over.

Browser – this is the interface that helps display web pages. Some examples are Chrome, Firefox, and Safari.

Cookies – a cookie on a website refers to a text file that is created by a website and stored on a visitor's computer. Cookies help to recognise visitors and keep track of their preferences.

Domain name – the name used to identify the location of a website.

Home page – the main page of a website.

Navigator bar – also called 'menu', helps users find their way around a website.

Plug-in – a piece of software that adds new features to an application, for example a security plug-in for a WordPress website.

SEO – Search Engine Optimisation is the process of improving how your website performs in search engine results.

URL – a uniform resource locator is the address of a web page. It usually starts with 'www'.

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.

info@fshd-europe.info