UK FSHD Patient Registry
Registration User Guide

How to join the UK FSHD Patient Registry as a patient, or as the parent/carer of a patient

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Step 1 – Setup your user account

- Go to the registry website - https://www.fshd-registry.org.uk/
- Click ‘Register now’
- You will see the registration page that looks like the image below. Add your information, tick the box at the bottom of the page, then click the green ‘continue’ button.
- Please ensure you keep your email address and password somewhere safe – you will need to remember the details you have used in order to log in to the registry to provide updates in future.
Step 2 – Confirm your details

- Check that you have entered your name, date of birth, sex and email address correctly.
- Press the yellow ‘back’ button if you need to make any changes (don’t use your web browser’s back button).
- If you are happy your information is correct, press the green ‘continue’ button

- After pressing ‘continue’, your user account will be setup and you will receive a confirmation email, but your registration is not yet complete.
- You are, however, now able to complete the rest of your registration in stages if you wish, as you can log in and out of the website using your email address and password from step 1
- The following message will now appear in the top right of the screen when you are logged in:
Step 3 – Add your address

- Add your postal address on this page. Please ensure you select ‘United Kingdom’ from the country dropdown options.
- If you do not live in the UK, please contact the registry curator before continuing.
Step 4 – Add your phone number

- Add your phone number(s) on this page
- Please note we will only contact you by telephone if we are unable to reach you by email. It is important to have more than one way of contacting you in case you lose access to the email account you used to register.
Step 5 – Add patient information

- On this page you should declare whether you are registering for yourself, or for someone else.
- You can come back to this page if you need to add another patient - you can only register one patient at a time.
- Please add the patient’s NHS or PPS number if known, then press the green ‘continue’ button to proceed.
Step 6 – Complete the patient consent form

- Please read through the consent form on this page. If you are registering on behalf of a patient, please ensure they understand all the information provided.

- If you or the patient have any questions about anything in the consent form, please contact the registry curator before continuing.

- If you do decide to pause your registration at this page, please be reassured that you can pick up the process from this point and won’t need to start from the beginning.

- Take your time to read through the whole page....
• When you reach the bottom of the page, please enter your initials in each text box to indicate you agree with each statement.

• If you do not enter your initials in each box, you will be unable to continue with your registration.

• Press the green ‘continue’ button to proceed.
Step 7 – Select your doctor

- The next step is to select your doctor from the list. This should be your FSHD specialist, not your local GP or family doctor.

- If you don’t see your specialist doctor on the list, please choose the ‘no selection’ option at the end of the list.

- If your doctor is not listed, please contact the registry curator with the full name of your specialist and which hospital they are based at, and they will be invited to join the registry.
Step 8 – Provide information about your / the patient’s condition

- At this point you have registered as a patient on the registry, but now we need to collect information about your / the patient’s condition.

- These questions are split into 3 sections asking about your condition, your pain levels, and your wellbeing/quality of life.

- Please complete each page as thoroughly and honestly as you can, then click the green ‘save’ button at the end of the page to continue.

- If you need a break at any time you can logout and come back to this section by logging back in and clicking on ‘your patient data’ from the menu on the left of the screen

- Once you have completed section 3b ‘Your Quality of Life’ and clicked ‘save’, you have completed your registration and provided all the information we need for this patient for now.

- You will receive a reminder email in a years’ time to ask you to log back on to the website using the email address and password you entered in step 1. You can log in to update your answers to these questions as often as you like, but we ask that this is done at least annually

- You have now completed your registration! If you need to add another patient, please proceed to the next step.
Step 9 – Adding another patient

- This step is only required if you will be providing patient information for more than one patient (i.e., if you have two children with the condition, or if you are entering information for yourself as a patient and also for your partner as a patient). If an adult patient is willing and able, they should set up their own registration and complete the information themselves, however we appreciate this is not always possible.

- Ensure you are still logged in to the website (look for the ‘you are logged in as _________’ message in the top right of the screen. If you don’t see this, click ‘login’ from the menu on the left of the screen and enter the email address and password you used to register in step 1.

- Once you are logged in, click ‘overview’ from the left menu, then click ‘add new patient’

- Repeat steps 5 – 8 for this patient. Once this is complete, both patient names will then appear on the overview page so you can easily see whose information you are updating.

- You can add as many patients as you want to by repeating this step, however please note you should only register patients for whom you are a parent or carer, and you will be responsible for keeping the information updated for any patients you have added.

- When a patient turns 16 years old, they will be required to complete the consent process again and given the option of creating their own user registration to take ownership of their patient record.
Troubleshooting

- If you see an error message at any point, please try to take a screenshot or a photograph of the screen if possible, and make a note of the time when the error occurred. This can help our IT team identify what has caused the problem.

- Please do not hesitate to contact the registry curator if you have any problems using the registry or are unsure what to do. You can click here to send them an email, or contact them by telephone on 0191 241 8640. The curator can guide you through the process step by step, or can even complete your registration for you over the phone if you are not confident using the website.

- If you do encounter an error message on the website, there are a couple of things you can try yourself that may resolve the issue without the need for any further steps...
  
  o Refresh the webpage. The refresh button usually looks like a circular arrow and will be somewhere near the website address (example circled in green below). It might look slightly different or be in a different position at the top of your screen depending on which web browser you are using. Clicking this button will re-load the page you were on so you may need to enter a small amount of information again.

  ![Refresh Button](fsdh-registry.org.uk)

  o If refreshing the page does not work, try going back to the registry homepage. You may need to log in again (check for the message in the top right of the screen that will appear if you are already logged in).

  o When you are logged in, you can click ‘overview’ from the left menu to navigate back to the page you were on when the error happened.

Problems logging in?

- If you have any problems with logging in to the registry, please do not try to register again as this can lead to duplicate records. Please contact the registry curator who can help identify and resolve the issue.

- If you are unsure if you have registered previously or not, please contact the registry curator who can check if you have any historical or partially completed registrations.

If you have any questions, comments, or feedback, or would like more information about anything to do with the UK FSHD Patient Registry please get in touch with the registry curator who is on hand to help.