FSHD European Patient Survey

Page 1: Welcome

Welcome to the FSHD European Patient Survey

You have been invited to participate in a research study titled “FSHD European Patient Survey”. The purpose of this study is to find out what FSHD (Facioscapulohumeral Muscular Dystrophy) patients and their caregivers want from future clinical trials and what would encourage them to participate.

FSHD Europe are working in partnership with the John Walton Muscular Dystrophy Research Centre at Newcastle University, UK, to develop, manage and analyze this survey. This information will be used by FSHD Europe and pharmaceutical companies to ensure that when trials are developed, they are designed and organised in a way to maximise patient involvement and participation.

If you agree to take part in this study, you will be asked to complete a survey on the next page. This survey will ask you questions about your condition and how it is currently being managed. It will also ask you your thoughts on clinical trials and what might help you to decide to participate in the future.

The survey should take approximately 45 minutes to complete. You may not directly benefit from this research; however, we hope that your participation in the study may help guide future clinical trials.

Some demographic information is collected in this survey; however, it is treated in an entirely anonymous fashion and the identity of whoever is completing the form
cannot be traced. The data from this survey will be used to produce a report which will be shared with FSHD Europe and pharmaceutical companies.

Your participation in this study is completely voluntary and you can withdraw at any time. You are free to skip any question you choose.

1. Please indicate that you have read and understood this consent form and if you agree to participate in this research study. ***If the patient is under the age of 18, their***

parent or legal guardian must complete the consent below on their behalf. *

Required

- I have read and understood this consent form and agree to participate in this study
- I no longer wish to participate in this study

Page 2: Participant information

2. Why have you chosen to participate in this survey?

- ☐ I care about the FSHD community
- ☐ I am interested in the study
- ☐ Want to help research for FSHD
- ☐ Other

2.a. If you selected Other, please specify:

3. Where did you hear about this survey?

- ○ Social media
- ○ FSHD Europe mailing list
- ○ Mail from national patient organisation
- ○ Patient registry
- ○ Other

3.a. Please specify:

4. Are you completing this survey as a patient or caregiver?

- ○ Patient

- Caregiver
- I am both a patient and caregiver

4.a. What is the relationship between you and the person you care for?

4.b. Is the person you care for also completing this survey?

5. Which country do you currently live in?

6. It is important to capture the ethnicity of the patient to measure the inclusion and diversity within clinical trials. What is the ethnicity of the patient?

- Prefer not to say
- Arab or North African
- Asian or Asian European
- Black, Black European, Caribbean or African
- Mixed or multiple ethnic groups
- White or Caucasian
- Other

6.a. Other ethnic group (please specify):

6.b. Asian or Asian European

- Indian
- Pakistani
- Bangladeshi
- Chinese
- Japanese
- Korean
- Thai
- Vietnamese
- Other

6.b.i. If you selected Other, please specify:

6.c. Black or Black European

- African
- Caribbean
- Other

6.c.i. If you selected Other, please specify:

6.d. Mixed or multiple ethnic groups

- White and Black Caribbean
- White and Black African
- White and Asian
- Any other Mixed or multiple ethnic background
- Other

6.d.i. If you selected Other, please specify:

6.e. White or Caucasian

- British: English, Northern Irish, Scottish or Welsh
- Dutch
- French
- German
- Irish
- Italian
- Spanish
- Other

6.e.i. If you selected Other, please specify:

7. Current age of the patient

8. Sex of the patient

- Female
- Male
- Prefer not to say

Page 3: Current management of FSHD

9. Are you taking any medication for FSHD-specific issues or related symptoms?

- No, never
- Yes, in the past
- Yes, currently

10. What medications are you currently taking to help manage your condition, if any? Select all that apply.

- Nothing
- Prescription medication (such as steroids, anti-anxiety medication, pain relief)
- Over the counter medication such as paracetamol or ibuprofen
- Dietary and herbal supplements
- Other

10.a. Please specify:

11. Other than medication, are you using any of the following to help manage your condition? Select all that apply.

- Not currently using anything
- Exercise
- Physical or occupational therapy

- ☐ Braces, splints, kineso tape etc
- ☐ Mobility aids (such as a walker or wheelchair)
- ☐ Respiratory aids (such as BiPAP machine)
- ☐ Surgery (such as scapular fixation)
- ☐ Diet modification
- ☐ Complementary or alternative therapies
- ☐ Counselling/therapy
- ☐ Adjustments to my house
- ☐ Adjustments to my car
- ☐ Other

11.a. If you selected Other, please specify:

12. How well do you think that your current regimen controls your overall condition and symptoms?

- ○ N/A I am not using any treatments or other therapies
- ○ Not at all
- ○ Very little
- ○ To some extent
- ○ To a great extent

13. What are the biggest limitations of your current treatment regimen? Select all that apply.

- [ ] N/A I am not using any treatments
- [ ] Not very effective
- [ ] High cost
- [ ] Limited availability or accessibility (e.g., do not live close to a specialist centre)
- [ ] Number of medications that I have to take daily
- [ ] Time consuming
- [ ] Requires a lot of effort
- [ ] Other

13.a. If you selected Other, please specify:

Page 4: Thoughts and expectations of clinical trials

In the next section of the survey, we are going to ask about your thoughts and expectations of clinical trials.

Clinical trials are research studies involving people. They test whether particular treatments are safe and how well they work.

If you take part in a clinical trial, you may be one of the first people to recieve a new treatment. There's a chance that the new treatment turns out to be no better, or worse, than the standard treatment. It's also possible you'll experience unexpected side effects.

You could also be given a placebo. A placebo is used in clinical trials to test the effectiveness of treatments and is most often used in drug studies. For instance, people in one group get the tested drug, while the others receive a fake drug, or placebo, that they think is the real thing. This way, the researchers can measure if the drug works by comparing how both groups react. If they both have the same reaction — improvement or not — the drug is deemed not to work.

You may have to visit your place of treatment more often, or have more tests, treatments or monitoring. You may also need to travel to a specialist centre to take part.

It's important to find out about the inconvenience and risks involved before you sign up, and to carefully weigh up whether it's worth it.

Bear in mind:

- It can be time consuming – you may be expected to attend a number of screening and follow-up sessions, and some trials require you to stay overnight
- Some of the tests can be tiring, or take a long time to complete
- Some of the tests could be painful, such as a muscle biopsy
- There may be restrictions on what you can and cannot do – for example, you may be asked to not eat, or not drink alcohol, for a period of time
- You may experience unknown side effects from the treatment

For further information you can visit the following links

- NHS - Clinical trials

- National Institutes of Health - What are clinical trials?

Page 5: Thoughts on clinical trials

14. Would you consider participating in a clinical trial

- Yes
- No
- Not sure

15. What would encourage you to participate in a clinical trial? Please rank the following from 0 (not encouraging) to 5 (most encouraging)

Please don't select more than 1 answer(s) per row.

	0 (Not encouraging)	1	2	3	4	5 (Most encouraging)
Compensation for travel/time	☐	☐	☐	☐	☐	☐
Access to new investigational product or therapy	☐	☐	☐	☐	☐	☐
Help in organising my visit (e.g. booking hotels and transport for me)	☐	☐	☐	☐	☐	☐
Access to trial results when published	☐	☐	☐	☐	☐	☐
To be seen by a specialist centre	☐	☐	☐	☐	☐	☐

Flexibility in appointment times	☐	☐	☐	☐	☐	☐
Meet other patients with the same disease	☐	☐	☐	☐	☐	☐
Benefits for the FSHD community	☐	☐	☐	☐	☐	☐
Benefits for my family	☐	☐	☐	☐	☐	☐
Clear indication of level of commitment required	☐	☐	☐	☐	☐	☐

15.a. Is there anything else that might encourage you to participate in a clinical trial that was not listed here?

16. What would discourage you from participating in a clinical trial?
Please rank the following from 0 (not discouraging) to 5 (most discouraging)

Please don't select more than 1 answer(s) per row.

	0 (not discouraging)	1	2	3	4	5 (most discouraging)

Fear of side effects from treatment	☐	☐	☐	☐	☐	☐
Lack of transportation to get to trial site	☐	☐	☐	☐	☐	☐
I could be in the placebo group	☐	☐	☐	☐	☐	☐
Too many appointments are required	☐	☐	☐	☐	☐	☐
Facility of the clinical trial is far away	☐	☐	☐	☐	☐	☐
Lack of flexibility in appointment times	☐	☐	☐	☐	☐	☐
Would have to miss work/school	☐	☐	☐	☐	☐	☐
Lack of financial compensation for time spent on the trial	☐	☐	☐	☐	☐	☐
Do not want FSHD diagnosis on medical records	☐	☐	☐	☐	☐	☐
Travel is expensive	☐	☐	☐	☐	☐	☐

Long time to wait between trial and results	☐	☐	☐	☐	☐	☐

16.a. Is there anything else that might discourage you from participating in a clinical trial that was not listed here?

17. What would you be willing to participate in during a clinical trial? Select all that apply. **More information on some of the tests is available below**.

More info

- ☐ Blood sample
- ☐ Open muscle biopsy
- ☐ Needle muscle biopsy
- ☐ MRI machine
- ☐ Functional assessments e.g. grip strength, timed up and go
- ☐ Lung function assessment
- ☐ Use a wearable device e.g. fitbit for several weeks
- ☐ Other

17.a. If you selected Other, please specify:

17.b. During a clinical trial, it can be important to monitor the effects that a new therapy might have. You could therefore be subjected to a test multiple times. How many needle muscle biopsies would you be willing to have?

More info

- One muscle biopsy only
- Two or more muscle biopsies

17.c. How long would you be willing/able to sit in an MRI machine?

More info

- Less than 30 minutes
- Up to an hour
- Up to 90 minutes
- 2 hours or more

18. Is there a procedure that would discourage you from taking part in a clinical trial? Select all that apply.

- Blood sample
- Needle muscle biopsy
- Open muscle biopsy
- MRI machine
- Functional assessments e.g. grip strength, timed up and go
- Lung function assessments
- Use a wearable device e.g. fitbit for several weeks
- Other

18.a. If you selected Other, please specify:

19. Some of the tests during a clinical trial could be strenuous and take a lot of effort. If you had travelled a long way to take part in a clinical trial, how long would you require to recover from your journey before taking part in these tests?

- Less than one hour
- Several hours
- I would prefer not to travel on the same day as the tests (Arrive the day before and stay at a hotel)

20. How long would you be willing to travel to take part in a clinical trial?

- Less than one hour
- 1-2 hours
- 3-4 hours
- 5 or more hours

21. Would you be willing to stay overnight in a hotel that was suitably equipped to meet your needs?

- Yes
- No

21.a. How many nights would you be willing to be away from home?

- One night
- 2-3 nights
- 4 or more nights

22. Would you be willing to travel abroad for a clinical trial?

- Yes
- No
- Not sure

22.a. Would you be willing to travel to a country with a different language?

- Yes
- No
- Not sure

23. Would you require a companion to travel with you to a clinical trial? (e.g., parent, partner or friend)

- Yes
- No

24. Would you be willing to complete self-monitoring assessments at home as a part of a clinical trial? E.g., Complete a strength test and send in the results electronically

- Yes
- No

- Not sure

25. Would you be willling to take part in phone/video call assessments from home?

- Yes
- No

26. Would your relatives/friends be willing to participate in a clinical trial which included people with and without FSHD?

- Yes
- No
- Not sure

Page 6: Expectations of clinical trials

27. Is there something that you have lost the ability to do because of your FSHD, that you would like to regain?

28. Is there a particular symptom of FSHD that you would like to be improved first? Select up to 3 options.

Please select no more than 3 answer(s).

- [ ] Pain
- [ ] Fatigue, Energy and Endurance
- [ ] Not being able to walk or impaired mobility
- [ ] Difficulty using arms or hands
- [ ] General muscle weakness
- [ ] Impaired facial expression
- [ ] Balance and coordination
- [ ] Mood and motivation (e.g., depression or anxiety)
- [ ] Breathing issues
- [ ] Poor sleep
- [ ] Impaired vision
- [ ] Speech or swallowing difficulties
- [ ] Urinary or bowel incontinence
- [ ] Independence
- [ ] Other

28.a. If you selected Other, please specify:

29. What do you feel is the most important outcome of a new therapy? Select up to 3 options.

Please select no more than 3 answer(s).

- ☐ Stopping the progression of the disease
- ☐ Reduction in pain
- ☐ Reduction in fatigue, increased energy and endurance
- ☐ Regaining strength
- ☐ Preserving respiratory and lung function
- ☐ Strengthening facial muscles
- ☐ Improved balance and coordination
- ☐ Improved mobility
- ☐ Improved mood and motivation
- ☐ Reducing fall risk
- ☐ Increased independence
- ☐ Other

29.a. If you selected Other, please specify:

30. What is your minimum expectation for a clinical trial?

Please select at least 1 answer(s).

- ☐ Improving research of FSHD
- ☐ Feedback of the results
- ☐ Being seen in a specialist centre
- ☐ Other

30.a. If you selected Other, please specify:

31. What social benefits of a therapy would you consider important? Select up to 3 options.

Please select no more than 3 answer(s).

- ☐ Increased independence
- ☐ Improved speech and communication
- ☐ Less fear of falling over
- ☐ Attending work or school
- ☐ Participation in sports and hobbies
- ☐ Other

31.a. If you selected Other, please specify:

32. If a treatment was available that could potentially help your symptoms of FSHD, which side effect would you be concerned about experiencing? Select all that apply.

- ☐ Headaches
- ☐ Muscular pain
- ☐ Stomach or gut effects, such as nausea, lack of appetite or diarrhoea
- ☐ Liver or kidney problems
- ☐ Increased susceptibilty to infection
- ☐ Changes in blood pressure
- ☐ Behavioural side effects such as change in mood; anxiety, insomnia etc
- ☐ Heart related effects such as palpitations
- ☐ Changes in weight
- ☐ All of the above
- ☐ Other

32.a. If you selected Other, please specify:

33. How would you prefer to receive updates or results of a clinical trial?

- ☐ Newsletter
- ☐ Website
- ☐ Post
- ☐ Email
- ☐ Phone call

34. Do you have any other thoughts, expectations, or concerns about taking part in a clinical trial that you haven't had an opportunity to share in this survey?

Page 7: Information about current condition

35. At what age did symptoms first appear?

36. What was the first symptom experienced?

- Weakness in arms/hands
- Pain
- Scapular winging
- Facial weakness
- Weakness in legs/feet
- Other

36.a. If you selected Other, please specify:

37. FSHD may be diagnosed based upon a clinical examination, identifying key characteristics of the condition, family history and genetic testing. Have you received a diagnosis of FSHD from a healthcare professional?

37.a. At what age was the diagnosis given?

37.b. Has the diagnosis been genetically confirmed?

38. How would you describe the current severity of your disease overall?

- Not at all affected
- Mildly affected
- Moderately affected
- Severely affected

39. How do you feel that your condition has changed in the last 6 months?

- Very much improved
- Much improved
- Minimally improved
- No change
- Minimally worse
- Much worse
- Very much worse

40. How do you feel that your condition has changed in the last 3 years?

- Very much improved

- Much improved
- Minimally improved
- No change
- Minimally worse
- Much worse
- Very much worse

Page 8: Information about current condition

41. Which of the following are you able to do? Select all that apply

- ☐ Hold head up without support
- ☐ When lying down, I can roll onto my side without assistance
- ☐ I can sit up straight without using my arms or hands to balance
- ☐ Crawl on hands and knees for at least three movements (e.g., move arms and legs three times)
- ☐ I can stand up for at least 10 seconds without support
- ☐ I can stand up for at least 10 seconds, but I would need support (e.g., holding onto a chair)
- ☐ I can walk at least 100 metres without assistance
- ☐ I can walk at least 10 metres without assistance
- ☐ I can walk at least 5 steps without assistance
- ☐ I can walk at least 5 steps, but I would need to hold on to something for support
- ☐ I can climb at least 4 stairs independently (holding on to a railing)
- ☐ I can use my hands to hold pencil, drive wheelchair or use phone keypad
- ☐ When sitting, I can raise both arms at the same time above my head
- ☐ When sitting, I can raise one or both of my hands to my mouth

42. Do you have any difficulty with the activities listed below because of problems with your arms or hands? Please rank from 0 (extreme difficulty or unable to perform activity) to 4 (no difficulty)

Please don't select more than 1 answer(s) per row.

	N/A	0 (extreme difficulty or unable to perform activity)	1	2	3	4 (no difficulty)
Any of your usual work, housework, or school activities	☐	☐	☐	☐	☐	☐
Your usual hobbies, recreational or sporting activities	☐	☐	☐	☐	☐	☐
Lifting a bag of groceries to your waist level	☐	☐	☐	☐	☐	☐
Lifting a bag of groceries above your head	☐	☐	☐	☐	☐	☐
Grooming your hair	☐	☐	☐	☐	☐	☐
Pushing up on your hands (e.g. from bathtub or chair)	☐	☐	☐	☐	☐	☐
Preparing food (e.g. peeling, cutting)	☐	☐	☐	☐	☐	☐
Driving	☐	☐	☐	☐	☐	☐
Vacuuming, sweeping, or raking	☐	☐	☐	☐	☐	☐
Dressing	☐	☐	☐	☐	☐	☐

Doing up buttons	☐	☐	☐	☐	☐	☐
Using tools or appliances	☐	☐	☐	☐	☐	☐
Opening doors	☐	☐	☐	☐	☐	☐
Cleaning	☐	☐	☐	☐	☐	☐
Tying laces on shoes	☐	☐	☐	☐	☐	☐
Sleeping	☐	☐	☐	☐	☐	☐
Laundering clothes (e.g. washing, ironing, folding)	☐	☐	☐	☐	☐	☐
Opening a jar	☐	☐	☐	☐	☐	☐
Throwing a ball	☐	☐	☐	☐	☐	☐
Carrying a small suitcase	☐	☐	☐	☐	☐	☐

Page 9: Information about current condition

43. How is your walking ability?

- Not at all affected
- Mildly affected: My walking ability is affected but I do not use walking aids
- Moderately affected: I require aids to help me walk
- Severely affected: I require a wheelchair

43.a. What walking aids do you use, if any? Select all that apply.

- Walking stick
- Splints
- Walking frame
- Wheelchair for part of the time (sometimes able to get around without a wheelchair)
- Wheelchair for all of the time (unable to get around at all without a wheelchair)

44. How often do you experience falls?

- N/A I do not experience falls
- N/A as I use a wheelchair full time
- At least once a day
- At least once a week
- At least once a month
- At least once a year

44.a. What causes you to fall? Select all that apply

- Muscle weakness

- [ ] Poor balance
- [ ] Fatigue
- [ ] Pain
- [ ] Other

44.a.i. If you selected Other, please specify:

[   ]

44.b. Have you ever sustained injuries due to a fall?

- ( ) No injury
- ( ) Yes, minor injuries (e.g. some bruising)
- ( ) Yes, major injuries (e.g. broken bones)

45. How do you feel your respiratory (breathing) health has been affected by FSHD?

- ( ) Not affected
- ( ) Mildly affected
- ( ) Moderately affected - require non-invasive ventilation (e.g., BiPAP machine)
- ( ) Severely affected - require invasive ventilation

45.a. If you require ventilation, is this full time or part time?

- ( ) N/A I do not require ventilation
- ( ) Part time - less than 16 hours per 24 hours
- ( ) Full time - 16 hours or more per 24 hours

46. Has your speech been affected by your FSHD?

- Not at all affected
- Mildly affected: usually understood and rarely asked to repeat things
- Moderately affected: poorly understood by strangers, frequently asked to repeat things
- Severely affected: poorly understood by family and friends, uses communication aids

47. Do you have any difficulties in swallowing?

- Not at all affected
- Mildly affected: occasional feeling of solids 'sticking'
- Moderately affected: Frequent feeling of solids 'sticking'. Some adaptations to diet. Coughing/choking infrequent (1-4 times a month)
- Severely affected: Requires adapted diet - regular coughing or choking (more than once a week)

48. Which symptoms of your condition cause you concern?

Please don't select more than 1 answer(s) per row.

	0 (no concern)	1	2	3	4	5 (very concerned)
Pain						
Fatigue, energy and endurance						
Not being able to walk or impaired mobility						

Difficulty using arms or hands	☐	☐	☐	☐	☐	☐
General muscle weakness	☐	☐	☐	☐	☐	☐
Impaired facial expression	☐	☐	☐	☐	☐	☐
Balance and coordination	☐	☐	☐	☐	☐	☐
Mood and motivation (e.g., depression or anxiety)	☐	☐	☐	☐	☐	☐
Breathing issues	☐	☐	☐	☐	☐	☐
Poor sleep	☐	☐	☐	☐	☐	☐
Impaired vision	☐	☐	☐	☐	☐	☐
Impaired hearing	☐	☐	☐	☐	☐	☐
Speech or swallowing difficulties	☐	☐	☐	☐	☐	☐
Urinary or bowel incontinence	☐	☐	☐	☐	☐	☐

48.a. Are there symptoms not mentioned in this list which cause concern?

Page 10: Information about current condition

49. Which symptoms of your condition causes difficulty in daily activities?

Please don't select more than 1 answer(s) per row.

	0 (No difficulty)	1	2	3	4	5 (Causes great difficulty)
Pain	☐	☐	☐	☐	☐	☐
Fatigue, energy and endurance	☐	☐	☐	☐	☐	☐
Not being able to walk or impaired mobility	☐	☐	☐	☐	☐	☐
Difficulty using arms or hands	☐	☐	☐	☐	☐	☐
General muscle weakness	☐	☐	☐	☐	☐	☐
Impaired facial expression	☐	☐	☐	☐	☐	☐
Balance and coordination	☐	☐	☐	☐	☐	☐
Mood and motivation (e.g., depression or anxiety)	☐	☐	☐	☐	☐	☐
Breathing issues	☐	☐	☐	☐	☐	☐
Poor sleep	☐	☐	☐	☐	☐	☐
Impaired hearing	☐	☐	☐	☐	☐	☐
Impaired vision	☐	☐	☐	☐	☐	☐
Speech or swallowing difficulties	☐	☐	☐	☐	☐	☐

Urinary or bowel incontinence	☐	☐	☐	☐	☐	☐

49.a. Are there any other symptoms that hinder you greatly that are not mentioned in this list?

50. Could you describe in more detail how these symptoms impact your daily life?

51. Thinking about the future, what concerns you most about your condition?

Please don't select more than 1 answer(s) per row.

	0 (Not at all concerned)	1	2	3	4	5 (Causes great concern)
The stress of not knowing how my disease will progress	☐	☐	☐	☐	☐	☐
Losing independence	☐	☐	☐	☐	☐	☐

Losing mobility/ability to walk	☐	☐	☐	☐	☐	☐
Losing the ability to communicate and/or swallow	☐	☐	☐	☐	☐	☐
Developing respiratory issues	☐	☐	☐	☐	☐	☐
Not having the energy to work or live as I want to	☐	☐	☐	☐	☐	☐
Coping with chronic pain	☐	☐	☐	☐	☐	☐
Financial concerns	☐	☐	☐	☐	☐	☐
Becoming a burden to my family	☐	☐	☐	☐	☐	☐
Losing social connections	☐	☐	☐	☐	☐	☐
Fear of seeing family affected	☐	☐	☐	☐	☐	☐

51.a. Is there anything not mentioned in this list that you would like to add?

52. Could you describe this concern in more detail?

53. Do you have any diagnosed illnesses or conditions, alongside your FSHD?

54. Is there any aspect of your condition or treatment that you feel are not covered in this survey?

Page 11: Final page

Thank you for taking the time to complete this survey.

If this survey has raised questions about your condition or participation in a clinical trial, please get in touch with your doctor or patient organisation. A link to patient organisations can be found here https://fshd-europe.info/member-organisations/

If you have any questions about the survey and how this information will be used please contact Megan McNiff at the John Walton Muscular Dystrophy Research Centre, Newcastle University by email: megan.mcniff@newcastle.ac.uk

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Key for selection options

4.b - Is the person you care for also completing this survey?

Yes
No
We are completing this survey together

5 - Which country do you currently live in?

United Kingdom
Afghanistan
Albania
Algeria
Andorra
Angola
Antigua & Deps
Argentina
Armenia
Australia
Austria
Azerbaijan
Bahamas
Bahrain
Bangladesh
Barbados
Belarus

Belgium
Belize
Benin
Bhutan
Bolivia
Bosnia Herzegovina
Botswana
Brazil
Brunei
Bulgaria
Burkina
Burundi
Cambodia
Cameroon
Canada
Cape Verde
Central African Rep
Chad
Chile
China
Colombia
Comoros
Congo
Congo {Democratic Rep}
Costa Rica
Croatia
Cuba
Cyprus
Czech Republic
Denmark
Djibouti
Dominica
Dominican Republic
East Timor
Ecuador
Egypt
El Salvador
Equatorial Guinea
Eritrea
Estonia

Ethiopia
Fiji
Finland
France
Gabon
Gambia
Georgia
Germany
Ghana
Greece
Grenada
Guatemala
Guinea
Guinea-Bissau
Guyana
Haiti
Honduras
Hungary
Iceland
India
Indonesia
Iran
Iraq
Ireland {Republic}
Israel
Italy
Ivory Coast
Jamaica
Japan
Jordan
Kazakhstan
Kenya
Kiribati
Korea North
Korea South
Kosovo
Kuwait
Kyrgyzstan
Laos
Latvia

Lebanon
Lesotho
Liberia
Libya
Liechtenstein
Lithuania
Luxembourg
Macedonia
Madagascar
Malawi
Malaysia
Maldives
Mali
Malta
Marshall Islands
Mauritania
Mauritius
Mexico
Micronesia
Moldova
Monaco
Mongolia
Montenegro
Morocco
Mozambique
Myanmar, {Burma}
Namibia
Nauru
Nepal
Netherlands
New Zealand
Nicaragua
Niger
Nigeria
Norway
Oman
Pakistan
Palau
Panama
Papua New Guinea

Paraguay
Peru
Philippines
Poland
Portugal
Qatar
Romania
Russian Federation
Rwanda
St Kitts & Nevis
St Lucia
Saint Vincent & the Grenadines
Samoa
San Marino
Sao Tome & Principe
Saudi Arabia
Senegal
Serbia
Seychelles
Sierra Leone
Singapore
Slovakia
Slovenia
Solomon Islands
Somalia
South Africa
South Sudan
Spain
Sri Lanka
Sudan
Suriname
Swaziland
Sweden
Switzerland
Syria
Taiwan
Tajikistan
Tanzania
Thailand
Togo

Tonga
Trinidad & Tobago
Tunisia
Turkey
Turkmenistan
Tuvalu
Uganda
Ukraine
United Arab Emirates
United States
Uruguay
Uzbekistan
Vanuatu
Vatican City
Venezuela
Vietnam
Yemen
Zambia
Zimbabwe

7 - Current age of the patient

Less than one year old
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35 - At what age did symptoms first appear?

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37 - FSHD may be diagnosed based upon a clinical examination, identifying key characteristics of the condition, family history and genetic testing. Have you received a diagnosis of FSHD from a healthcare professional?

Yes
No