



FSHD

UNIVERSITY

Getting trial ready

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FSHD Society

What is trial readiness?

For the individual

- Having a doctor's diagnosis
- Genetic testing
- Being up to date on trials that are recruiting or soon will be
 - FSHD Society website
 - FSHD Society newsletters
 - [Clinicaltrials.gov](https://clinicaltrials.gov)
- Be in the best health you can be



Things you can do

See a neurologist and discuss whether any upcoming trials are a good fit

- Find a suitable neurologist.
 - [Clinical Trial Research Network \(CTRN\)](#).
 - [Contact the Society](#) if you are not near a CTRN site
- Educate your doctor
 - [FSHD Masterclass](#)

Get a genetic test if you haven't had one

- [Genetic testing page](#) on our website
- [TestFSHD program](#)



Be connected and informed

- Make sure you are in [our contact registry](#)
 - How we use the registry for outreach
- Make sure you are reading our newsletters
 - We email two newsletters per month
 - If you're not getting them, check your spam folder
- Find out about clinical trials and research
 - Visit [our page on clinical trials and studies](#)
 - How to read clinicaltrials.gov



Be in the best health possible

[FSHD University](#) on the website

Connect with others for information and support

- [Local chapters](#)
- [The Gathering Place](#)
 - Wellness Hour, Women on Wellness, Feeling Fit with FSHD
 - CarePartner Hour and Early-onset Parents Roundtable
- [Facebook](#) and [Instagram](#)

Do it for the community – even if you aren’t in a clinical trial

- Know what’s going on so you can tell others
- Be present. If you are near a CTRN site, get to know them
- Tell your doctor and physical therapist about what’s going on
- Share information with family members and friends
- Share your FSHD journey through testimony & surveys
- Support the community. [Raise awareness. Raise funding. Raise friends.](#)



Thank you for all
you are doing to
help make our
community
trial-ready!

