



# New Zealand Aotearoa

JULY 2024 NEWSLETTER

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Together  
We Can!



## Saliva Tests - We want you!

Anyone with FSHD symptoms, family history, or even a clinical or blood test diagnosis, can take advantage of **free access to FSHD Research Saliva testing** through FSHD Global & the MyFSHD lab!

Here's why:

- Support MyFSHD researchers to improve FSHD diagnostics, and better understand the genes involved (more info [here](#))
- Support FSHD Global to understand prevalence of FSHD, and make diagnosis more accessible (more info [here](#))
- Improve your readiness for FSHD clinical trials
- Learn about your [methylation](#)

To find out how to access your free Research Saliva test, use the contact details on page 2



## Richard Roxburgh: Young kiwi to be first to trial new muscular dystrophy drug

Listen here to [here](#) Dr Roxburgh talk about the first person with FSHD to be treated in the Arrowhead's ARO-DUX4 Trial, based here in New Zealand. Find trial information [here](#)



## AVIDITY SHARES INTERIM DATA FROM ITS FORTITUDE TRIAL

Overseas, the pharmaceutical company Avidity has shared some early data from its FSHD trial: “...its investigational therapy for facioscapulohumeral muscular dystrophy (FSHD) reduced by more than 50% the expression of genes that are regulated by DUX4 – widely viewed as the gene that triggers muscle weakness and degeneration in FSHD. What’s more, the company reported trends showing improvement in muscle strength, reachable workspace, and other outcomes reported by participants and clinicians” Read more of this article [here](#) on the FSHD Society website, or listen to Dr Jones discuss the results on his [podcast](#).



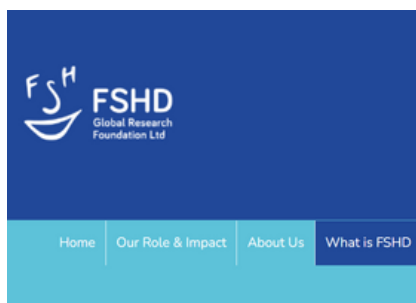
## LEARN MORE ABOUT FSHD

Interested to learn more about your genes, what to expect, and managing symptoms? Here are some places to find reputable information and advice:



MyFSHD is a great source of information on genetics and therapeutics.

[Click here](#)



The FSHD Global website has easy to read information, from the types of FSHD, thorough to useful therapies.

[Click here](#)



FSHD University is a free online portal for education about the “art and science” of living with FSHD. They have regular webinars that are recorded. [Click here](#)

## Need some more support?



Reach out to the **Muscular Dystrophy Association NZ** for support, resources, and advocacy. See their website [here](#)

Join our **FSHD NZ Facebook page**, where we stay in touch with other kiwis with FSHD, and meet once a month online to connect and learn from each other. Join [here](#)



Learn more about supports for your area and/or needs on the Ministry of Disabled People **Whaikaha** website. Click [here](#)



## Contact the author

My name is Kayla, live with FSHD1 in Auckland, and after my (hard to get!) diagnosis in 2022 I have been supported by FSHD Global to help my fellow FSHD kiwis to be connected and supported. If you are interested in saliva testing or anything else FSHD, get in touch through the above Facebook page, or email: [nz@fshdglobal.org](mailto:nz@fshdglobal.org)

