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Dear <<First Name>>,

FSHD Global has been busy planning for an exciting year ahead. As we look towards 2021 with optimism, hope and a renewed energy to build on the strategic virtual platform we instilled into the Foundation in 2020. We look forward to working with our strong, committed and loyal supporters in 2021 to continue the work of FSHD Global in funding world's best medical research into FSHD.



### 2021 NRL Footy Tipping Competition

FSHD Global is launching their 2021 NRL Footy Tipping Competition. Join in the fun of tipping your teams each week and have the chance to win 2 x tickets to the NRL Grand Final. Registration fees are \$30 per person, which will support FSHD Global in their work to find treatments and a cure for FSHD. Invite your family, friends and colleagues to join the competition by registering [here](#)



### **Save the Date - 2021 Muscles for Muscles Squat Challenge**

We are proud to announce that the annual Muscles for the Muscles Squat Challenge will be held during the month of May 2021. The aim of this campaign is to build muscles for those who can't and importantly drive awareness and funding towards finding treatments and a cure for FSHD. Can't squat - no problem! This campaign is ideal for you to rally up your mates, family and friends to participate in the challenge and build muscles on your behalf.

Over the month of May, we want to collectively achieve over 1 million squats, which represents the number of people living with FSHD globally. You can choose to track your squats daily or plan to supersize a day in May with a 24 hour challenge. How you squat is up to you! There will be prizes up for grabs - with further details to be announced shortly.

This challenge is perfect for corporates, gyms, sporting clubs and schools, so stay tuned to get involved!

Want to become a Muscles for Muscles Ambassador? Contact the Foundation for further information on how you can get involved: [admin@fshdglobal.org](mailto:admin@fshdglobal.org)

### **FSHD Medical Education Portal**

Thank you to our wonderful community who have registered with our FSHD Medical Education Portal. We have received a wonderful response since launching the Portal in December 2020. The purpose of this initiative is to:

- Roll out an FSHD Saliva Research Testing program nationwide to ascertain disease prevalence across Australia

- Help educate individuals and their families living with FSHD on new and improved diagnostic technologies
- Provide an accessible way for patients to test their DNA relating to FSHD, with testing kits delivered straight to their home
- Assist FSHD patients to test if this hereditary disease is in their family tree
- Share global research publications and global medical breakthroughs
- Connect people with professional health services and assistance networks who are experienced with the disease
- Actively keep the FSHD community informed on current and proposed FSHD clinical trials, with the opportunity to partake in future clinical trials
- Create a FSHD Global Registry to connect diagnostic data which will aid medical research and link the community to the FSHD Clinical Trial Readiness Program

We would like to encourage our community to explore this Portal, and become an active member of the FSHD global community, supporting the fight against FSHD. Go to [fshdmedicalportal.org](https://fshdmedicalportal.org)

### **2021 Science Information Sessions**


Over the years, FSHD Global has hosted Science Information evenings in Sydney, Melbourne, Brisbane, Perth and even Auckland New Zealand, with the aim to educate and update our FSHD community on medical research advances and to provide the opportunity to ask some of our expert panel questions relating to FSHD. Attended by many of our FSHD Global funded grant recipients, we have been honored to hear from some of the world's leading researchers into FSHD.

Due to COVID restrictions, we have decided to re-commence our Information Evenings by taking them virtual, giving more of our FSHD community access to this vital information. There will be 2 x Information Evenings held in 2021, with details to be announced shortly.

### **2020 Annual Report**

The 2020 FSHD Global Annual Report is a valuable resource, providing information on the Foundation, our work, our community and supporters. To view the report, visit <https://fshdglobal.org/annual-reports> to download a copy of our online version.

Kind Regards,



Danielle Thomson

**Chief Executive Officer | FSHD Global Research Foundation**



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