

## Newsletter Update



### MADISON MARCUS RAISES FUNDS FOR FSHD GLOBAL IN THE 2018 CITY TO SURF



Congratulations to FSHD Global supporters – Madison Marcus for partaking in the 2018 City to Surf and raising money for FSHD Global.

Thank you to the team at Madison Marcus for their continued support of FSHD Global and their constant support in not only raising money for FSHD Global but creating awareness for our important cause.

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### AUSTRALIAN FIRST: FSHD INFANTILE GRANT RECRUITS FOR STUDY

#### GRANT 36 UPDATE

Researchers at The Royal Children's Hospital are looking for children aged 5-18 years who have been diagnosed with FSHD, to participate in one or both of these studies. The Royal Children's Hospital and researchers would be really

interested in hearing from anyone in the FSHD community who meets the criteria.

### **WHO?**

Researchers at The Royal Children's Hospital are looking for children aged 5-18 years who have been diagnosed with FSHD, to participate in one or both of these studies:

1. The effect of the nutritional supplement (creatine monohydrate) on strength and muscle mass in children and young adults with FSHD
2. Investigating the use of FSHD specific patient reported and physical performance assessments to measure strength and function in children with FSHD

### **WHAT?**

The creatine study involves 5 visits over an 8 month period and requires your child to drink a supplement in a glass of milk each day. We will assess strength and function to see if taking the supplement has any effect.

The assessment arm of the study requires two visits 2-4 weeks apart. These will be done in conjunction with the creatine study and will not require any extra time if you choose to participate in both research studies.

Recruitment of participants has begun at The Royal Children's Hospital and researchers would be really interested in hearing from anyone in the FSHD community who meets the criteria.

### **WHO TO CONTACT?**

If you would like more details about the research, please contact:

Katy de Valle

Neuromuscular Research Physiotherapist and FSHD Study Coordinator

The Royal Children's Hospital

50 Flemington Rd, Parkville, Victoria, 3052

P. 03 9345 4287

E. [katy.devalle@rch.org.au](mailto:katy.devalle@rch.org.au)

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# WYNDHAM DESTINATIONS CORPORATE SURF CHALLENGE

Our friends at Wyndham Destinations are once again hosting their annual Corporate Surf Challenge with all money raised from the event being donated to FSHD Global.

The Wyndham Destinations Corporate Surf Challenge will be held on Friday 12 October 2018 at Duranbah Beach NSW and will include a fun filled day of surfing with the likes of Layne Beachley and industry leaders.

Registrations are now open for you to enter your team, so get on board (literally) and enter your team today. Click on the image below for further information about the day and how you can register your team.....

**WYNDHAM  
• DESTINATIONS**

# CORPORATE SURF CHALLENGE

FRIDAY 12TH OF OCTOBER 2018

**HAWAIIAN  
AIRLINES.** WIN TICKETS TO **HAWAII** COMPETITION WINNERS RECEIVE A **CUSTOM SURFBOARD**

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## FSHD GLOBAL ENTERS A NEW CHAPTER

As FSHD Global reaches its 10 year milestone, it is critical to have the best team in place to progress the Foundation and its work to the next level. With that said, we are proud to announce a new leadership team that has been appointed to drive the Foundation forward and execute on the excellent progress that is being made in medical research around the world.

### **Danielle Thomson – Chief Executive Officer**

Danielle is no stranger to FSHD Global. She has worked with the Foundation as Director of Events and Fundraising for over 9 years as the driving force behind our world class event and fundraising programs. Her commitment, knowledge and experience of the Foundation, is what will drive FSHD Global into the very exciting future ahead.

### **Norma Cooper – Executive Office and Operations Manager**

Norma joins us from the Scouts Association of Australia, having worked as National Operations Manager. Norma brings a wealth of knowledge and experience to the Foundation and is critical to ensuring our operations run in a seamless and efficient manner during this crucial time at the Foundation.

### **FSHD Global Core Team**

Please feel free to reach out to our team:

#### **Danielle Thomson**

Chief Executive Officer

[danielle@fshdglobal.org](mailto:danielle@fshdglobal.org)

#### **Norma Cooper**

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