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Dear Loyal Supporter,

2020 has been nothing short of challenging, unprecedented and extraordinary. As a result of COVID-19, we saw the cancellation of our blue ribbon major fundraiser – the Sydney Chocolate Ball which essentially provides funding not only for medical research but our annual operational and fundraising costs.

Whilst most of the world paused its operations, FSHD Global set out to revise its operational and fundraising strategy by delivering virtual campaigns and streamlining operations. Despite the loss of the Sydney Chocolate Ball and challenging economy, our financial results were positive and we saw the launch of new initiatives.

### **Sydney Chocolate Ball Goes Digital**

FSHD Global launched Sydney Chocolate Ball goes Digital. This online platform was a replica of the fundraising initiatives that would have been held at the Sydney Chocolate Ball event. With thanks to our many loyal supporters and sponsors, we raised over \$104,000.

### **Double Your Dollar**

Our End of Financial Year Campaign was led by our Founder and Chairman, Bill Moss AO, as a "Double Your Donation" matching campaign. Mr Moss generously donated \$250,000 which was the catalyst in driving another \$250,000 in donations. With thanks to our generous community, sponsors and supporters, FSHD Global was successful in raising over \$514,000 in donations.

### **Muscles For Muscles**

In September, we launched a new initiative - the Muscles for Muscles Squat Challenge. The aim of this campaign was to build muscles for those who can't and importantly raise awareness, expand our network into new audiences and drive donations. The Squat

Challenge was a month long campaign with over 286 participants, 58 registered teams across Australia, New Zealand, the USA and the UK, raising over \$46,000. This is an outstanding achievement for our inaugural year and we will be back with our Muscles for Muscles Squat Challenge in May 2021.

### **FSHD Medical Education Portal**

FSHD Global has always been an innovator and disruptor. In December, we launched another innovative milestone for the field, establishing the [FSHD Medical Education Portal](#). This Portal brings education, allied health assistance and revolutionises diagnostic methods offering a complimentary FSHD Saliva Research Test sent to a participants home. The Portal connects research, diagnostics, and patients via newly established 'FSHD Global Registry' and furthermore connects people living with FSHD to our new 'FSHD Clinical Trial Readiness Program'.

### **Medical Research Grants**

In 2020, FSHD Global funded 3 new medical research grants across Australia, USA and the Netherlands, in addition to managing 9 active grants. Key research projects include: targeting and correcting FSHD sequences in the human genome through CRISPR inhibition therapy, DNA cell characterization sequencing and development of therapies towards clinical trials by Facio Therapies, a FSHD biotech.

Since its inception, the Foundation has raised over \$11 million in tax deductible donations, funding 54 medical research grants across 10 countries and is the major catalyst for global research into finding a cure for FSHD.

### **Changing of the Guard**

During our September Board Meeting, Founder and Chairman, Mr Bill Moss AO announced his departure from his role as Chairman of FSHD Global. Bill has proudly held this role for 13 years, since he established the Foundation in 2007. Bill remains an active Board Member of FSHD Global, and will remain highly engaged in the Foundations scientific strategy and drive. The Board elected Managing Director, Natalie Cooney as the new Chairperson to lead the Foundation to new heights. Natalie echo's Bills vision, passion and dedication in understanding the complex science behind FSHD, and will continue (with the help of the Foundation's Board of Directors) to uphold the highest standards of transparency and accountability in funding world's best research.

### **FSHD Global wins 2020 Outstanding Achievement Award**

As we reflect on what has been perhaps one of the most challenging years for FSHD Global (and the charity sector at large), it is with pride that we announce that the

Foundation has won the "Outstanding Achievement Awards" in the Australian Charity Awards 2020.

The 2020 Australian Charity Awards have recognised only 13 organisations for their contributions and achievements in the management of programs, projects and services that improve people's lives. This in itself is an amazing achievement when you consider there are over 55,000 charities registered in Australia.

The Outstanding Achievement Award exists to highlight charities that adopt a culture of innovation as the sector seeks to transform in response to COVID-19 and continue to provide fundamental support and services to millions of Australians.

Receiving such acknowledgement is testament to our dedicated team of supporters, community, sponsors, ambassadors, donors and the entire FSHD Global team.

RECOGNISING AUSTRALIAN  
**CHARITABLE  
INITIATIVES**



**THANK YOU**

Thank you to our community and sponsors who continued to support FSHD Global this year by way of monetary donations or the donation of goods and services, which enabled us to deliver our successful campaigns and continue our work to fund world's best medical research into FSHD.

The future remains bright for FSHD Global and I look forward to working with our strong, committed and long standing supporters and community in 2021, as we work together to achieve new benchmarks in raising funds and creating awareness of the Foundation's work.

The FSHD Global team wishes you a very Merry Christmas and a Happy, Healthy and Safe New Year.



Kind Regards,

Danielle Thomson

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



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