

HEAVYWEIGHT JOINS THE FIGHT TO END AGE DISCRIMINATION BY COMMONWEALTH GOVERNMENT

The Disability Doesn't Discriminate campaign continues to build momentum in the leadup to the federal election as Bill Moss AO, Founder and Patron of FSDH Global Research Foundation today announces support for the campaign.

Mr Moss called for a review of the NDIS and for age discrimination to cease back in May 2021.

"FSDH Global Research Foundation is fully supportive of the national DDD campaign aiming to end aged discrimination in the NDIS. We are urging Australians to sign the petition to put pressure on the Government to remove age discrimination from the provision of disability support services. With over 20,000 Australians already supporting the campaign, we are keen to help to continue to build the pressure on the government to realise this is an election issue.

"I have raised this issue with several MPs, including the Prime Minister himself in private meetings, but all Australians need to take a stance on this important issue to ensure it is discussed in the lead up to the federal election.

"I reject the Government's assertion that people over the age 65 are catered for under the My Aged Care scheme. The inequities between the two schemes are shocking and clearly discriminatory and need to be resolved immediately."

Facioscapulohumeral Muscular Dystrophy (FSDH) is a genetic muscle-wasting disease present from birth, but Australians with FSDH who had not applied for the NDIS before the age of 65 have been excluded, discriminated against by the Commonwealth Government.

The second most common form of muscular dystrophy, with an estimated 1 in every 7500 Australians affected, FSDH affects both adults and children, males and females alike.

"FSDH does not discriminate, but the current system does. Our Foundation is advocating for our community through the DDD campaign because we can see how much inequity there is." says Emma Weatherley, Executive Director of FSDH Global Research Foundation. "To have people with FSDH excluded from the NDIS on the basis of age is un-Australian."

"We have been gathering feedback from our FSDH community and have come across many instances of undeniable age discrimination," says Mrs Weatherley. "For example, the Heldson family from Toowoomba, Qld, have a family member who has worked all his life, and had a diagnosis of FSDH for over 50 years, and is now struggling to afford basic care and a wheelchair under the My Aged Care system because he didn't apply for NDIS before the age of 65. He is "lucky" because his daughter also has FSDH and has an NDIS plan which they have been relying on to effectively supplement his package for home support services. This does not help him access assistive technology that he needs. The Aged Care system may work for some people who are aging but it is not designed to provide disability specific needs that occur on top of what we would consider usual aged care needs. This is not the way Australia should be treating people with disabilities, no matter their age."

"Some of our FSDH Community members have missed out on NDIS funding packages by weeks and most of the time they have had an FSDH diagnosis for years prior but have been managing without support or reluctant to go to the government for help. These are Australians who have been fiercely independent, fought in wars, and paid taxes all their life, and need basic disability equipment and support. They don't deserve to be discriminated against," Mrs Weatherley said.

"We call for all Australians to join the campaign to end this inequity and make a fairer Australia for all by signing the online petition at www.disabilitydoesntdiscriminate.com.au." Each website sign-up triggers an email to the person's local member of Federal Parliament.

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For more information on the FSDH Global Research Foundation please visit www.fshdglobal.org or contact Emma Weatherley – emma@fshdglobal.org

For more information on the Disability Doesn't Discriminate campaign, please visit www.disabilitydoesntdiscriminate.com.au or call Chief Executive Officer Mark Townend 0404 871 579.

ABOUT FSHD GLOBAL RESEARCH FOUNDATION

The FSHD Global Research Foundation's mission is to find treatments and a cure for Facioscapulohumeral muscular dystrophy (FSHD). A disease that affects an estimated one million people globally. It is caused by an overexpression of a protein called DUX4, which is toxic to muscle.

The true prevalence of this disease is still unknown. Due to poor diagnostics and misdiagnosis, many people live unaware they carry the genetic gene, at risk of passing down generations. The Foundation's aim is to increase awareness and fund national and international researchers to undertake both clinical and basic research projects that can lead to identifying the cause and a future cure for FSHD. We also aim to increase the knowledge and awareness of FSHD among medical practitioners, researchers, patients, donors and the general community.

The Foundation values strong governance in its commitment to execute world's best practice, medical research and leadership amongst the field of FSHD. With a mission to find treatments and a cure for FSHD as soon as possible, the Foundation is advancing towards drug developments and clinical trials aimed at preventing muscle wasting and improving quality of life for those living with FSHD.

In addition to traditional forms of medical research, FSHD Global also invests directly into well managed FSHD focused Biotechs that focus on technologies with a prospect of leading to clinical trials in patients with any muscular dystrophy that can:

- Grow muscle cells in human tissue
- Improve muscle wellness
- Develop wearable technology to assist in movement.

Since establishment, the Foundation has run an innovative and award-winning charity model, donating 100% of all tax deductible donations funding current and future medical research grants. The Foundation is a true success story, with no Government funding, the Foundation has raised over \$18 million in revenue, funding over 55 medical research grants, across 10 countries. Fast tracking global research, unlocking the mechanism of the disease.