

ILC Grant awarded to Muscular Dystrophy Foundation to develop online support system for the neuromuscular community

The development of an online integrated, technology system to build the capacity and skills of all people living with muscular dystrophy and neuromuscular conditions, their families and carers is now possible thanks to a commitment of funding through the ILC Readiness Grants through the National Disability Insurance Agency (NDIA).

Announced Monday 1 May 2018, this ground-breaking project will see our community more connected & informed to make decisions about their own personal needs and more integrated with specialist & mainstream service provision & support networks in their local area.

Through Australian surveys, it is evident the neuromuscular community is overwhelmed by the lack of clear, consistent information that is age, diagnostic stage, cultural and condition specific.

Karen, a community member living with a neuromuscular condition says she is excited to see something "Targeted towards peoples life stage and a place that we can get all information when, where and how we want it".

The project will be overseen by Muscular Dystrophy Foundation Australia (MDF) governed by an independent National Board of Directors. The consortium of CEOs and Community Services Managers of seven state and territory neuromuscular associations will be directly involved in the operational management and delivery of the project. Content will be developed in consultation neuromuscular specialists in primary and allied health sectors, and directly with the neuromuscular community through Community Consultation Groups.

David Kay, Chair of MDF says "The success of this grant demonstrates the unity and collaboration that continues to occur at State and Territory Association level. A huge achievement by our team of CEOs and testament to the hard work this group continues to do behind the scenes. As a collective it demonstrates that we continue to listen to our community as we aim to deliver supports and resources that will positively impact their lives. Without this support of the NDIA, this project would not be possible".

MDF, together with State and Territory Associations, aims to provide support, linkages and increased capacity to the 20,000 Australians individuals living with muscular dystrophy and neuromuscular conditions. David says, "People with neuromuscular conditions deserve the opportunity to achieve their goals and to live the life they choose".

Harnessing the benefits of relevant local, state & territory specific evidence, linking with global best practice and condition-specific health care and well-being components, the project will link communities with mainstream services in their own geographic region and will bring together communities to embrace diversity and their individual challenges living with these conditions.

Upon completion, the project will ensure mainstream supports and the broader community have a much greater understanding of the needs of the neuromuscular community and as such will be in a better position to support their needs going forward.

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