



THE MOTOR NEURONE DISEASE  
ASSOCIATION OF NEW ZEALAND

# RESEARCH STRATEGY 2019-2022

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CURE • CARE • COMMUNICATE • COLLABORATE

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2016-2017

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# Community survey – research

- Most respondents considered “developing clinical pathways” to be most important research objective.
- At 86%, 85% and 85% the next most-supported research objectives were: improving quality of life, finding a cure and connecting New Zealand to global MND research

		Mean of all groups	PwMND	Families & carers	Previous carers	Health professionals	Supporters
Connecting New Zealand to global MND research	Very Important	83	90	86	84	73	83
	Reasonably important	16	10	13	15	27	17
Enabling New Zealanders with MND to participate in clinical trials	Very Important	75	78	83	80	60	75
	Reasonably important	25	22	17	20	39	25
Developing MND research in New Zealand	Very Important	71	80	74	77	53	73
	Reasonably important	24	16	19	20	45	22
Supporting research trying to cure MND or investigate causes	Very Important	85	88	88	90	68	90
	Reasonably important	14	11	9	10	30	9
Supporting research to improve quality of life with MND	Very Important	86	87	85	86	85	86
	Reasonably important	14	12	13	14	15	14
Developing clinical pathways so all New Zealanders with MND are given consistent, high-quality care	Very Important	91	90	90	94	88	91
	Reasonably important	9	9	8	6	12	9

# MND New Zealand Research Strategy 2019-2022

The aim of the MND New Zealand Research Strategy is to promote and foster a national MND Research programme to ensure all people with MND living in New Zealand receive **the best available evidence-based care and support**, whilst remaining part of **the international effort to identify the causes, and ultimately a cure for MND.**



# CURE & CARE- WHAT IS OUR ROLE?



Funding Body –targeted funding in priority areas

MND Registry, MND Research Network, Scotter Lab eg genetics study



Facilitate increased communication and cooperation across DHBs eg development of clinical pathways

Inaugural MND Hui with Clinicians and MOH- September 2019



Advocate for issues important to pwMND and whanau eg better access to specialist care/equipment/financial assistance

Submission to the govt Health & Disability review



Provide opportunities for researchers to connect- promote clinical research and in turn, develop the MND research workforce

Inaugural MNDNZ Research Conference 9<sup>th</sup> December 2019



Professor Chris McDermott  
Sheffield



Professor Orla Hardiman  
Dublin



Professor Ammar Al-Chalabi  
KC, London



Professor Chris Shaw  
KC, London

Inaugural MNDNZ Research Conference 9<sup>th</sup> December 2019

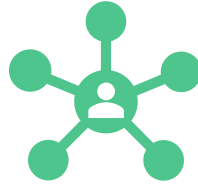


# COMMUNICATE AND COLLABORATE



**Work with researchers and clinicians to ensure we are a trusted source of accurate up-to-date information**

**Working towards having an “expert panel”**



**Enhance the ways by which we share information with our community**

**Facilitate face to face “ask the expert” information sessions ; website blog; online forums**



**Strengthen relationships with associated neurological groups- ensure that MND is represented at a national level**

**BRNZ; Neurological Foundation**

# FUTURE PROJECTS



**Research project grant**



**Scholarship for PhD  
student**



**Annual clinical  
education sessions for  
main centres**

# Walk 2 D'Feet MND

Sunday 10 November







# Inaugural MND New Zealand Research Conference

## Auckland 9<sup>th</sup> December 2019