

Muscular Dystrophy Association of New Zealand (Inc) (MDA)

Research Priorities

The Neuromuscular Research Foundation Trust (NRFT) is accepting funding applications for research relevant to New Zealanders living with neuromuscular conditions which address the MDA's research priorities as follows.

Standards of care

“Standards of care” may include best and/or innovative practice in supporting people with neuromuscular conditions; the extent to which New Zealand service delivery is consistent with best practice standards and norms; and/or the effectiveness and/or cost benefit of service delivery modes and interventions.

It is expected that research into these dimensions of standards of care will assist in positively influencing policy, resource allocation and clinical decision making for people living with neuromuscular conditions.

Condition specific standards of care are produced by Treat NMD, while general standards of care can be inferred from overseas service critiques such as the Walton Report in the UK.

Managed clinical networks are being seen by the New Zealand Ministry of Health as one way of addressing geographical and age related service delivery disparities.

The results of research into standards of care could influence the development of managed clinical networks which in turn could assist in ensuring services of a consistently high standard irrespective of geographical domicile, ethnicity and/or age of service recipients.

Habilitation and rehabilitation

Research into habilitation and rehabilitation would be expected to result in improved opportunities for people living with neuromuscular conditions to live well with the best possible quality of life, and to function optimally given their condition. This could include ensuring that people are supported to live “ordinary lives” with valued social roles, to pursue their goals and interests, to participate as fully as they wish in their communities, and to be fully accorded all of the rights citizenship that people without disabilities are able to take for granted.

New Zealand prevalence and incidence of neuromuscular conditions.

Having an understanding of the prevalence and incidence of neuromuscular conditions can assist in both planning for the future delivery of the MDA

delivered services, and in making the case for improved delivery of externally provided services. Funding applicants interested in addressing this priority should familiarise themselves with the research already initiated by AUT's Dr Alice Theadom.

Treatments and cures

Given the level and type of research that is being conducted internationally and the current limited availability of resources, research into treatments and cures are considered to be of lesser priority unless it can be clearly shown that the results are likely to have a direct benefit to New Zealanders living with neuromuscular conditions and that it extends international research already underway.

Priority will be accorded to research which is:

- Conducted in New Zealand and of primary relevance to New Zealanders living with any or all of the neuromuscular conditions that are within the scope of the New Zealand Muscular Dystrophy Association; and
- Associated with short to medium term time frames of no more than three years
- Associated with applications seeking NRFT funding of up to \$30,000 per proposal

Priority will also be accorded to research which is:

- Of a preliminary nature with the intention of developing further proposals for substantial financial support from research funding agencies such as the Neurological Foundation, Health Research Council etc; or
- Being undertaken by postgraduate students; in which case the NRFT may award up to two New Zealand Muscular Dystrophy Association postgraduate student scholarships per year of \$5000

2nd August 2013