

MEETING THE CHALLENGES OF CARING FOR CHILDREN AND ADULTS AFFECTED BY NEUROMUSCULAR DISORDERS IN AUSTRALIA AND NEW ZEALAND



The Australasian Neuromuscular Network (ANN) is a coordinated and collaborative network that enables health professionals to work together across Australia and New Zealand, for the well-being of people affected by neuromuscular disease.

Nationally, the ANN is partnered with patient support groups including the Muscular Dystrophy Foundation. Internationally, the ANN is part of the European neuromuscular network as a partner of TREAT-NMD, and is closely affiliated with US consortia - allowing us to gain from and contribute to a global effort. For example, the recently established Australian Duchenne muscular dystrophy (DMD) registry connects Australian and New Zealand DMD patients with more than 10,000 patients worldwide across more than 30 countries.

The aims of the ANN include working towards equitable access to clinical trials (via TREAT-NMD), new gene discoveries, improved diagnosis and new therapies to name a few. The overarching goal is to achieve coordinated excellence of care for people with neuromuscular conditions throughout Australia and New Zealand.

In Australia and New Zealand an imbalance exists in the care and treatment provided to individuals affected by neuromuscular disorders. Currently, doctors and medical professionals have no centralised framework to draw on when treating these disorders, nor is there an established pathway for new laboratory discoveries to find their way into clinical practice. This means that for many patients, their diagnosis remains unknown and their treatment may not be optimally tailored for their disorder.

Given the rare nature of the disorders, and the geographical spread throughout Australia and New Zealand, a collaborative network to address diagnosis, prevention and treatment is extremely important. The ANN involves over 280 doctors, medical professionals, scientists and representatives from advocacy groups. This network aims to facilitate the translation of evidence from our clinical and laboratory based research into best clinical practice.

Research into neuromuscular disorders has entered a new era. Advances in sequencing technologies are accelerating gene discovery and therefore our ability to provide an accurate genetic diagnosis is improving. Clinical trials for novel drugs and gene-based therapies are currently underway and hold great promise. The ANN will provide a forum to advance and disseminate information and guide best practice in diagnosis, care and treatment. This includes promoting integrated training programs for clinicians and researchers.

Importantly, the ANN will also provide a single voice to advocate for persons with a neuromuscular disorder and their families. The diagnosis, prevention and treatment of neuromuscular disorders will benefit greatly from a more integrated and united national approach.

The ANN is structured into various areas including clinical care, diagnosis, clinical trials and research. Each area has a steering committee comprising individuals with expertise in each area. These different areas have short (1 year) and long term (5 year) goals. These goals and progress reports are all available on the ANN website (www.ann.org.au), with newsletters available to provide regular updates on progress.

Within the next five (5) years, the ANN has committed to:

- o Increasing access for patients to new therapies by expanding clinical trial centres in Australia
- o Expanding registries so that patients can access trials undertaken anywhere in the world
- o Promoting the expansion of multi-disciplinary clinics
- o Ensuring that 90% of patients will receive an accurate diagnosis
- o Promptly translating research advances into improved health outcomes
- o Making best practice guidelines widely available to clinicians
- o Training clinicians of the future.

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ONE VOICE

OVER **280 MEMBERS**
 CLINICIANS PATHOLOGISTS ALLIED HEALTH RESEARCHERS
 ADVOCACY GROUPS

FOR **EVERY** INDIVIDUAL AFFECTED BY A
 NEUROMUSCULAR DISORDER TO HAVE EQUAL ACCESS TO
 CARE & TREATMENT