

Your MDNSW Community mdnsw.org.au

Muscular Dystrophy NSW is a membership-based, not-for-profit organisation, empowering, supporting and connecting people with neuromuscular conditions and their families.

We support our community by providing:

- · Information, support coordination and direct services such as camps and retreats
- Events that bring people together to share, learn from and support each other
- A strong commitment to research into treatments for neuromuscular conditions, raising funds to sponsor individual researchers and research institutions

Ultimately, every person with a neuromuscular condition should be able to live the life they choose. That's why we're always here for our member community with a listening ear and advice in times of transition.



G Here at Muscular Dystrophy NSW, we create a community for people living with a neuromuscular condition and their families; one where they can connect, learn, grow, share, have fun and be treated with respect and equality.

CHARLOTTE SANGSTER Chief Executive Officer, Muscular Dystrophy NSW

What is **MUSCULAR DYSTROPHY?**

Muscular Dystrophy is a neuromuscular, genetic disorder which results in the progressive deterioration of muscle strength and function. Muscular Dystrophy is the name of one of many different neuromuscular conditions.

Neuromuscular conditions can affect people at different stages of their lives and onset of symptoms can occur from birth to adulthood, depending on the condition.

The rate of progression and pattern of inheritance also varies depending on the condition and the individual.

Neuromuscular conditions are relatively rare, affecting approximately *I in 500* people ______

By that calculation, there are approximately **13,000** people living in NSW with a neuromuscular condition

and **40,000** people Australia wide

Our SERVICES

All the milestones every child goes through during this time – starting school, making friends, homework to name a few – are also all there for children living with muscular dystrophy.

Negotiating the school environment can be especially challenging for children when they start to lose muscle strength, as they become limited in what they can physically do and may need to transition into a wheelchair.

Our supports help children and families through these challenging stages, providing information, support and advice on transition, as well as programs that enrich a child's life, like our Camps and the Duke of Edinburgh's Award.

We also provide support coordination for many children, adults and families, as well as an information and referral service. We support the ongoing medical research in to neuromuscular conditions, facilitating research information sessions, liaising with clinics, providing training and funding a PhD Scholarship. The average age of the majority of our members living with a neuromuscular condition is between 6 and 25





G We are committed to providing quality services and programs for all our clients and members. We make a point of being there for our members at each stage of life, including in times of transition when they might not know what to expect next. We maintain a continuity of support, providing information and advice along the way, focussing on the specific needs of each member and anticipating their future supports.

JOAN MARTIN

Client Services Manager, Muscular Dystrophy NSW

We need your **SUPPORT**

You can help people living with muscular dystrophy and their families build strength and reach potential.

There are many ways for you to get involved and contribute to empowering, connecting and supporting children, teens and adults whose lives are impacted by muscular dystrophy.

Whatever you can do will make a big difference for a person living with a neuromuscular condition and your generosity will be truly valued and appreciated.





Join our ONLINE COMMUNITY! (7) (1) (2) (2)

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