

# EDUCATION, HEALTH & COMMUNITY

In our promise to provide *Support for Life* to our community, Neuromuscular WA has a strong focus and investment into the mental and physical wellbeing of our community, and with these numbers growing faster than expected, our resources are stretched.

Our Community Services team provide social events, educational sessions, capacity building programs, vital life-supporting equipment, NDIS support, research and treatment updates, counselling and advocacy to our people.

Our education sessions are designed to bring increased condition awareness and care options to our community. We expand this by sharing our bank of knowledge with staff in school settings as well as allied health professionals including physiotherapists, OTs and speech therapists, consequently improving health outcomes for our community.

To augment this support, we launched a System Navigation service in 2023, linking our community with a range of mainstream systems that reach beyond health and disability services, including aged care, Centrelink, advocacy support, equipment, transport, education and housing. This critical service is complimentary but comes at a considerable cost to our organisation.

Neuromuscular WA continues to invest in local health research which has been adapted and implemented globally, providing world-leading treatments. We have initiated ongoing PhD Scholarships along with several in-clinic studies and projects that provide incredibly positive health outcomes that are felt directly by our community here in WA.

These include a Respiratory Health study, which determines whether alternative methods to sleep studies can better predict and delay the onset of respiratory failure so treatment can be initiated earlier, preventing premature death. The findings have also helped develop clinical guidelines for monitoring respiratory function in patients to determine relevant outcome measures for future trials.

Running concurrently at PCH is an enhanced nutrition service to children with NMCs which has helped identify that 47% of patients were malnourished, overweight or obese. Without this project these children would not have been identified as at risk or have received dietetic services. It also instigated the creation of a database of nutritional information to facilitate further research and statistics.

We are committed to providing a holistic approach to the care of our community, which stretches far beyond medical treatment for the individual, by providing complementary support to ensure quality of life and better overall health outcomes for all concerned.

## \$2,584,023

invested into community & programs  
from 2018 to 2022

## 844

attendees at  
education sessions  
from 2018 to 2022

## 210

community events  
conducted from  
2018 to 2022

## \$560,557

devoted to our community in 2022



# MEDICAL RESEARCH

**Since our inception in 1967, Neuromuscular WA's pillar of strength has been our strong commitment and investment into world-renowned research**

In 1991, Professors Sue Fletcher and Steve Wilton began research into gene therapy for boys with Duchenne muscular dystrophy (DMD). This early pioneering work was financially supported by significant seed funding provided by our organisation and this work translated into groundbreaking global treatments for DMD and other genetic conditions. Professors Wilton and Fletcher have since lead a team of researchers, now based at Murdoch University, who have developed drugs to treat DMD patients by 'skipping over' the faulty part of the gene message.

Neuromuscular WA continues to invest in local research which has been adapted and implemented around the world and have initiated the following ongoing PhD Scholarships with incredibly positive health outcomes being felt directly by our community right here in WA.

## **RESPIRATORY HEALTH IN PAEDIATRIC NEUROMUSCULAR CONDITIONS**

The primary purpose is to determine whether alternative methods to sleep studies such as lung function testing, symptom scores, quality of life indicators, or motor function assessment can better predict the onset of respiratory failure so treatment can be initiated earlier (delaying the onset of respiratory failure and death).

The secondary aim is to use the findings to describe the natural history of respiratory disease in these conditions, allowing them to construct clinical guidelines for monitoring respiratory function in patients and determine relevant respiratory outcome measures for future trials.

## **PHD SCHOLARSHIP FOR SPINAL MUSCULAR ATROPHY RESEARCH**

In 2018, the WA State government did not allocate funding towards the neuromuscular clinic nurse position at Perth Children's Hospital (PCH) to administer the drug Spinraza® to 11 SMA patients. We stepped in to ensure this critical service could happen, literally saving lives. The outcomes from this initial funding have now seen this critical clinic funded by the State government ongoing.

## **NUTRITION PROJECT AT PERTH CHILDRENS HOSPITAL (PCH)**

From 2018 a 2-year project at PCH was funded to provide enhanced nutrition services to children with NMCs. 54 patients (47%) of those tested were identified as malnourished, overweight or obese.

Without this project these children would not have been identified as at risk or have received dietetic services. Another outcome is the creation of a database of nutritional information to facilitate further research and statistics.

# \$505,921

**funds invested into research projects,  
grants & scholarships from 2018 to 2022**



# YOUTH

## Neuromuscular WA provides a number of programs which help to build resilience and a sense of belonging for the young members of our community

For our school-aged children with neuromuscular conditions and their siblings, we hold fully accessible events each school holidays. This includes an **Annual Camp** and two separate **School Holiday Programs**.

We also host our **Young Adults Social Group** events for those aged 17 years and over, giving them the chance to get together and connect in a fun, social environment. This group is particularly tight-knit and also catch up outside of our facilitated events.

We also offer our community a range of **Capacity Building Programs** targeting specific ages, that aim to build knowledge, improve self-development and increase self-confidence and resilience.

We do this because we know how important community engagement and social integration is for positive mental health.

**Hale Mates** is a peer mentoring program for youth in our community aged between 11 and 17 years old, where Hale School students mentor them and help them learn new skills, embrace new experiences and forge strong friendships.

**The Ignite Award** is for 10 to 18 year olds, promoting positive self-development and leadership skills – this is a great tool for transitioning into secondary school.

The main outcomes of these peer programs are inclusion and mateship, developing individual strengths through fun activities, whilst building resilience.

We also invite siblings to join in on these events as it not only provides a level of support for their brother or sister, but also allows these siblings to connect with others in similar circumstances.

# 1,094

youth attended programs  
between 2018 and 2022

# 132

activities hosted  
between 2018 and  
2022 for youth



# MENTAL WELLBEING & CAPACITY BUILDING

Students with disabilities experience bullying at a rate 2-4 times greater than their non-disabled peers\*

Adults with disability are more likely (32%) to experience high or very high levels of psychological distress than adults without disability (8%)\*

This places an unacceptable number of our community at risk, leading to increased vulnerability and prolonged withdrawal from mainstream society.

Bullying, particularly when perpetrated on children with a disability is often focused on verbal aggression such as name-calling, threats or imitation. Verbal bullying is as distressing as physical bullying, with the following effects\*:

- Acute despair, anxiety or depression
- Suicide
- Poor concentration
- Low morale and self-esteem
- Decreased academic performance

To counteract these impacts on our most vulnerable and at-risk cohort, Neuromuscular WA's Capacity Building Program was designed, providing coping mechanisms for our community and their families. We do this because we know how important community engagement and social integration is for positive mental health, building resilience and combatting social isolation.

Programs that underpin our Capacity Building Project include:

- School Holiday Program
- Hale Mates Peer Mentoring Program
- Camp
- Resilience Doughnut Program
- Ignite Award
- Transition Program

The outcomes from our youth program surveys revealed that participants demonstrated strong improvements in their personal development as outlined in the statistics to the right.

**89%**  
enhanced confidence  
to try new things

**100%**  
increased  
communication skills

**78%**  
increased general  
belief in abilities

**66%**  
showed increased  
independence



\*Carter & Spencer, 2006 Hart, Heaver & Brunberg, 2014  
\*\* Australian Institute of Health and Welfare, 2022

# EMPOWERMENT

The Neuromuscular WA Empower Fund was created in 2018 as a vehicle for our community to access funding for specific items or experiences that are unmet by typical grant providers or the NDIS.

Members of our community can apply for financial support to help them live their life to its fullest. It also covers off situations of hardship when necessary. It allows them to enjoy life experiences that they might not have otherwise been able to due to the increased cost of living to those with disability.

Grant rounds are open every 6 months and our entire community are encouraged to apply for varying amounts up to \$2,500. This can partially or fully fund a range of equipment and/or experiences, making a massive impact on people's lives and allowing them to live life and enjoy experiences just like anyone else without disability can.

Donors to the Empower Fund are given regular updates on who they have supported and how their funding has been allocated to our community.

We have funded over \$168,000 in grants since the Empower Fund began and a contribution from your Foundation will help us continue providing *Support for Life* to our community.

Since 2018 we have given 78 grants, including items such as:

- electric sports wheelchairs
- a trip to Disneyland
- car modifications to fit wheelchairs
- flights & accommodation to neuromuscular conference
- an Apple watch
- a MacBook Pro
- hydrotherapy and water equipment
- solar heating for outdoor pools
- specialised camping equipment
- an Xbox series S
- a ski trip to New Zealand
- drumming lessons
- accessible kitchen items for independent living

**\$168,655**  
granted since 2018

“ We received an Empower Grant for solar heating for our backyard swimming pool as it was far too cold for Dexter to use. Now that we've got it, he and his sister Addison can be in there for hours together, which has been really lovely ”

- Donna Stewart

