



NEURO
MUSCULAR
WA



2023
Annual Report

WE'RE HERE
FOR YOU





Vale Emeritus Professor Byron Kakulas AO

2023 began with us very sadly bidding farewell to the great Emeritus Professor Byron Kakulas AO, a caring and passionate man whose drive to improve the lives of local communities and lifelong dedication to medical research changed the world.

Since our inception 56 years ago, supporting Western Australians with muscular dystrophy and other neuromuscular conditions has been at the heart and soul of our organisation – one of Prof's founding principles.

As a child, Prof always knew he wanted to do something in science that would help people, leading him to set his sights on medical research.

What he didn't know then was the momentous and ground-breaking discovery he would make just four years after graduating from medicine.

After qualifying as a clinical neurologist, Prof decided to specialise in neuropathology. In 1960 this decision fatefully led to a then 28-year-old Prof being presented with a quokka that had died of paralysis in a lab at UWA.

After scouring veterinary literature and drawing on his medical background, he treated some of the living but paralysed quokkas with oral Vitamin E tablets. This had never been done in any animal before and he was amazed to witness their recovery.

A biopsy revealed the total regeneration in skeletal muscle tissue, proving the potential for all muscle diseases to be treatable.

The results were published immediately, prompting worldwide research and Prof becoming an overnight authority in this field. It was a momentous discovery that would directly impact the treatment of muscular dystrophy.

Seven years later, in a suburban house in South Perth on April 13, a small group of parents whose children were impacted by muscular dystrophy gathered for a meeting with other interested parties.

Chaired by Mr J W Downie of the Rotary Club of West Perth and with the support of Prof, it was decided to establish 'The Association to Foster Research into Muscular Dystrophy and Allied Conditions'.

At a second meeting, the official name was confirmed as the Muscular Dystrophy Research Association (MDRA) of



WA with Prof appointed as Founding Medical Director. This was the very beginning of what is now Neuromuscular WA.

Through his unwavering dedication, Prof continued to make significant contributions to research into neuromuscular conditions.

He was central to the establishment of the world's first carrier detection and genetic counselling program in WA which lowered the incidence of new muscular dystrophy cases by more than half and was the first to identify Inclusion Body Myositis as an entity. His defined principles of myopathy became the standard of teaching globally.

In 1996, Neuromuscular WA provided the initial funding to Professor Sue Fletcher AO and Professor Steve Wilton AO to undertake research into therapies utilising the insights gained from Prof's quokka discovery.

The outcome was a ground-breaking treatment for Duchenne muscular dystrophy, which became the first of its kind to be authorised by the FDA in 2016.

In April 2012, after 45 years as our Medical Director, Prof stepped down from his official role but remained one of our biggest supporters and advocates.

He continued to personally meet with each of our new employees to share the organisation's vast history and his knowledge of neuromuscular conditions.

We are so very grateful for the enormous contributions Prof made to our organisation, our community and people across the globe.

Prof is dearly missed and his family are always in our hearts and thoughts.



“ I recognise and acknowledge Prof's enormous global contributions to research into so many neurological conditions, it was Prof's commitment and focus on muscular dystrophy that lay the strong foundations for us to be able to still be providing support to Western Australians living with neuromuscular conditions today.

I will always remember Prof for his kindness, his humour, his immense knowledge, and his meticulous way of doing things. It has been an enormous privilege knowing this phenomenal man who changed history. ”

- Hayley Lethlean, CEO

“ Prof Kakulas has left a void in our lives that cannot be filled. Clinician, researcher, mentor and family man, he impacted so many lives. For the DMD families, he was the person who championed DMD genetic diagnosis and helped them work through the difficulties that come with having this very unfair familial disease. For the many clinical and research scholars, he was a mentor, expert and role model. For those of us who worked under his leadership in the institute he founded, he was always enthusiastic when talking science, brainstorming ideas and supporting our young scientists. A dotting family man and adoring grandfather, he told us family comes first and he led by example, balancing work and family. Prof, you are missed. ”

- Professor Sue Fletcher

“ We met Professor Byron Kakulas as our son Joel's first Neurologist for a short time after leaving CDC at 15 years-old. We were humbled to have this amazing man, a luminary in his field of medicine, caring for our son. But meeting him, totally shed another beautiful and personal picture of who Prof was. Gentle, caring and supportive always, and with a wonderful sense of humour.

We are honoured to have known Professor Kakulas, a true gentleman who changed the world with his knowledge and changed our lives continually, with his genuine care of the Western Australian neuromuscular community. Thank you Professor Kakulas. ”

- Jackie & John Slinger and family

The Beginning of a New Era - Our Rebrand



Our massive purpose is to be known for supporting everyone with a neuromuscular condition in WA, who need us.

At the very end of 2022, as we were embarking on our strategic planning for 2023, an idea was tabled about changing our name to help achieve this.

Our data show that 43% of the community we provide support to are actually people with a condition that is not muscular dystrophy.

Whilst our service provision has included all neuromuscular conditions for quite some time, our name hadn't caught up so to align with our vision going forward, we renamed to Neuro Muscular WA.

This decision followed much consideration and input from a cross-section of our stakeholders to ensure interest and support, including our founder, Prof Byron Kakulas before he sadly passed.

Prof was incredibly supportive of this change and the greater access it would provide for new community members to reach us.

We also received some feedback out of our system navigation pilot project which suggested that we may struggle to have people referred to us based on our name being so specific to muscular dystrophy and that those searching for support on their own may not know to get in touch.

As with all that we do, gaining input from our stakeholders is important to us so we chose several long-term community members, supporters and professionals in our field and put forward our proposal to change our name to gather their feedback.

Some of the consultation questions we posed to our chosen stakeholders included:

- Do you think there could be any negative implications with the name change?
- Are there any obstacles you think we might face along the way when we communicate the change with others?
- Would it change how you feel about our organisation and how engaged you might be going forward?

We received unanimous support in the change and it was approved by our membership via Special Resolution at the Special General Meeting held on February 1, 2023.

We put our rebrand out for tender and selected a small agency, TwofromTwo, to run the project. After much deliberation from our entire team around the design put forward, we collectively chose our final design and set to work rolling it out across all of our collateral.

A special thanks to those who provided their invaluable feedback during the rebrand consultations.

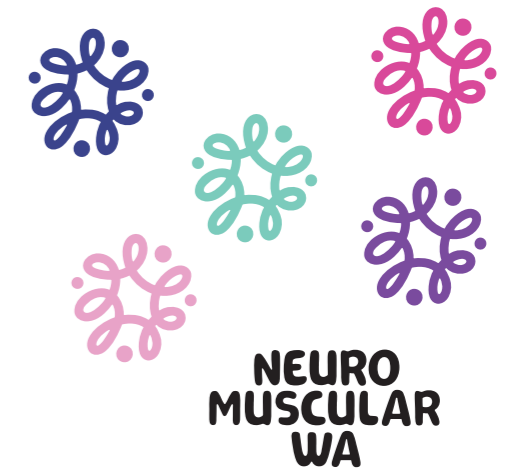
LOGO MEANING

The Neuromuscular WA logo has several elements with different meanings that represent who we are as an organisation and who we support.

The dots are representative of a cross section of muscle fibres, which tie in nicely with the swirls which not only characterize motor neurons, but also represent a group of people holding hands or interlocking arms, showing connection and togetherness.

The logomark is also symbolic of a nest which is seen as warm, safe and caring. The typography chosen is rounded, friendly and spongy and softens the overall design, creating a stronger connection to the logo mark.

To be unique, like our community, we decided to utilise a variety of colours for our brand. They have been chosen as they represent the values, personality and ideals of our organisation, as well as having contrast, making them visible for those with visual impairments.



APPLICATION OF THE BRAND

Over a couple of months we applied the new logo, colour palette and design across all of our existing collateral.

This included stationery, banners and signage, staff and volunteer tees and uniforms, our website, brochures, policy documents, annual report, marketing collateral and anywhere else our logo might appear (including other sites not owned by us).

It also involved a new photoshoot with a cross-section of our community.

The bright colours have made their mark at our events throughout the year, making our team and organisation more visible at all that we do.

We have also incorporated our values into most of the branding to reiterate who we are and what we stand for. You'll see them scattered throughout this report.

The result is a beautiful new design and cohesion across all that we produce, that is lively and engaging and stands out from the crowd.





CEO & Chair Report



We warmly welcome you to the 2023 Annual Report for Neuromuscular WA. What a whirlwind of a year it has been, packed with successes and memorable moments for our entire team and community.

Following lengthy community, stakeholder, and Honorary Life Member consultation, 2023 saw an exciting transformation with significant constitutional change and a rebrand to Neuromuscular WA.

As an organisation of whom 43% of our membership has a neuromuscular condition, our rebrand has enabled us to be more inclusive to all neuromuscular conditions, reflecting a commitment to serving a broader community.

As most would know, rebranding and repositioning an organisation with such a longstanding and strong history requires careful consultation to mitigate risks, align with strategic objectives and maintain positive relationships with all who engage the organisation.

By involving relevant parties in the decision-making process, we better navigated the complexities of the rebrand and with the communications team's huge efforts in rolling out the brand, resulted in a well-received transition to Neuromuscular WA. We're thrilled about the possibilities this brings for our future endeavours.

It is a privilege to have 10 dedicated Board members whose voluntary commitment and strategic guidance steer our organisation's direction.

At the AGM in June, Dr. Peter Rowe, a dedicated 12-year Board member, stepped off the board leaving a legacy of significant experience and knowledge within the organisation for years to come. We also thank outgoing Board Member and past Chair, Tanvi Haria, for her 6 years of service to the membership.

The Board welcomed new leadership with the appointment of Josh Davenport as the new Board Chair, Cara Philpott as the Vice Chair and Abby Niven as the Treasurer.

The Board expanded its membership with the addition of community members Deema Audeh and Nirbhay Gupta, and we also welcomed back past Board member and community member Cara Philpott.

We'd like to acknowledge the many hours our Board put in at both board and sub-committee meetings, and we thank

them all for their unwavering support of our cause. At a national level, Board member Aaron Schier stepped up as the WA representative and Board Chair of the Muscular Dystrophy Foundation Australia.

In late January, our organisation grieved the passing of Prof. Byron Kakulas, our founder and Honorary Life Member. His forward-thinking guidance significantly influenced the organisation's mission and values, moulding us into the entity we are today.

His legacy will always be remembered and will undoubtedly influence our future endeavours within the neuromuscular community for years to come.

National advocacy for health, aged care and disability remains a key role for Neuromuscular WA as it helps raise awareness and a targeted focus on challenges faced by our collective community at both a State and Federal level.

Advocating nationally alongside our counterparts in State and Territory muscular dystrophy foundations and the Neurological Alliance Australia, we offered input to influence policy and process which hopefully will lead to improved access to healthcare, better support services, and increased inclusivity in society.

We provided a thoughtful and detailed viewpoint regarding various healthcare reform initiatives, including the Primary Health Care Reform, the NDIS Annual Pricing Review, the 2023 Federal Budget, which proposes increased funding for healthcare, Community Pharmacy, IVF assistance, aged care, the Disability Support for Older Australians Program, NDIS efficiencies, energy price relief, and Disability Workforce COVID-19 Leave Grant Payments.

Members of our team in the office and a couple of Board members also offer their time on various external State and national committees, reference groups and community of practices, ensuring that the needs and voices of those with neuromuscular conditions are heard and perspectives offered for greater inclusion and access opportunities.

Representation at these levels brings greater awareness for neuromuscular conditions and increases opportunities for sharing and learning from others who may be leaders in their fields and the rare disease and disability sectors.

The Community Services team continued to deliver robust and much-needed services and programs. Member

numbers grew and with that, the number, type of programs and team expanded.

Launching System Navigation through pilot project funding from the WA Department of Health saw us welcome Josh Wells as System Navigator, who brings valuable expertise.

Amy Murphy concluded her role as the System Navigation Project Coordinator in June, who during her tenure not only contributed significantly to the successful rollout of the program but across the whole organisation.

Please read the Community Services team's report for insight on the amazing services and supports that were offered throughout the year.

In August, we finished an interim NDIS Quality and Safeguarding audit. The audit team provided us with particularly positive feedback, and we did not receive any non-conformances.

This demonstrates our longstanding commitment to maintaining high standards of service delivery and compliance, with the community at the heart of everything we do.

We are proud to be a registered provider for NDIS services and look forward to rolling these out in 2024 through our Camp.

A special acknowledgment goes to our FUN(draising) team for their innovative efforts in broadening our revenue streams and organising outstanding events. Their unwavering commitment not only brings in essential funds but also spreads joy and awareness.

Their dedication and creativity are pivotal in making a significant impact on our community. They guarantee that our fundraising events yield high net returns, enabling us to advance our cause efficiently and with enthusiasm.

The introduction of several new initiatives and the expansion of existing ones enabled us to optimise our resources and deliver high yields.

Our heartfelt thanks go out to our longstanding donors, sponsors and supporters in MyattsField Vineyards, Toyota WA, The Perron Group, The Stan Perron Foundation, West Perth Rotary Club, Kailis Bros Leederville and Clip Media Motion, who believe in our cause and provide invaluable support.

Our deep appreciation goes out to our donors whose contributions, no matter how big or small, go a long way in supporting our efforts.

We collectively thank the team for their enormous efforts and commitment to the organisation and our community. We are a close-knit little family and you all go above and beyond. This Annual Report reflects your spirit, adaptability and commitment to Neuromuscular WA, our mission and our values.

Working alongside your tremendous efforts and the

strategic focus of the organisation, consistent and directed Board changes, operational successes, and personnel transitions, we have laid solid groundwork for sustained growth and lasting impact in the years ahead.

In closing, we extend our heartfelt thanks to the entire neuromuscular community for allowing us the privilege to serve you. Your strength and resilience inspire us daily, and we stand with you every step of the way.

Josh Davenport, Chair and Hayley Lethlean, CEO





Treasurer Report

The Statement of Comprehensive Income shows a surplus (prior to research grants and scholarships) of \$128,622 (2022: \$687,464). This results in an overall deficit on 31 December 2023 of \$83,598 after payment of research grants and scholarships.

The total income of \$1,487,045 in 2023 reflects a decrease of \$772,683 from 2022. Whilst there was a general increase across most other income streams, the key variance from 2022 was the research grant of \$923,587 in 2022 from NDC.

The total expenditure of \$1,358,423 in 2023 decreased by \$213,841 compared to 2022, largely in line with movement in value of the investment portfolio.

During 2023, investment markets commenced the year facing recession fears as a result of persistently high interest rates and inflation. However, stock markets proved to be resilient throughout, and encouraged by the combination of a solid economy, better than expected corporate earnings and an end to interest rate hikes in many countries, shares rallied 25% in 2023. Bond holders, meanwhile, experienced relief with a positive return in 2023, after losses in the previous two years.

The beginning of 2024 calendar year has seen a strong start in both equity and bond markets, in light of optimism for a soft landing for the US and other economies. Falling interest rates and earnings growth could prove to be a strong tailwind for markets, although we are still cautious considering continued high inflation and debt levels, in addition to a US presidential election creating some volatility in markets.

The Neuromuscular WA investment portfolio is carefully structured and monitored in order to withstand shorter-term market pressures and is managed for longer term sustainable performance in various market conditions. The Board continues to work closely with our financial planner to ensure that the portfolio remains robust and appropriately positioned for the current environment.

Net assets and liabilities show some variation to 2022 balances with change in cash position from \$1,654,381 to \$1,280,503 predominantly as a result of the NDC funds into research projects and grants, our rebrand and the increased expenses associated with our community programs.

Key current liabilities variances from 2022 include changes to our reporting on our lease in line with accounting standards AASB16.

As at December 2023, the Association's financial position decreased by \$83,598, resulting in a closing net assets balance of \$3,160,976. This was a planned deficit budget for 2023 given our significant investments into strategic projects including the rebrand to Neuromuscular WA, greater investment in research and community services through expansion of the Community Services programs and team.

As the Treasurer, I am pleased to say the overall financial position of the Association remains strong and I wish to thank and acknowledge the Board and the Finance and Risk Committee in particular for their oversight and rigour in ensuring our finances are well-managed. I acknowledge our financial planner Neil Hancy from Armada Financial who puts in significant effort to ensure our investment portfolio is well-positioned and performs in line with market expectations.

Finally, I thank Hayley and the team in the office for their ongoing commitment and hard work throughout the year to best position the organisation in always looking for new opportunities to generate funds and seeking ways to save costs where possible. I thank them for once again putting the community needs at the front and centre of everything they do.

Abby Macnish Niven, Treasurer

The Neuromuscular WA Board

Elected by the Association's members during the Annual General Meeting or appointed by the Board, Neuromuscular WA is fortunate to boast a dedicated Board of volunteers who ensure the Association remains focussed on achieving our mission and following our strategic plan.



TANVI HARIA
Chair to June 2023
Board member
2016 - June 2023



JOSH DAVENPORT
Vice Chair January - June
Chair from June 2023
Board member since 2020



CARA PHILPOTT
Vice Chair since June
Board member 2020-22,
Elected 2023



ABBY MACNISH NIVEN
Treasurer
Board member
since 2020



DR PETER W ROWE
Board member
2012 - June 2023



AARON SCHIER
Board member
since 2017



SHANE POWELL
Board member
2017 - June 2023



LISA KING
Board member
since 2022



DR ADELAIDE WHITHERS
Board member
since 2022



ELLEN STOREY
Board member
since 2022



MATTHEW CURNOW
Board member
since 2022



NIRBHAY GUPTA
Board member
Elected June 2023



DEEMA AUDEH
Board member
Elected June 2023

\$3,160,976
total accumulated funds

\$663,268
investment into community & programs

\$707,145
total fundraising & donation income

10%

administration expenses in
respect to annual turnover

\$176,520
funds invested into research
projects, grants and scholarships

Strategic Overview

ANNUAL OBJECTIVES

- > Build organisational capacity to ensure sustainability
- > Review and expand mid-term funding options and security through diversity
- > Increase awareness in line with our massive purpose
- > Build a sustainable service delivery model
- > Explore and fund an epidemiology study of neuromuscular conditions in WA

2023 KEY MEASURES

	Income	Profit/ Loss	Fundraising Revenue	# of New Active Supporters	# of Community Connections	# of New Community Members	TARGETS
	\$1,521,524	-\$319,191	\$907,900	380	1013 /1300	45 / 72	
	\$1,487,045	-\$83,598	\$707,145	359	1271	93	RESULTS
	2.26% ↓	73.8% ↑	22.1% ↓	5.5% ↓	25.4% ↑	107% ↑	
	# PAFS engaged	# new PAFS	# PAFS successful	# Grants applied for	# Grants successful	New Revenue	
	19	9	4	16	6	\$87,000	

KEY CHALLENGES

- > Extensive impact on team implementing the rebrand
- > Budget constraints and time demands of automation
- > Ongoing impact of IT issues, exacerbated by the resulting administrative burden
- > The loss of community members exacts a deep emotional toll on the team and affects their wellbeing
- > Limited progress of the Epidemiology Data Project
- > Restricted fundraising income due to modest grant revenue, limited success engaging new PAFs and fresh revenue streams
- > Striving for breadth of impact at the expense of depth,
- > Service delivery model review faced challenges in assessing long-term sustainability and service enhancements due to insufficient demographic data, hindering a comprehensive understanding of all needs

KEY ACHIEVEMENTS

- > Successful launch of System Navigation
- > Successful rebrand – name change, website redesign and connection to new community
- > Expanded dataset by modifying the Customer Relationship Management System and enhancing our reporting capabilities
- > 31% Membership growth
- > Successful NDIS Audit
- > Successful delivery of new Impact Art Exhibition fundraiser
- > Successful service delivery model review
- > Collaboration in fostering team unity and rekindling past connections
- > Bereavement program launch

10 Year Comparison

2013 FIGURES



2023 FIGURES



Staff, Volunteers & Ambassadors



Back row L to R: Mark Hullett, Louise Storey, Brooke McGregor, Hayley Lethlean, Bryony Whitwell, Holly Redman
Front row L to R: Sarah Williams, Cathy Donovan, Piper Marsh, Sue Fidock, Emma Kenton, Josh Wells

Staff

Wow, what a year it's been! It's such a joy to sit down and reflect on everything that's happened, and I want to start by giving a huge shoutout to our amazing team of staff and volunteers who've truly made magic happen this year!

We kicked off the year with some exciting changes and growth in our programs and community. In May, we welcomed the fabulous Josh Wells as our new System Navigator, bringing with him a ton of knowledge about NDIS and other services for people with disabilities. Josh has a wonderful knack for spreading positivity and empathy wherever he goes, and he has been an incredible addition to our team.

Of course, with growth comes some bittersweet moments. In late June, we had to bid farewell to Amy Murphy, who did an outstanding job laying the groundwork for our System Navigation initiative. Amy, we can't thank you enough for your dedication over the past year.

Strategic focus has been key to our success this year. Our Executive team Piper, Emma and Mark have been meeting monthly, staying laser-focused on our goals, tackling challenges head-on, and making sure we are always one step ahead. We have been working hard to improve our policies, procedures and operations, finding smarter ways to do things to save time and money.

And through it all, we've remained a tight-knit team, thanks to everyone's commitment and our shared sense of fun and camaraderie.

Speaking of fun, our Christmas in July team-building day was a blast. Piper's Christmas murder mystery was a hit, with laughter and team spirit in abundance. A special shoutout to Mary Christmas (aka Holly) for her winning speech and detective skills! My years of Christmas pageants as a youngster helped me win some of the carolling – although I'm sure my team might not agree with my singing capabilities and are relieved that I'm sticking to my day job.

And let's not forget our amazing sponsors, SeaLink, who helped us make memories on Wadjemup (Rottneest Island) in December. It was a day filled with bonding, laughter and, of course, another epic activity facilitated by Piper.

Throughout the year, our team has been honing their skills with a range of training workshops. These have covered everything from fundraising strategy to SEO optimisation, first aid, NDIS compliance, aged-care, grief counselling, financial and risk management, and HR management. We're committed to staying current and ensuring our service to the community is both compliant and of the highest quality.

Last but certainly not least, I want to express my deepest gratitude to each and every member of our team. Your hard work, dedication and selflessness have made a real difference in the lives of those we serve. I know balancing work with everything else life throws at us can be tough, but your commitment this year has been truly inspiring. Here's to an amazing team and the enormous accomplishments that were achieved.

Hayley Lethlean, CEO

Volunteers

We extend our heartfelt appreciation to our dedicated volunteers – you are the backbone of our organisation. Their unwavering commitment and generosity is extremely valuable to us. Whether it's assisting at community and fundraising events or providing essential administrative support, their diverse contributions are vital to our mission.

In 2023, their collective efforts amounted to an impressive 1,256 hours of volunteer support, equivalent to over \$58,554 in additional resources. This significant contribution has had a profound impact on our ability to serve our community.

We would like to offer special recognition to our esteemed volunteers, Louise Storey and Sue Fidock, whose consistent dedication and positive attitude exemplify the spirit of giving.

Ambassadors

Our small team of generous Ambassadors continued to dedicate their precious time, regularly bringing humour, banter, fun and commitment to our program of community and fundraising events throughout 2023. Their contribution across the year is priceless and we could not be more grateful.

Matt Haddon was back in full swing after his northern sojourn, helping at our Young Adult Social Group event, continuing to support his beloved Hale Mates program and again donating his time to volunteer at our annual Rhythm and Views fundraiser at MyattsField.

Ross Wallman continues to regularly feature and get his hands dirty with our Hale Mates on a Monday evening. Ross loves dropping in on our community and fundraising events, including his late call-up to MC the Scarborough Beach Carols in December.

Adam Voges is always a popular addition to our program, with his likeable nature and thoughts on leadership always a big hit. Adam is a regular contributor at our Tall Tales and Kailis Club events and in May the Voges family hit the pavement to raise funds at the HBF Run for a Reason.

Simon Beaumont just keeps stepping up to the plate, charming the audiences at many of our events with his humour, warmth and understanding of neuromuscular conditions. Simon is a genuine and professional advocate for our organisation, always happy to meet new families, supporters and team members with a welcome smile.



Matt Kelly with Ambassadors Simon Beaumont and Adam Voges



Community member Ethan Bryne with Ambassador Ross Wallman and his son, Ollie



Ambassador Matt Haddon

Honorary Life Membership

Our Honorary Life Members have given exceptional service to our organisation. As esteemed individuals, they are nominated by fellow members in recognition of their significant contributions to our mission and unwavering dedication to our cause, which spans at least ten years.

We proudly acknowledge and celebrate the invaluable role of our Honorary Life Members, whose enduring support continues to shape our organisation. Their collective impact serves as a testament to the enduring spirit of collaboration and generosity that defines our organisation.

Susan Trahar - Honorary Life Member

In 2023, with endless gratitude and appreciation, we presented the generous and kind-hearted Susan Trahar with Honorary Life Membership.

Susan is a much-loved community member and supporter, who also served on our Board for an impressive 12 years, making her one of the longest-serving Member since 2000.

Susan chaired our Research Advisory Committee for seven years and her expertise in allied health, management and law made her an invaluable asset to our Board. Her knowledge of the NDIS was also a game-changer for our organisation.

The Trahar's are amazing supporters – sponsoring events and donating generously. In 2014, Susan played a key role in launching the successful Truffles for Muscles fundraising auction (now known as Kailis Club) and she continues to be instrumental in bringing VIP guests to this event and others.

Not only is Susan incredibly professional, she's also warm, friendly and a joy to have around. Whether it's Board meetings or interacting with our community and team, she's always kind, warm, ethical and dependable.

Susan's dedication and contributions to Neuromuscular WA are truly remarkable and we thank her for making a lasting impact and being an inspiration to us all.

Susan joins an esteemed list of people who have made a lasting impact on our organisation.



Neuromuscular WA Honorary Life Members

Sr Dorothy Davies SRN - 1972
 Peter Kallenberg - 1972
 Michael G Kailis AO CBE - 1974
 Dr Patricia Kailis AM OBE - 1975
 Judy Hammond - 1976
 Mary Webster - 1976
 Fred Coldham - 1977
 Charles Cornish MBE - 1981
 Lillian O'Shaughnessey - 1981
 Tom O'Shaughnessey - 1981
 Dr Reg Ward PhD - 1981
 Norman Blythe OAM - 1983
 Sir Thomas Wardle Kt - 1983
 Pauline Langford - 1984
 Yvonne Lowe - 1984
 Neil Crawford - 1985
 Maureen Archer - 1994
 Mary Broere - 1994
 Connie Coldham - 1994
 Olga Daws OAM - 1994
 Irene Kallenberg - 1994
 Eunice Ludwig ONMG - 1994
 Mary O'Brien - 1994
 Bernice Shaddick - 1994
 Trixie Shaddick - 1994

Maria Vooles - 1994
 Ellen Walton - 1994
 Barbara Cameron - 1995
 Ellen Crawford - 1996
 Glennie Cumming-Summers OAM - 1996
 Peggy Davies - 1996
 Lorna Mitchell OAM BEM - 1996
 Bill Harwood MBE - 1997
 Beryl Mackin - 1998
 Major Jeff Mackin - 1998
 Lena Oortwyn - 1998
 Arie Oortwyn ONMG - 1998
 Mabel Bell - 2000
 Hugo Bowen - 2004
 Colin Jeeves - 2005
 Shirley Jeeves - 2005
 SdnLdr Des McLean MBE - 2005
 Hugo Button - 2009
 Jill Button - 2009
 John Hollingshead OAM - 2009
 John Howard - 2009
 Harold Rowell OAM - 2009
 Sylvia Rowell OAM - 2009
 Yvonne Day - 2009
 Pat Emery OAM - 2009

Corinne Flick - 2009
 Dave Flick - 2009
 Dorothy Howard - 2009
 Margaret Hart - 2013
 Professor Byron Kakulas AO - 2013
 Joan Martin - 2013
 Professor Frank Mastaglia AM - 2013
 Elizabeth Ritchie - 2013
 Professor Sue Fletcher AO - 2014
 Lesley Murphy OAM - 2014
 Professor Steve Wilton AO - 2014
 Rachael Davenport - 2017
 Josh Davenport - 2017
 Michael G Kailis AM CBE - 2017
 Theo M Kailis - 2017
 Conor Murphy - 2017
 Stan Perron AC CitWA - 2017
 Robert Storey - 2017
 Geoff Woods - 2019
 Brianna O'Donnell - 2020
 Rick Steven - 2021
 Ruth Steven - 2021
 Susan Trahar - 2023



Honorary Life Members and staff at the Honorary Life Member Luncheon at Kailis Bros. Leederville.

YOU MATTER,
YOU BELONG



Community Services Program



2023 was a year of change for Neuromuscular WA as well as the Community Services Department, particularly with the team. We welcomed new team member Josh Wells, welcomed back Brooke McGregor, and farwelled Amy Murphy, hopefully for only a short time.

Brooke rejoined us as Community Programs Officer, supporting our school-aged services after the arrival of her fourth child.

Josh Wells, who many may know from his active role in the neuromuscular community, commenced with us in May, in the new role as a System Navigator. Josh along with Sarah, are making a big impact on the neuromuscular community through the delivery of the System Navigation Pilot Project.

Amy Murphy left Neuromuscular WA, to continue travelling with her family. Amy along with Bryony, worked diligently to ensure the System Navigation Program was ready for Sarah and Josh to implement. Despite the changes, the Community Services team achieved remarkable results in 2023 and should be immensely proud of their accomplishments.

The Board tasked the team with conducting an in-depth analysis to identify opportunities for improvements in gaps in our current services.. To facilitate this, we invited several community members who have a long history of attending specific programs to participate in focus groups and share their insights. Additionally, the team met with numerous key stakeholders who support our programs in various ways to gather their feedback.

We extend our gratitude to everyone involved in this process. Please stay tuned for the launch of several new initiatives in 2024, which have been developed based on the review.

Finally, we had a bumper year which saw 93 new community members joining us for the first time. While we are unsure of the exact reasons for this success, we are eagerly anticipating the opportunity to see these new members at our numerous events throughout 2024.





SOCIAL PROGRAMS

We offer an extensive program of social get-togethers for different age groups and carers that are all about nurturing connections with people in our community.

Made up of people of all ages, race, gender, and abilities, together we like to think of ourselves as a big family – here for one another to share experiences and grow together. We love a good get-together as it is a way of escaping the sometimes all too serious stuff and feeling comfortable spending time with people in similar situations.

SCHOOL-AGED PROGRAMS

Hosted during the school holidays, these fully accessible events invite children with a neuromuscular condition and a school-aged sibling to attend and enjoy a variety of fun activities.

Fun Day

2023 began with our annual Fun Day, where we made pizzas, learnt about an array of insects and bugs and watched how fast a turtle could race across the conference room. In the afternoon, a visit from Birds of Prey captivated the group before we finished the day with a magic show full of tricks and surprises.

Family Day

We loved bringing our school-aged community and their families together this year, especially as we have been unable to host the event for the past two years. Held at Outback Splash, families enjoyed a social catch up with friends over lunch, then had the opportunity to enjoy some family fun, which included getting lost in the mazes, meeting some furry friends and having some water play fun.

July School Holiday Program

Over two days in July, energetic kids exploded through our doors for two days of fun activities. The program was filled with learning, fun and laughter, and we were delighted to see some solid friendships developing.

The children enjoyed battling robotics with Edgy X, a woodwork and terrarium workshop with Bunnings, designing their own power force with PLAYworks, making playdoh and funny face biscuits and were amazed by a special visit from Perth Reptile.



Camp

As we gear up for Camp each year, there's always a buzz of excitement and energy. Our school-aged families eagerly anticipate three days filled with respite, friendship building, self-development, opportunities for independence, and, most importantly, fun. Campers have the option to be day campers or to experience the full day and night activities.

We extend our gratitude to Ern Halliday for kicking things off with team-building activities, to the WA Police Airwing and Canine Unit for showcasing their helicopter and police dogs, to Accolade Catering for hosting a Masterchef pizza challenge, to PLAYworks for unleashing our artistic talents with a "This is Me" activity for our collective artwork project, and to the Swan Valley Cuddly Animal Farm for sharing their furry friends with us.

Platinum Healthcare provides us with highly trained support workers who stay with us at Camp, assisting with all personal care needs. Thank you to Ern Halliday Recreation Camp for hosting us and for their year-round commitment and collaboration to ensure accessibility and inclusion for all our campers.

OTHER SOCIAL PROGRAMS

Young Adults Social Group

Our Young Adults Social Group (YASG) sees our community with a neuromuscular condition who are over 17 years old connect with others while enjoying a variety of accessible activities.

Five events were conducted across 2023 and saw us welcome several new members to the group. The year commenced with a visit to the Fringe Festival watching Laser Kiwi perform their unique acrobatic comedy show.

Our second get-together immersed us in all things Alice in Wonderland at the WA Museum Boorla Bardip and enjoying a Mad Hatter High Tea. Keeping out of the winter cold, the YASG group held a classic games night at the Niche with an extensive range of board and card games.

Our ambassador Matt Haddon joined us for the night, which saw our biggest gathering of the year. Later in 2023, the visual spectacle of the Fire Gardens, a part of the Evernow Festival, was enjoyed by the YASG crew before a delicious dinner at the Reveley.

Finally, to round off the year, we met for a Christmas lunch kindly hosted by longtime supporter MyattsField Vineyards, and enjoyed a festive afternoon of Christmas trivia, lunch and laughs.





Adults with an NMC

Our Adults with an NMC program provides an opportunity for our adult members to connect with each other, share experiences and life hacks while attending accessible events.

Partners are also welcome to attend with activities ranging from dinners to tours, special events and more.

The Adults group grew throughout 2023 with two well attended events. In March, we held an Adults and YASG combined sundowner event at the Niche, this event allowed our community to move around and connect with new people.

In October we enjoyed lunch on the verandah at Oakover Grounds in the Swan Valley, where we were able to increase awareness of our other events and services to those who attended.



Carers

The Carers social group events provides a much-needed break and the chance to take some time out for our family carers.

This program provides a lifeline and connects parents, partners, and other family carers together to spend time with those who are in similar situations.

We started the year off with a combined lawn bowls and sundowner evening in February, giving parents, partners, and family members a chance to unwind.

In August, we had a well-attended Female Carers lunch at Dilly Dally. It was great to have several new members attend this event.

Lastly in October we had our Male Carers event where the attendees had a hit at the Wembley Driving Range, followed by dinner at 300 Acres restaurant.



Community Day

Our Annual Community Day was once again a highlight of the year, bringing together so many members of our community for a social day to celebrate and reflect on challenges, celebrate the wins and share experiences as the year drew to a close.

We played lawn bowls, giant games, enjoyed a buffet lunch and refreshments at Hollywood Subiaco Bowling Club, surrounded by friends.

It was great to see so many new faces join our regular attendees to be a part of the day. Thanks to the Department of Communities for their support of this event.

CAPACITY BUILDING PROGRAMS

We offer a range of capacity-building programs targeting specific ages that aim to build knowledge, improve self-development and/or increase self-confidence and resilience.

We do this because we know how important community engagement and social integration is for positive mental health, but sometimes it's difficult.

Hale Mates

This is our peer mentoring program for members aged between 11 and 17 years, delivered in conjunction with Hale School. Hale Mates aims to reduce the participants' social isolation by increasing their community engagement.

This year the program went from strength to strength with the greatest number of community participants we have ever had.

The year 11 service-learning Hale student mentors blew us away with their commitment and carrying out their tasks for the year.

Participants enjoyed a vast array of activities including cooking, gaming, learning how to be a DJ, making loud music, playing with chemistry, enjoying art, making cat toys for our friends at GOSAC, visiting NOVA radio station, decorating baked goods and Christmas baubles, and letting loose at our end of year party!

We are ever grateful for the commitment from Wendy Keene and Ross Wallman as they continue to encourage and support us throughout the year.

Ignite

Ignite is a self-development program challenging those aged between 10 to 18 years to learn valuable skills, be physically active, assist others in the community and experience adventures. In 2023, Ignite was conducted through the Hale Mates program.

Conversations & Connections

A new addition to our program, Conversations and Connections events bring together members of our community to learn new information and be educated on relevant topics by guest speakers while they connect with other community members.

Four of these events were held across the year including a discussion on NDIS appeals processes from Midlas, advice on accessing mental health supports and self-care from Helping Minds, an introduction to genetic counselling by Genomic Health and a visit from Carers WA to tell us about the numerous carer supports available and strategies to prevent burn out in your carer role. Thank you to all of these organisations for sharing their expertise and insights with our community.





SYSTEM NAVIGATION

Our System Navigation Program launched in May after 12 months of extensive research, program design and resource development. The program, funded by the WA Department of Health, was developed after a 2020 rare disease community needs assessment identified that a lack of coordination of information and care was a key gap in services and supports.

The Program provides assistance to individuals with a neuromuscular condition or those awaiting a diagnosis, guiding them through various sectors including health, disability, education, housing, and employment.

Participants can enter the program either through a referral by a health professional or by self-referral. Our Navigators guide them through the program pathway, prioritising their most pressing needs and connecting them with suitable services. They offer accurate information and support to help address these needs promptly. This process saves them considerable time and frustration in researching information and grants access to support much sooner than before.

Our System Navigation Program was developed collaboratively, drawing insights from a Community Consultation Committee. We extend our gratitude to Cara Philpott, Kim Armstrong-Wood, Sarah Ye, Gary Burgess, Sam DeBonde and Bernadette Straker for generously contributing their expertise and time to ensure the program aligned with the needs of the neuromuscular community.

This program has significantly impacted our service delivery approach, empowering us to create various supportive resources for individuals navigating their journey. These include:

- Enhancing our database and reporting systems
- Gathering comprehensive data on condition journeys
- Facilitating service enhancements
- Cultivating stronger connections with healthcare professionals supporting the neuromuscular community
- Boosting participation in our other services

However, the most profound impact lies in the invaluable support, guidance, and direction provided to numerous families.

One participant aptly described their experience as “excellent,” expressing being “blown away” by the assistance received. They praised the Navigator for their exceptional support and guidance, highlighting how they were introduced to invaluable resources they wouldn’t have otherwise known about, thereby easing their entire journey with the condition.

OTHER SERVICES

Bereavement Program

This year we launched the Bereavement Program, a vital service that was seven years in the making. Since its establishment, we’ve received high levels of engagement from our community.

The program has several important components including the development of the online Information Support Package, which provides information on support services, the importance of counselling, the benefits of sharing stories and information on end-of-life preparation, an important and often difficult subject.

A principal component of the Bereavement Program is an annual education session which introduces a range of topics that sometimes we find hard to talk about even in a supportive environment. In 2023, our topic was the importance of Advanced Care Planning.

Our Annual Day of Reflection is a key part of our Bereavement Program. At the inaugural Day of Reflection, several families joined us for an intimate Reflection Ceremony, where we spent time remembering and honouring members of our community who are no longer with us, as we planted a tree in their honour.

All families who participated reported how important this day and the Bereavement Program is to them and the rest of our community.

Counselling

Our Counselling program provides short-term grief and bereavement counselling during transition phases or times of bereavement through third-party services.

This crucial guidance helps individuals navigate these challenges with compassion and resilience, by validating their emotions, providing support and equipping them with coping strategies to prevent mental health complications.

In 2023, our community received 98 hours of counselling support, which helped many families and individuals impacted by neuromuscular conditions.

Education & Information Program

Our education and information sessions play a vital role in bringing our community together to foster sharing and encouragement. We find this helps to empower them with knowledge of their conditions, treatments, and healthcare options, leading to improved health and wellbeing outcomes.

2023 saw education session and attendance numbers return back to pre-COVID times with nine sessions on topics such as Advanced Care Planning and Guardianship and Administration presented to 249 attendees.





Equipment

We provide a range of equipment for our community. 2023 saw the addition of four new Pegaso CoughAssist™ machines, funded by Telethon, this now provides us with options when loaning CoughAssist™ machines to the community.

We would also like to thank Variety WA who funded two new Firefly Scoot mobility aids for our paediatric community (pictured left).

EMPOWER FUND

Our Empower Fund provides financial support to members to help them live life to its fullest, or make things a little easier for those experiencing financial hardship.

Across 2023, 20 Empower grants were funded to a total of \$35,700 across two rounds. These included unfunded therapy and equipment upgrades, travel expenses to visit family and participate in the WheelWOD Games (international adaptive cross fit competition), drumming lessons, a telescope, a computer to pursue DJing as a hobby and accessible kitchen appliances, among other things.

“ Thanks to the Empower Fund I was able to purchase a new hairdryer made for curly hair. It has made drying my hair easier as it's lightweight, balanced and has significantly cut down drying time. ”
- Linda Vandergoes

“ Our family received funding towards a wheelchair hire car in September. Mackenzie's 'Leavers' looked a little different to the norm, but she chose a trip to Perth, so she could enjoy shopping, eating out and the theatre. She was also able to do some important transition stuff like attend YASG (which was awesome) and meet her new medical team at Sir Charles Gairdner Hospital. Having a convenient hire car to do all of these things made a real difference - the funding really helped bridge the gap because these vehicles are expensive to hire/not included under NDIS transport options and are so much easier than relying on taxis and public transport. ”
- Jodie Crane

STATISTICS

93
new community members

67%
increase in attendance at Carers events

299
people living with a neuromuscular condition supported

53%
increase in social program attendance

200%
increase in connections through website

46
community events conducted

598
community enquiries

161%
increase in face-to-face appointments

315%
increase in education session attendance

657
total number of people supported (incl. family and carers)

PROGRAM SUPPORT

As a not-for-profit we rely heavily on the financial support of grants, partners, sponsors and supporters to continue to provide Support for Life to our community.

We'd like to acknowledge the following sponsors who provide direct funding towards our social programs:



WE
LOVE
FUN



Fundraising & Communications



Like the rest of Western Australia, we bounced back to something resembling our full, normal schedule after a couple of years of date-shifting and tweaking our program.

We have the enduring support of the most altruistic community of supporters by our side – people and businesses who give because they know it's a great thing to do.

We are so appreciative to everyone who attends our events, helps with venues, donates items or experiences, provides food and beverage, or partners with us to alleviate event costs.

2023 saw the winds of change sweep through our organisation, including our name change. When revealing our rebrand and the philosophy behind it to our supporters, we were overwhelmed by how popular the change was.

It was gratifying to see so many of our friends becoming advocates, bringing their own networks along for the ride and in turn increasing our reach to new supporters, both at events and in donations.

Our program relies heavily on great attendance numbers from small-medium businesses, mums and dads, and the WA community.

Event costs continued to escalate through 2023 as the state rebounded from a few quiet hospitality years. However we pride ourselves on always seeking multiple quotes for services and partner with those who are willing to go the extra mile for us

We owe a great debt to our partners who stuck with us. Josh and Rachael from MyattsField Vineyards, Mark and Gary at Toyota, Matt and his team at Kailis Bros Leederville, the talented and generous Prof Sue Fletcher AO, Abbie Adams and the Trahar family were all instrumental in

helping deliver strong fundraising outcomes throughout the year.

After very fruitful conversations with Holly and her family friend Gary Kay, we became the aligned charity partner of an incredible new event – the Impact Art Exhibition hosted by Linton and Kay at their West Perth gallery. The exhibition spanned two weeks, highlighted by a sundowner launch for 80 guests.

On behalf of the staff, Board and members of Neuromuscular WA, we express our heartfelt gratitude to all of our supporters who are making such a huge difference to our community.



Our Partners:



P E R R O N G R O U P





FUNDRAISING EVENTS

Toyota Golf Classic

The 16th annual Golf Classic was hosted at Joondalup Resort, with 34 corporate teams battling it out on another perfect March afternoon. As usual we had a team representing our community tee off and join the fun.

There was a great mix of our regular corporate friends along with Toyota WA, Toyota Autoparts and Toyota Finance networks. We were thrilled to introduce five brand-new teams and meet a host of new players.

We are very grateful to the teams who purchased eight starting hole signage packages, with the event generating \$74,322 in net proceeds – bringing the total raised by the Toyota Golf Classic to nearly \$800,000 across 16 years.



Rhythm & Views

This year's event at MyattsField Vineyards was held in April to avoid the Christmas season and was once again well supported by our supporters, staff and volunteers.

With beautiful conditions, great music from These Galahs and fine wine from MyattsField, the event was another success.

Ticket sales, sponsorships and donations were similar to the previous year and we look forward to growing this great event in 2024.

Thanks to EngineRoom's burger bar, we received part-proceeds from food sales and a percentage of sales totalling \$3,276 thanks to MyattsField's wine bar, helping us raise a net total of \$16,533.



Tall Tales

Our EOFY panel show, Tall Tales with Simon Beaumont, was hosted at Surrounds in Nedlands, with guests enjoying an entertaining live chat with Perth Scorchers' coach Adam Voges and star player Matt Kelly.

Our resident MC Simon led the conversation, interacting with the crowd who were treated to several breakout rooms with huge TV screens to watch some live Ashes coverage from London.

Guests enjoyed an intimate panel show with community member Sarah Ye offering an insight into her own sporting achievements, including playing powerchair football for Australia.

Our thanks to event sponsors Andrew Mostyn, Prof Sue Fletcher, Scardifield Smash Repairs and Surrounds for making the event a success, with some terrific new supporters and net proceeds of \$26,500.

Kailis Club

We once again welcomed 100 VIP guests to Kailis Bros, Leederville for our annual cocktail event and auction in August, featuring plenty of laughs and a lively auction led by Tiny Holly.

Some event highlights included an interview by MC Simon Beaumont with community member Santiago Martinez, followed by the hotly-contested auction of MyattsField Vineyards' Row 38 winemaking experience for a record-breaking \$23,000. It was amongst other blue chip holidays, fine dining experiences and a pearl masterclass, generating nearly \$110,000 from activations.

We thank our community members Santi and Sarah who attended the event and gave wonderful insights in their interviews with our indefatigable MC, Simon Beaumont.



Impact Art Event

The newest addition to our event calendar was the Impact Exhibition, generously hosted by the team at Linton & Kay Galleries in West Perth in October.

Guests took in an eclectic selection of artworks generously donated by 26 local artists in the 'Wall of Smalls' whilst enjoying decadent canapés from Catering Essentials, wines from MyattsField and live music by the Emma Franz Trio.

Our thanks also go to Arlec Australia for sponsoring the event and the 100-strong audience who joined us.

The broader Impact Exhibition was extended for two weeks and proceeds from donated pieces and commissions totalled \$31,500.



Busselton Toyota Golf Day

The 7th annual Busselton Toyota Golf Day was held in November with Laurie Saltarini and his team once again stepping up and networking the event to their clients and the wider Busselton community.

With 19 teams vying for bragging rights at the Busselton Golf Club, players enjoyed near-perfect conditions while the course presented immaculately. Our thanks to Ross Davis and his team for running the day.

Teams were treated to post-golf catering, presentation of awards, and a lively auction of a handful of items, generating just over \$20,000 in net proceeds.



Carols at Scarborough

We once again were the aligned charity of the 2023 event, with support from the Scarborough Beach Association and grant funding from LotteryWest and the City of Stirling.

The event was MC'd by Ambassador Ross Wallman who skilfully stepped in for Simon Beaumont. Our team of enthusiastic staff and volunteers raised \$3,477 in donations, raffle tickets, candle and booklet sales.



OTHER FUNDRAISING

Peer to Peer Fundraising

Supporter Leigh Farnell runs a small group called **Swim for Empowerment** and supports a handful of charities including Neuromuscular WA. His support of our organisation is in remembrance of his grandfather, uncles and cousin who lived with myotonic dystrophy. In 2023 he took part in the Rottneest Swim and Port 2 Pub, raising \$1,000 to help us support our community.

We were excited to see the return of the iconic **HBF Run for a Reason** in May. We had a strong contingent of runners, walkers and rollers who raised a collective \$14,938 through the generosity of their family and friends.

The Hale Mates (\$2,710) and Caitlyn Sunjich (\$681) smashed the 12km course. The 4km racers included Team Voges (\$2,491), Tommy and Lottie Cameron (\$6,824) and community member Benn Tobey who literally juggled his way around the track (\$2,200) – it was an amazing effort by all.

We have been heavily involved in the **Dwellingup 100** for many years and whilst our team numbers were lower than previous years for a variety of reasons, our small group of dedicated fundraisers helped raise an incredible \$16,292.

Our CEO Hayley again rode with the support of community member Reuben Cheuk, raising \$7,400. 15-year fundraising veteran Peter Campbell raised \$3,000 and regular supporter Brett McCamish generated \$1,700 while wearing our brand-new Neuromuscular WA jerseys sponsored by Fred Aube at Galaxy Visual Displays.

Supporter Run Events

It was fantastic to see the golden oldies of **TEAM Spencer** take on the Greg Jelks Team at Empire Ballpark in February. With a \$2 coin entry fee and part-proceeds from TEAM Spencer merchandise, plus raffle ticket sales the event generated \$5,366 thanks to the efforts of Rick and Ruth Steven.

The **Hale Mates Buntine House** ran their own event in 2022, raising a total of \$1,307.85 which was transferred to us in 2023. The Hale Mates continue to find ways to chip in and support our cause.

With the help of her parents, **Addison Stewart** organised a fundraising sausage sizzle at Bunnings in Ellenbrook. Addison's brother Dexter lives with spinal muscular atrophy and both are regulars at our school-aged programs and fundraisers throughout the year.

Addison spent ten hours selling snags on the day, did all of the liaising with Bunnings, sourced the produce and managed volunteers. A huge thank you to Addison, Adam, Donna, Dexter, Chris, Jo and John for rallying together to raise \$2,300.

The **Salt Sixes** cricket tournament was hosted by Glen O'Brien from Salt Property Group at Tompkins Park on the Swan in December with proceeds from the event coming to us via an auction and raffle of donated prizes. We generated \$3,200 with the help of Australian cricket legend Mike Hussey who signed several memorabilia items.

We were the aligned charity of **T14 Events and Promotions' Legends Lunch** in December at the Hyatt Regency, with special guests Mitch Johnson, Damien Fleming and Wasim Akram keeping a capacity crowd entertained. Part-proceeds from raffle ticket sales generated \$2,200.

In December, community members Jaiden, Jess and Josh brought their local community together for a festive fundraiser. The evening saw hundreds unite for a special visit from Santa, face painting, an up-close meet and greet with reptiles, children's entertainers and 200,000 Christmas lights expertly put up by Josh and Jaiden over 2 weeks. Thank you to the Patriarca/Wright family for their incredible work, raising \$2,300.

Tax Appeal

The 2023 appeal was the first to feature our new branding, logo and name, along with a revamped 4-page format acknowledging our history and the passing of our founder, the late Emeritus Professor Byron Kakulas AO.

The appeal recognised Prof, the incredible contributions he made to medical research (particularly NMCs) and the crucial role he played in our organisation, as without him we wouldn't exist.

The Tax Appeal generated our highest historical gross return of \$62,345, in part due to a longer 4-page appeal, the content honouring Prof Kakalus' legacy, our rebrand and the generosity of our supporters.

Christmas Appeal

This year's appeal was very well received, following on from the Tax Appeal with our new brand and messaging. We successfully implemented a digital campaign, attaching dollar handles for donors to help send one child to our community Fun Day for \$62 or a child and their sibling for \$125.

The appeal generated over \$16,000 with \$4,160 coming from our digital campaign, which demonstrates the generosity of our supporters in sending kids to our community events.

Friends with Benefits

The Friends with Benefits committed giving program continued strongly into 2023.

Members receive a range of vouchers and goods from our valued partners in return for their annual contribution of \$520 which is 90% tax-deductible.

Thanks to the supportive people in the program, we generated \$8,260 in 2023 and look forward to continuing to grow this support into the coming years.

Grants & Private Ancillary Funds (PAFs)

We were once again grateful to receive funding of \$19,400 from the Theodore and Isabella Wearne Foundation whose generous contribution again went towards our annual Camp for school-aged kids in our community.

Funding of \$3,335 was confirmed with thanks to Variety WA to purchase two mobility chairs (Scooot Paediatric Mobility Aids) for the exclusive use of our babies with SMA who attend Perth Children's Hospital for treatment.

We were again the recipient of funding from Telethon, with \$107,500 going towards the Little Ones Program - Phase II.

The Stan Perron Charitable Foundation has been a regular contributor for many years, with Mr Perron having held the role of Patron of our organisation for 30 years. We were very thankful to be granted \$95,000 by the foundation, with \$45,000 helping to deliver the 2024 Lessons for Life program.

Our application for Bupa Foundation grant funding was supported by a close friend of Board Member Cara Philpott, resulting in a positive outcome and \$9,770 going towards our ARC Program costs.

We also applied for QBE Foundation funding via one of their local team members and received the great news in late 2023 that they will be providing \$20,000 in early 2024.

COMMUNICATIONS

We are always eager to learn more about what motivates and inspires our loyal band of supporters, so we conducted a survey to glean information about giving patterns, funding areas of interest and communication methodology.

The survey results were overwhelmingly positive, informing how often we should be in touch with our supporters and which types of events and campaigns they prefer.

We also caught up with our significant stakeholders and event partners to ensure that their commercial and networking markers are being met, and again the feedback was encouraging and beneficial.

Education, awareness raising, advocacy and providing our community with useful content remains a priority of our organisation across our social media channels.

This year, we transitioned to Campaign Monitor for newsletters and Loomly for social media planning, which served us well in the rollout of our new brand

We continued to advance our data collection of both community and supporters through improvements to our customer relationship management system.

**WE ARE
WHO WE
SAY WE ARE**



Community Engagement & Research Report



Committee Members

Chair Josh Davenport, CEO Hayley Lethlean, Cara Philpott, Deema Audeh, Dr Adelaide Withers, Shane Powell (Community Representative)

On behalf of the Community Engagement and Research Advisory Committee (CERAC) I present the report for 2023.

Our committee saw several changes this year. At the AGM in June, we farewelled longstanding and inaugural CERAC member Dr Peter Rowe. Peter has been an enormous contributor to both the Board and the advisory committee, with over 20 years of extensive knowledge as a Paediatric Neurologist in clinical care, treatments and clinical trials.

Peter consistently offered honest and considered feedback on strategy and bigger-picture planning, while also actively contributing ideas and insights regarding upcoming treatments and trials. We deeply appreciate your dedication and contributions over the past eight years on this subcommittee, Peter.

CERAC is pleased to announce the addition of new Board members, Deema Audeh and Cara Philpott, who bring a strong interest in research and clinical trials. Both Deema and Cara have personal experience with neuromuscular conditions, providing valuable insights to our committee.

Additionally, we extend our gratitude to Shane Powell, a former Board member of Neuromuscular WA, for his dedicated service as a committee member and for amplifying another crucial voice within the community.

Dr Adelaide Withers, a member of the committee for two years, was a past recipient of the TEAM Spencer SMA scholarship in 2016 and along with the neuromuscular and respiratory teams at PCH and TKI, continues to undertake research in muscle weakness and respiratory health. Dr Withers has provided an update on her team's research outcomes and will also be presenting their findings at research evenings throughout 2024.

We express our gratitude to our longtime funding partner, TEAM Spencer, whose support has been instrumental in advancing our research and enhancing clinical care outcomes since 2012. We appreciate their ongoing dedication to investing in this crucial area.

We are fortunate to have the opportunity to meet annually with the founders of TEAM Spencer, Rick and Ruth Steven, to seek their continued support and endorsement for our projects and research initiatives, which they generously fund. Specifically, the physiotherapy project at PCH

relies heavily on their contributions. Nicola Hanlin and Lisa Patterson, physiotherapists at PCH, have provided comprehensive updates on these projects.

Thanks to our Honorary Life Member and founder Emeritus Professor Byron Kakulas AO and Honorary Life Member Professor Steve Wilton AO, in 2022 the Neurodegenerative Center donated over \$900,000 which has been earmarked for research initiatives over coming years.

During 2023, we once again consolidated the program's funding in past years and renewed engagement, partnership and friendship with the team at the Centre for Molecular Medicine and Innovative Therapeutics (CMMIT) at Murdoch University.

We are excited to be supporting the work of Dr Loren Flynn and Prof Anthony Akkari and their teams with a key focus on MND treatments.

I encourage you all to read the individual updates provided by our research and project partners who have contributed to ongoing research and development for the neuromuscular community through 2023.

Josh Davenport, Chair CERAC



Research Partners



RESEARCH PROJECTS FOR 2023

Progress Toward Treatments for Motor Neurone Disease

Motor Neurone Disease (MND) leads to muscle wasting because of damage to the motor neurons that connect muscles to the brain via the spinal cord. MND is a disease that progresses rapidly in affected people leading to serious immobility and death typically within 2-5 years of diagnosis.

There are limited therapeutic options for MND with little or no extension of life or improvements in quality of life. Dr Loren Flynn and Prof Anthony Akkari have been developing therapeutics that can precisely regulate individual genes, determined to be involved in damaging motor neurons. They and others think that using these precise gene targeting technologies called antisense oligonucleotides (AOs) is an important way forward for neuromuscular and neurodegenerative diseases.

Using AO's they can control genes that carry mutations or do not function correctly and as a result produce damaging or toxic proteins. These proteins specifically damage the motor neuron, eventually leading to a break in the connection of the neuron to the muscle. Using these AOs they can turn down the gene message that instructs a cell to build the toxic protein and ultimately prevent production. Once the toxic protein is turned down, evidence has emerged that this approach slows down the nerve damage and disease.

The group is focused on targetting genes previously demonstrated to be linked to MND using this AO technology, which was pioneered in Perth by Professors Steve Wilton and Sue Fletcher for Duchenne muscular dystrophy. Using similar approaches in MND-related genes they have developed a number of therapeutics that they are at present testing in the laboratory in preparation for the clinic.

Last year they advanced their lead candidate AO that turns down a toxic protein through a toxicology study to understand if it would be appropriate for clinical trials. Based on those studies the therapy continues to look very promising and it is their plan to advance this therapy into the clinic over the next 12-18 months.

Physiotherapy for Children with Neuromuscular Conditions at PCH

Nicola Hanlin has continued in her role in the position created at the start of 2020 with funding from Neuromuscular WA.

She has continued seeing newly diagnosed children, assessing them and assisting in the NDIS process. Once

their NDIS plans and service providers are chosen, she liaises with community therapists and offers resources and any assistance. There are standards of care that have been developed for most neuromuscular conditions (NMCs) which are comprehensive, and these are forwarded to therapists together with resources about recommended assessments. The North Star Ambulatory Assessment (NSAA) and timed function tests are foundational clinical assessments of function completed during the ambulatory period and should be done every 6 months. These tests have predictive capabilities regarding functional motor changes that are important in monitoring clinical progression. They are often one of the key clinical indicators for children in drug trials. They also can guide proactive care and future equipment needs.

Nicola works in both spinal orthopaedic clinics and liaises back to community therapists regarding any issues and plans. A few of the children with NMCs have undergone surgeries for their scoliosis deformities in the past year and it has been beneficial that she was in those clinics, has a relationship with the children and families and could advocate for them.

She also works in the newly-named Neuromuscular Orthopaedic Clinic with Dr Kate Stannage and sees current and new children referred to orthopaedics with NMCs, ensuring that our children have a physiotherapist who is present to relay relevant information.

Nicola attends the neuromuscular clinic on Fridays and is utilised by the neurologists if there are specific queries or issues about orthopaedics, mobility or other concerns. She does a Charcot Marie Tooth clinic with Professor Lamont once a month. A brief assessment is completed and those that are more significantly impacted are offered separate appointments with a lengthier assessment.

Last November Nicola commenced intensive training for SMA in Sydney at STEP-IN SMA – an internationally recognised training for physiotherapists. It is an extensive 3-part program that entails pre-course completion of multiple modules, 3 days of intensive training, followed by multiple assessments and treatments of children that are then assessed. Once this is completed Nicola will receive accreditation for being a world expert in the treatment and assessment of children with SMA. This was supported and funded through the neuromuscular team at PCH.

Nicola also attended the Australian Neuromuscular Network seminar on the Sunshine Coast in May, which provided relevant and up-to-date information about a variety of NMCs as well as multiple opportunities to liaise with other therapists who work in the neuromuscular area.

Respiratory Physiotherapy for Children with Neuromuscular Conditions at PCH

Lisa Paterson has provided specialised respiratory physiotherapy assessment and management for children attending neuromuscular clinics at Perth Children's Hospital (PCH) since April 2022, thanks to Neuromuscular WA funding. Lisa has a background in acute respiratory management for children with complex medical conditions and oversees the management of all children at PCH with technology-related needs.

Lisa works alongside the respiratory consultant during neuromuscular clinics, enabling her to proactively implement respiratory physiotherapy treatments and prescribe home programs focusing on airway clearance and chest wall mobility based on outcome measures including lung function and cough strength.

Children with NMCs commonly present with, or develop, respiratory muscle weakness which significantly impacts their ability to cough, as the muscles required to take a deep breath and cough are not strong enough or fatigue easily. As a result, the child is at risk of developing respiratory complications such as pneumonia if they are unable to clear their respiratory secretions effectively.

During clinics, Lisa introduces families to using a mechanical insufflation/exsufflation device which helps to augment a child's cough strength. Lisa teaches the child and family how to use the device, titrates settings to optimise effectiveness and routinely reviews these at subsequent clinic appointments. Usually once a child commences using such a device, they require it on a long-term basis. Lisa assists with writing support letters for families to receive their own device via NDIS funding.

In September 2023, Philips ceased production of their E70 CoughAssist™ machine. Lisa has been liaising with other centres around Australia to investigate replacement models such as the Pegaso and Nippy 2 and is best placed to assist families in sourcing replacement devices in the future.

Lisa also liaises with community providers to optimise respiratory health in the community by promoting and exploring ways to remain physically active, especially if the child becomes less mobile.

Behind the scenes, during 2023 the team at PCH have commenced development of a new database system to help capture clinical information to be able to record outcomes and contribute to research more easily.

Having Lisa, a specialist respiratory physiotherapist, based in the neuromuscular clinic facilitates a strong bond with children and their families, streamlines their respiratory care and optimises their respiratory health.

Developing Clinical Predictors of Disease Progression in Children with Neuromuscular Conditions

The TEAM Spencer SMA Research Scholarship continues to support Dr Adelaide Withers' research which explores the impact of muscle weakness on sleep and respiratory health. 2023 turned out to be a great year for the Neuromuscular Research Team at PCH and Telethon Kids Institute, with many exciting developments to share with the neuromuscular community.

The focus of this research is identifying hypoventilation, which occurs when weak respiratory muscles are not able to expand the chest adequately during sleep, leading to accumulation of carbon dioxide in the bloodstream.

Accurate and early diagnosis is essential as hypoventilation can be treated. Unfortunately, symptoms are vague and non-specific, and currently hypoventilation can only be detected during a sleep study. This research aims to identify other factors, such as lung function tests, symptom scores or clinical measures which could indicate the presence of hypoventilation. The multi-centre collaborative study is nearing completion, with all data collected from local participants and data collection ongoing at collaborative sites in California and Queensland. Preliminary analysis is underway, and these results will be essential in developing evidence-based clinical guidelines to ensure hypoventilation is diagnosed as early as possible to avoid treatment delays.

Dr Withers was very proud to have published two papers in 2023; 'Diagnosis of Nocturnal Hypoventilation in Pediatrics Neuromuscular Disorders: A Survey of Clinical Practice in Australia and New Zealand' in the Journal of Sleep Medicine and 'Interobserver Agreement When Diagnosing Hypoventilation in Children with Neuromuscular Disorders' in Sleep Medicine Research. Both studies found significant variation in how hypoventilation was defined within Australian and New Zealand, and even between sleep doctors in the same centre. These studies highlighted the need for a unified and evidence-based approach when defining hypoventilation, particularly for individuals with NMD who may require more sensitive criteria.

Perhaps the most exciting development for 2023 is that all of the data comparing home sleep studies and laboratory sleep studies has been analysed and will be published in the near future. Results are still top-secret but will be shared with our community as soon as possible.

Dr Withers is extremely thankful for the ongoing support and funding from Neuromuscular WA, and is so grateful to all of the individuals and families who have participated in the research, members of the community reference group and wider neuromuscular community for all of their valuable input.



Neuromuscular WA Incorporated
ABN 49 158 959 834

*We acknowledge the traditional custodians of this land on which we live and work,
the Nyoongar Whadjuk people and we wish to acknowledge the strength of their continuing culture
and offer our respects to Elders past and present.*



NEUROMUSCULAR WA (INCORPORATED)
(FORMERLY MUSCULAR DYSTROPHY ASSOCIATION OF WESTERN AUSTRALIA)
A.B.N. 49 158 959 834

FINANCIAL REPORT
FOR THE YEAR ENDED 31 DECEMBER 2023

NEUROMUSCULAR WA (INCORPORATED)
A.B.N. 49 158 959 834

FINANCIAL REPORT FOR THE YEAR ENDED 31 DECEMBER 2023

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NEUROMUSCULAR WA (INCORPORATED)
A.B.N. 49 158 959 834

BOARD'S REPORT

The Board members submit the financial report of Neuromuscular WA Inc, for the financial year ended 31 December 2023.

Board Members

The names of Board members (alphabetical first name) throughout the year and at the date of this report are:

Aaron Schier
Abby Macnish Niven (Treasurer) - appointed June 2023
Adelaide Withers
Cara Philpott (Vice Chair) - elected June 2023
Deema Audeh (elected June 2023)
Ellen Story-Potter
Josh Davenport (Chair) - appointed June 2023
Lisa King
Matthew Curnow
Nirbhay Gupta (elected June 2023)
Peter Rowe (retired June 2023)
Shane Powell (term expired June 2023)
Tanvi Haria (Chair) – term expired June 2023

Principal activities

The principal activities of Neuromuscular WA during the financial year were the provision of services, education, and advocacy to Western Australians living with neuromuscular conditions and their families and raising funds to support these programs, services and activities. The Association funds research initiatives and projects focused on improving quality of life for people living with neuromuscular conditions.

Significant changes

No significant change in Neuromuscular WA activities occurred during the year.

Operating Results

The surplus prior to Grants and Scholarships expenses was \$128,622.

After granting \$212,220 for research projects, grants, and scholarships; including a provision for Harold and Sylvia Rowell Scholarships, TEAM Spencer projects, NDC research and the Empower Grants; it results in a net loss of (\$83,598).

Events Subsequent to the End of the Reporting Period

There are no other matters or circumstances that have arisen since the end of the year which significantly affected or may significantly affect the operations of the Association, the results of those operations, or state of affairs of the Association in future years.

Signed in accordance with a resolution of the Members of the Board.



Josh Davenport
Chair



Abby Macnish Niven
Treasurer

Date: 1/5/24

NEUROMUSCULAR WA (INCORPORATED)
A.B.N. 49 158 959 834

INCOME AND EXPENDITURE STATEMENT FOR THE YEAR ENDED 31 DECEMBER 2023

	Note	2023 \$	2022 \$
INCOME			
Fundraising and donations	2	707,145	616,493
Projects & Scholarships	3 & 6	5,715	923,587
Grants income	3 & 5	422,814	395,377
Dividends received		72,311	78,391
Interest received		46,918	16,545
Increase in value of investments		148,457	4,128
Other income		23,622	51,618
Bequest & Trusts		60,063	173,589
TOTAL INCOME		1,487,045	2,259,728
EXPENDITURE			
Depreciation expense		14,519	36,650
Audit fees		10,263	8,330
Bank charges		55	235
Community expenses		156,747	105,847
Community salaries and superannuation expense		506,521	454,710
Utilities expense		6,114	6,026
Unrealised loss of share valuation		-	323,233
Advertising and promotion expenses		41,417	13,285
Administration expenses		34,105	50,242
Outgoing expense		35,848	40,852
Salaries and superannuation expense		459,579	454,980
Fundraising expenses		93,255	77,874
TOTAL EXPENDITURE		1,358,423	1,572,264
Current year surplus prior to Research Grants and Scholarships Provision			
		128,622	687,464
Empower Grants	5	(35,700)	(27,737)
Harold and Sylvia Rowell Scholarships		(9,950)	(49,900)
Other Grants	6	(166,570)	(94,861)
Net position after Research Grants & Scholarships		(83,598)	514,966
RETAINED SURPLUS AT BEGINNING OF THE FINANCIAL YEAR			
		3,244,574	2,729,608
RETAINED SURPLUS AT END OF THE FINANCIAL YEAR			
		3,160,976	3,244,574

NEUROMUSCULAR WA (INCORPORATED)
A.B.N. 49 158 959 834

ASSETS AND LIABILITIES STATEMENT AS AT 31 DECEMBER 2023

	Note	2023 \$	2022 \$
CURRENT ASSETS			
Cash on hand	7	480,503	654,381
Accounts receivable and other debtors	8	821,575	1,017,478
Prepayments		4,746	3,198
TOTAL CURRENT ASSETS		1,306,824	1,675,057
NON-CURRENT ASSETS			
Financial assets	9	2,127,810	1,914,001
Property plant and equipment	10	47,248	18,087
Net ROU Asset	11	141,630	-
TOTAL NON-CURRENT ASSETS		2,316,688	1,932,088
TOTAL ASSETS		3,623,512	3,607,145
CURRENT LIABILITIES			
Accounts payable and other payables		24,641	40,723
TEAMSpencer SMA Funds	4	98,763	104,478
Unexpended grant funding		54,770	94,515
Employee Provisions		140,042	117,807
Current Lease Liability	11	40,237	-
TOTAL CURRENT LIABILITIES		358,453	357,523
NON-CURRENT LIABILITIES			
Employee provisions		10,128	5,048
Non-Current Lease	11	93,955	-
TOTAL NON-CURRENT LIABILITIES		104,083	5,048
TOTAL LIABILITIES		462,536	362,571
NET ASSETS		3,160,976	3,244,574
TOTAL ACCUMULATED FUNDS		3,160,976	3,244,574

NEUROMUSCULAR WA (INCORPORATED)
A.B.N. 49 158 959 834

STATEMENT OF CHANGES IN EQUITY FOR THE YEAR ENDED 31 DECEMBER 2023

	\$
Balance at 1 January 2022	2,729,608
Comprehensive income	
Surplus for the year attributable to members	514,966
Balance at 31 December 2022	3,244,574
Balance at 1 January 2023	3,244,574
Comprehensive income	
Loss for the year attributable to members	(83,598)
Balance at 31 December 2023	3,160,976

NEUROMUSCULAR WA (INCORPORATED)
A.B.N. 49 158 959 834

STATEMENT OF CASH FLOW FOR THE YEAR ENDED 31 DECEMBER 2023

	Note	2023	2022
		\$	\$
CASH FLOWS FROM OPERATING ACTIVITIES			
Receipts from donations, bequests, raffles and other receipts		1,175,517	2,289,551
Interest received		46,918	16,545
Dividends received		72,311	78,391
Payments to suppliers and employees		(1,559,994)	(1,329,296)
Net cash (used in)/generated from operating activities	12	(265,248)	1,055,191
CASH FLOWS FROM FINANCING ACTIVITIES			
Proceeds from term deposit		200,000	-
Proceeds from sale of investments		287,411	173,450
Payment for purchase of investments		(352,763)	(241,840)
Net cash used in financing activities		134,648	(68,390)
CASH FLOWS FROM FINANCING ACTIVITIES			
Payment of lease liabilities		(43,278)	-
Net cash used in financing activities		(43,278)	-
Net decrease in cash held		(173,878)	986,801
Cash on hand at the beginning of the financial year		654,381	667,580
Reclassification of term deposit to receivables		-	(1,000,000)
Cash on hand at the end of the financial year	7	480,503	654,381

NEUROMUSCULAR WA (INCORPORATED)
A.B.N. 49 158 959 834

NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 DECEMBER 2023

Note 1: Summary of significant accounting policies

The financial statements are special purpose financial statements prepared in order to satisfy the financial reporting requirements of the Associations Incorporation Act 2015 (Western Australia) The Board has determined that the Association is not a reporting entity.

Statement of Compliance

The financial report has been prepared in accordance with Associations Incorporation Act 2015 (WA) the basis of accounting measurement principles specified by all Australian Accounting Standards and Interpretations, and the disclosure requirements of Accounting Standards AASB 101: *Presentation of Financial Statements*, AASB 107: *Cash Flow Statements*, AASB 108: *Accounting Policies, Changes in Accounting Estimates and Errors*, AASB 124: *Related Party Disclosures*, AASB 1048: *Interpretation of Standards*, AASB 1054: *Australian Additional Disclosures* and AASB 1058: *Income for Not-For-Profit Entities*.

Basis of Preparation

The financial statements, except for the cash flow information, have been prepared on an accruals basis and are based on historic costs and do not take into account changing money values or, except where stated specifically, current valuations of non-current assets.

The following significant accounting policies, which are consistent with the previous period unless stated otherwise, have been adopted in the preparation of these financial statements.

(a) Income tax

The Association is exempt from income because it is a charitable body with Deductible Gift Recipient status.

(b) Property, plant and equipment (PPE)

Leasehold improvements and office equipment are carried at cost less, where applicable, any accumulated depreciation. The depreciable amount of all PPE is depreciated over the useful lives of the assets to the Association commencing from the time the asset is held ready for use. Leasehold improvements are amortised over the shorter of either the unexpired period of the lease or the estimated useful lives of the improvements.

The depreciation rates used for each class of depreciable assets are as follows:

Class of Fixed Assets	Depreciation Rate
Office equipment	10% - 40%

(c) Impairment of assets

At the end of each reporting period, the Board reviews the carrying amounts of its tangible and intangible assets to determine whether there is any indication that those assets have been impaired. If such an indication exists, an impairment test is carried out on the asset by comparing the recoverable amount of the asset, being the higher of the asset's fair value less costs to sell and value in use, to the asset's carrying amount. Any excess of the asset's carrying amount over its recoverable amount is recognised in the income and expenditure statement.

(d) Employee provisions

Provision is made for the Association's liability for employee benefits arising from services rendered by employees to the end of the reporting period. Employee provisions have been measured at the amounts expected to be paid when the liability is settled.

NEUROMUSCULAR WA (INCORPORATED)
A.B.N. 49 158 959 834

NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 DECEMBER 2023

Note 1: Summary of significant accounting policies (continued)

(e) Provisions

Provisions are recognised when the Association has a legal or constructive obligation, as a result of past events, for which it is probable that an outflow of economic benefits will result, and that outflow can be reliably measured. Provisions are measured at the best estimate of the amounts required to settle the obligation at the end of the reporting period.

(f) Cash and cash Equivalents

Cash and cash equivalents include cash on hand, deposits held at call with banks, and other short-term highly liquid investments.

(g) Accounts receivable and other debtors

Accounts receivable and other debtors include amounts due from financial institutions, members as well as amounts receivable from donors. Receivables expected to be collected within 12 months of the end of the reporting period are classified as current assets. All other receivables are classified as non-current assets.

(h) Leases

The Association as lessee

At inception of a contract, the Association assesses if the contract contains or is a lease. If there is a lease present, a right-of-use asset and a corresponding lease liability is recognised by the Association where the Association is a lessee. However, all contracts that are classified as short-term leases (lease with remaining lease term of 12 months or less) and leases of low value assets are recognised as an operating expense on a straight-line basis over the term of the lease.

Initially the lease liability is measured at the present value of the lease payments still to be paid at commencement date. The lease payments are discounted at the interest rate implicit in the lease. If this rate cannot be readily determined, the Association uses the incremental borrowing rate.

Lease payments included in the measurement of the lease liability are as follows:

- fixed lease payments less any lease incentives;
- variable lease payments that depend on an index or rate, initially measured using the index or rate at the commencement date;
- the amount expected to be payable by the lessee under residual value guarantees;
- the exercise price of purchase options, if the lessee is reasonably certain to exercise the options;
- lease payments under extension options if lessee is reasonably certain to exercise the options; and
- payments of penalties for terminating the lease, if the lease term reflects the exercise of an option to terminate the lease

The right-of-use assets comprise the initial measurement of the corresponding lease liability as mentioned above, any lease payments made at or before the commencement date as well as any initial direct costs. The subsequent measurement of the right-of-use assets is at cost less accumulated depreciation and impairment losses.

Right-of-use assets are depreciated over the lease term or useful life of the underlying asset whichever is the shortest. Where a lease transfers ownership of the underlying asset or the cost of the right-of-use asset reflects that the Association anticipates to exercise a purchase option, the specific asset is depreciated over the useful life of the underlying asset.

(i) Goods and services tax (GST)

Revenues, expenses and assets are recognised net of the amount of GST, except where the amount of GST incurred is not recoverable from the Australian Taxation Office (ATO). Receivables and payables are stated inclusive of the amount of GST receivable or payable. The net amount of GST recoverable from, or payable to, the ATO is included with other receivables or payables in the assets and liabilities statement.

NEUROMUSCULAR WA (INCORPORATED)
A.B.N. 49 158 959 834

NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 DECEMBER 2023

Note 1: Summary of significant accounting policies (continued)

(j) Financial assets

Investments and other financial assets are initially measured at fair value. Transaction costs are included as part of the initial measurement, except for financial assets at fair value through profit or loss. Such assets are subsequently measured at either amortised cost or fair value depending on their classification. Classification is determined based on both the business model within which such assets are held and the contractual cash flow characteristics of the financial asset unless, an accounting mismatch is being avoided.

Financial assets are derecognised when the rights to receive cash flows have expired or have been transferred and the Association has transferred substantially all the risks and rewards of ownership. When there is no reasonable expectation of recovering part or all of a financial asset, its carrying value is written off.

Financial assets at fair value through profit or loss

Financial assets not measured at amortised cost or at fair value through other comprehensive income are classified as financial assets at fair value through profit or loss. Typically, such financial assets will be either: (i) held for trading, where they are acquired for the purpose of selling in the short-term with an intention of making a profit, or a derivative; or (ii) designated as such upon initial recognition where permitted. Fair value movements are recognised in profit or loss.

Impairment of financial assets

The Association recognises a loss allowance for expected credit losses on financial assets which are either measured at amortised cost or fair value through other comprehensive income. The Association uses the simplified approach which does not require tracking of changes in credit risk at every reporting period, but instead requires the recognition of lifetime expected credit loss at all times.

This approach is applicable to:

- trade receivable; and
- lease receivables.

In measuring the expected credit loss, a provision matrix for trade receivables is used, taking into consideration various data to get to an expected credit loss (ie diversity of its customer base, appropriate groupings of its historical loss experience, etc).

(k) Revenue recognition

Revenue is measured at the fair value of the consideration received or receivable after taking into account any trade discounts and volume rebates allowed. For this purpose, deferred consideration is not discounted to present values when recognising revenue.

NEUROMUSCULAR WA (INCORPORATED)
A.B.N. 49 158 959 834

NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 DECEMBER 2023

Note 1: Summary of significant accounting policies (continued)

Contributed assets

The Association receives assets from the government and other parties for nil or nominal consideration in order to further its objectives. These assets are recognised in accordance with the recognition requirements of other applicable Accounting Standards (for example, AASB 9, AASB 16, AASB 116 and AASB 138.)

On initial recognition of an asset, the Association recognises related amounts (being contributions by owners, lease liability, financial instruments, provisions, revenue or contract liability arising from a contract with a customer).

The Association recognises income immediately in profit or loss as the difference between initial carrying amount of the asset and the related amount.

Operating grants, donations and bequests

When the Association receives operating grant revenue, donations or bequests, it assesses whether the contract is enforceable and has sufficiently specific performance obligations in accordance with AASB 15. When both these conditions are satisfied, the Association:

- identifies each performance obligation relating to the grant;
- recognises a contract liability for its obligations under the agreement; and
- recognises revenue as it satisfies its performance obligations.

Where the contract is not enforceable or does not have sufficiently specific performance obligations, the association:

- recognises the asset received in accordance with the recognition requirements of other applicable Accounting Standards (for example, AASB 9, AASB 16, AASB 116 and AASB 138);
- recognises related amounts (being contributions by owners, lease liability, financial instruments, provisions, revenue or contract liability arising from a contract with a customer);
- recognises income immediately in profit or loss as the difference between the initial carrying amount of the asset and the related amount.

If a contract liability is recognised as a related amount above, the Association recognises income in profit or loss when or as it satisfies its obligations under the contract.

Capital grant

When the Association receives a capital grant, it recognises a liability for the excess of the initial carrying amount of the financial asset received over any related amounts (being contributions by owners, lease liability, financial instruments, provisions, revenue or contract liability arising from a contract with a customer) recognised under other Australian Accounting Standards.

The Association recognises income in profit or loss when or as the Association satisfies its obligations under the terms of the grant.

Interest income

Interest income is recognised using the effective interest method.

Dividend income

The Association recognises dividends in profit or loss only when the right to receive payment of the dividend is established.

Income from sale of good

All revenue is stated net of the amount of goods and services tax

NEUROMUSCULAR WA (INCORPORATED)
A.B.N. 49 158 959 834

NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 DECEMBER 2023

Note 2: Fundraising and donations

Throughout the year, the Association receives income from voluntary contributions. The Association has the appropriate controls in place to ensure that subsequent to the initial entry of these amounts in the accounting records they are correctly accounted for and utilised. However, it is not practical for the Association to establish controls over these contributions prior to their initial entry in the accounting records to ensure that all contributions are received and recorded.

	2023	2022
	\$	\$
Collection Boxes Income	-	2,194
Toyota WA Golf Day	95,775	88,135
Dwellingup 100	17,810	23,021
Peer to Peer Events	14,828	20,479
Impact Art Event	35,546	-
Supporter Run Events	26,215	27,443
Rhythm & Views Event	23,336	17,404
Tall Tales Event	32,505	31,065
Busselton Toyota Golf Day	30,615	31,306
Mail Appeal Income	92,947	63,697
General Donations	190,311	150,372
Christmas Carols at Scarborough	3,504	3,920
Kailis Club Event	110,760	128,479
Private Ancillary Funds (PAFS)	24,735	18,960
Friends with Benefits	8,258	10,018
TOTAL FUNDRAISING AND DONATIONS	707,145	616,493

Note 3: Grants, Scholarship & Project income

The Association attains grant income from government agencies, corporate bodies, Private Ancillary Funds, targeted donations and private organisations. These grants are allocated to Community Projects, Events, Research Scholarships and Research Projects.

The Empower Funds relate to donations received to be allocated to the community as part of the Empower Grants process.

	2023	2022
	\$	\$
Telethon Grant	151,180	143,680
Scholarship & Projects Grants	5,715	923,587
Government Grants (Nonrecurrent)	187,199	204,545
Other Grant income	103,505	108,930
Empower Funds	35,700	32,737
Total Grant income	483,299	1,413,479
Unexpended Scholarship & Projects Grants	54,770	94,515
NET GRANT INCOME	428,529	1,318,964

NEUROMUSCULAR WA (INCORPORATED)
A.B.N. 49 158 959 834

NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 DECEMBER 2023

Note 4: Team Spencer Research Grants and Scholarships

Team Spencer was created by Rick and Ruth Steven, in honour of their son Spencer, who was born in March 2006 with SMA and who sadly passed away just seven months later. Team Spencer dedicates itself to raise funds through various events with funding earmarked for research initiatives and projects that will support individuals and families affected by Spinal Muscular Atrophy.

Note 5: Empower Funds

The Empower Fund Grants were approved in 2017 to provide funding to our community for initiatives not ordinarily funded or supplied via other agencies or funders. The Empower Fund Grants Committee provides advice and recommendation to the Board on successful application and distribution of grant funding.

Fundraising initiatives are aligned to the Empower Fund Grants with funds raised through these donations/activities allocated for and to be expended as per the Grants Committee recommendations.

The Board endeavours to expend the annual Empower Fund as per the grant's application process, when excess funds remain at the end of the year, the balance is transferred to retained surplus and is then attributed to future years applications. Costs associated with administering and promoting the fund will be included within the budget.

Note 6: Neurodegenerative Disorder Center Inc (NDC) Funds

July 2022 the Neurodegenerative Disorder Center Inc (NDC) Board transferred the balance of the NDC funds of \$923,587 to Neuromuscular WA as part of their legal requirement in winding up. This donation was made with the instruction to direct the funds to the research for Professor Anthony Akkari and support personnel. Neuromuscular WA will retain any interest earned from these funds. As agreed between Neuromuscular WA, The Perron Institute and Murdoch University, the payments will be made annually from 2022 to 2026.

Note 7: Cash on Hand

	2023	2022
	\$	\$
Cash at bank	480,503	654,381

Note 8: Accounts receivable and other debtors

	2023	2022
	\$	\$
Note 8: Accounts receivable and other debtors		
Term Deposit	800,000	1,000,000
Other debtors	21,575	17,478
	821,575	1,017,478

Note 9: Financial Assets

	2023	2022
	\$	\$
Note 9: Financial assets		
Non-current		
Investments at fair value through profit or loss	2,127,810	1,914,001

NEUROMUSCULAR WA (INCORPORATED)
A.B.N. 49 158 959 834

NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 DECEMBER 2023

Note 10 Plant and Equipment

	2023	2022
	\$	\$
Medical support equipment	347,025	309,645
Less accumulated depreciation	(299,777)	(291,558)
	47,248	18,087
Website	-	62,643
Less accumulated depreciation	-	(62,643)
TOTAL PLANT AND EQUIPMENT	47,248	18,087

Note 11: Right of use asset and Lease liability

Lease Liability and ROU under accounting standard "AASB 16". The full lease contract taken up on our Balance Sheet.

	2023	2022
	\$	\$
Right of use asset		
Right of use asset	169,023	-
Less: Accumulated depreciation	(27,393)	-
NET ROU ASSET	141,630	-

Additions to the right of use assets during the year were \$169,023 and depreciation charged to profit, and loss was \$27,393. The addition to the lease was for an office lease with 4 years remaining on the lease term.

Lease liability		
Current lease liability	40,237	-
Non-current lease liability	93,955	-
TOTAL LEASE LIABILITY	134,192	-

NEUROMUSCULAR WA (INCORPORATED)
A.B.N. 49 158 959 834

NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 DECEMBER 2023

Note 12: Cash Flow Information

	2023	2022
	\$	\$
Reconciliation of cash flows from operating activities with net current year surplus		
Net current year surplus	(83,598)	514,966
Non-cash flows in current year surplus:		
- Depreciation and amortisation	14,519	36,650
- Unrealised loss/ (gain)	(134,942)	323,233
- Loss on sale of property, plant and equipment and investments	(13,515)	(4,128)
- Depreciation of ROU asset	27,393	-
- Interest expense of ROU asset	7,514	-
Changes in assets and liabilities		
- Decrease/ (increase) in accounts receivable and other debtors	(4,097)	34,372
- Decrease/ (increase) in prepayments	(1,548)	84
- (Decrease)/increase in accounts payable and other payables	(104,289)	128,181
- Increase in provisions	27,315	21,833
	(265,248)	1,055,191

Note 13: Transactions with Key Management Personnel

Key Management personnel compensation comprises the following:

The aggregate compensation made to officers and other members of key management personnel of the Association are set out below:

Aggregate compensation	599,199	583,045
------------------------	----------------	----------------

There were no other transactions with key management personnel during the financial year or outstanding at balance date.

Note 14: Remuneration of Auditors

During the financial year the following fees were paid or payable for services provided by HLB Mann Judd (2022: Owen & Plaistow), the auditor of the Association.

Audit of the financial statements	10,263	8,330
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NEUROMUSCULAR WA (INCORPORATED)
A.B.N. 49 158 959 834

STATEMENT BY THE BOARD

The Board has determined that Neuromuscular WA Inc. (The Association) is not a reporting entity and that this special purpose financial report should be prepared in accordance with the accounting policies outlined in Note 1 to the financial statements.

In the opinion of the Board:

1. The accompanying special purpose financial report gives a true and fair view of the financial position of the Association for the year ended 31 December 2023 and its performance for the financial year ended on that date, in accordance with Australian Accounting Standards to the extent described in Note 1 and the Australian Charities and Not-for-profits Commission Act 2012 (ACNC Act) and the Associations Incorporation Act 2015 (WA);
2. The operations of the Association have been carried out in accordance with the Constitution of the Association; and
3. At the date of this statement there are reasonable grounds to believe that the Association will be able to pay its debts as and when they become due and payable.
4. The financial report of the Association has been properly prepared, and the Associated records have been properly kept for the year ended 31 December 2023, in accordance with the Charitable Collections Act (1946) (WA) and the Charitable Collections Regulations (1947) (WA);
5. Funds received as a result of fundraising activities conducted during the year ended 31 December 2023 have been properly accounted for and applied in accordance with the Charitable Collections Act (1946) (WA) and the Charitable Collections Regulations (1947) (WA);

The statement is made in accordance with a resolution of the Board and is signed for and on behalf of the Board by:



Abby Macnish Niven
Treasurer



Josh Davenport
Chair

1/5/24

Dated
Perth, Western Australia

Independent Auditor’s Report to the Members of Neuromuscular WA (formerly Muscular Dystrophy Association of Western Australia (Incorporated))

REPORT ON THE AUDIT OF THE FINANCIAL REPORT

Opinion

We have audited the financial report of Neuromuscular WA (the “Association”), which comprises the statement of financial position as at 31 December 2023, the statement of profit or loss and other comprehensive income, the statement of changes in equity and the statement of cash flows for the year then ended, and notes to the financial statements, including material accounting policy information, and the statement by the Board.

In our opinion, the accompanying financial report of the Association has been prepared in accordance with Division 60 of the *Australian Charities and Not-for-profits Commission Act 2012*, including:

- (a) giving a true and fair view of the Association’s financial position as at 31 December 2023 and of its financial performance for the year then ended; and
- (b) complying with Australian Accounting Standards to the extent described in Note 1 and Division 60 of the *Australian Charities and Not-for-profits Commission Regulations 2022*.

Basis for Opinion

We conducted our audit in accordance with Australian Auditing Standards. Our responsibilities under those standards are further described in the *Auditor’s Responsibilities for the Audit of the Financial Report* section of our report. We are independent of the Association in accordance with the auditor independence requirements of the Accounting Professional and Ethical Standards Board’s APES 110 *Code of Ethics for Professional Accountants* (“the Code”) that are relevant to our audit of the financial report in Australia. We have also fulfilled our other ethical responsibilities in accordance with the Code.

We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our opinion.

Emphasis of Matter – Basis of Accounting and Restriction on Use

We draw attention to Note 1 to the financial report, which describes the basis of accounting. The financial report has been prepared for the purpose of fulfilling the financial reporting responsibilities under the *Australian Charities and Not-for-profits Commission Act 2012*. As a result, the financial report may not be suitable for another purpose. Our report is intended solely for Neuromuscular WA and its members and should not be used by parties other than Neuromuscular WA and its members. Our opinion is not modified in respect of this matter.

hlb.com.au

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Liability limited by a scheme approved under Professional Standards Legislation.

Responsibilities of Management and Those Charged with Governance for the Financial Report

Management is responsible for the preparation of the special purpose financial report that gives a true and fair view and have determined that the basis of preparation described in Note 1 of the financial report is appropriate to meet the requirements of the *Australian Charities and Not-for-profits Commission Act 2012*. Management's responsibility also includes such internal control as management determines is necessary to enable the preparation of the financial report that is free from material misstatement, whether due to fraud or error.

In preparing the special purpose financial report, management is responsible for assessing the Association's ability to continue as a going concern, disclosing, as applicable, matters related to going concern and using the going concern basis of accounting unless management either intend to liquidate the Association or to cease operations, or have no realistic alternative but to do so.

Those charged with governance are responsible for overseeing the Association's financial reporting process.

Auditor's Responsibilities for the Audit of the Financial Report

Our objectives are to obtain reasonable assurance about whether the financial report as a whole is free from material misstatement, whether due to fraud or error, and to issue an auditor's report that includes our opinion. Reasonable assurance is a high level of assurance, but is not a guarantee that an audit conducted in accordance with Australian Auditing Standards will always detect a material misstatement when it exists. Misstatements can arise from fraud or error and are considered material if, individually or in the aggregate, they could reasonably be expected to influence the economic decisions of users taken on the basis of this financial report.

As part of an audit in accordance with the Australian Auditing Standards, we exercise professional judgement and maintain professional scepticism throughout the audit. We also:

- Identify and assess the risks of material misstatement of the financial report, whether due to fraud or error, design and perform audit procedures responsive to those risks, and obtain audit evidence that is sufficient and appropriate to provide a basis for our opinion. The risk of not detecting a material misstatement resulting from fraud is higher than for one resulting from error, as fraud may involve collusion, forgery, intentional omissions, misrepresentations, or the override of internal control.
- Obtain an understanding of internal control relevant to the audit in order to design audit procedures that are appropriate in the circumstances, but not for the purpose of expressing an opinion on the effectiveness of the Association's internal control.
- Evaluate the appropriateness of accounting policies used and the reasonableness of accounting estimates and related disclosures made by management.
- Conclude on the appropriateness of management's use of the going concern basis of accounting and, based on the audit evidence obtained, whether a material uncertainty exists related to events or conditions that may cast significant doubt on the Association's ability to continue as a going concern. If we conclude that a material uncertainty exists, we are required to draw attention in our auditor's report to the related disclosures in the financial report or, if such disclosures are inadequate, to modify our opinion. Our conclusions are based on the audit evidence obtained up to the date of our auditor's report. However, future events or conditions may cause the Association to cease to continue as a going concern.
- Evaluate the overall presentation, structure and content of the financial report, including the disclosures, and whether the financial report represents the underlying transactions and events in a manner that achieves fair presentation.

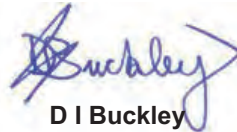
We communicate with those charged with governance regarding, among other matters, the planned scope and timing of the audit and significant audit findings, including any significant deficiencies in internal control that we identify during our audit.

We also provide those charged with governance with a statement that we have complied with relevant ethical requirements regarding independence, and to communicate with them all relationships and other matters that may reasonably be thought to bear on our independence, and where applicable, related safeguards.



HLB Mann Judd
Chartered Accountants

Perth, Western Australia
1 May 2024

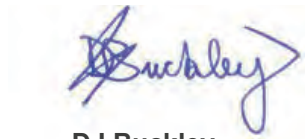


D I Buckley
Partner

AUDITOR'S INDEPENDENCE DECLARATION

We declare that, to the best of our knowledge and belief, there have been no contraventions of any applicable code of professional conduct in relation to the audit of the financial report of Neuromuscular WA for the year ended 31 December 2023.

**Perth, Western Australia
1 May 2024**



**D I Buckley
Partner**

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