



Muscular
Dystrophy WA

2019 Annual Report



President & CEO Report

Once again, we are honoured to present the President and CEO report for the MDWA Annual Report for 2019. The whole team including the Board, staff and volunteers continued to build upon the decades of service and support to the WA neuromuscular community. In 2019 the team delivered an exceptional number of events and programs to our community.

Not only were the number of events increased from the previous year, but 2019 saw record numbers of attendees as well. Coupled with a 95% increase in contacts that the community team are engaging in, we are doing things right and delivering the support that the community deserves.

We thank Piper, Brooke and Sarah for their efforts making sure the MDWA community remain our priority, ensuring they have access to the essential programs and information they need. We thank them in particular for their enormous efforts hosting the MD2019 conference in November with numerous national and international speakers and over 100 attendees.

Our programs are supported through grants and funds raised by our fundraising and marketing team. This year we embarked on event management and coordinated the Dwellingup 100 for the Shire of Murray. This was a huge feat for us to take on as a small team and we were grateful for Ashleigh Apps' efforts as our contracted Event Manager for a period during the year.

We also wish to acknowledge the huge efforts of our team in particular Emma, Mel and Mark who went above and beyond to support participants and fundraisers in their journey for the Dwellingup 100. An amazingly perfect day in September saw over 1,000 participants and the biggest ever number of our community attend the day in the beautiful town of Dwellingup.

While we are saddened that this longstanding 11-year partnership with the event has come to an end, we know the many hundreds of fundraisers who supported us along the way will still be there to support us in the future.

In 2019 we said goodbye to one of our stalwarts, Brianna O'Donnell.

Bri, who most will fondly know as the face of MDWA from 2005, certainly gave above and beyond to our organisation and community and we were super sad to see her go, but only too thrilled to see her continue her career with Profs. Sue Fletcher and Steve Wilton at Murdoch University.

In March we also said goodbye to Toby Gummer who had been overseeing the business administration for 6 years. We wish both Bri and Toby all the very best in the future and we thank them for their efforts over the years.

In June we were joined by Mel Dhillon who seamlessly picked up the ropes from Brianna, stepping in to support our fundraising team and rolling out the communications and marketing materials for MDWA. She is a massive asset to our team and Mel, Emma and Mark can collectively be commended for their efforts in making all of our fundraising events huge successes in 2019.

Our brand is truly on point and the professional presentation of our organisation to the broader public is very welcomed.

We continued to work nationally to ensure a united voice across the country with Vice Chair and Board Member Brendan Murphy as a representative on the Muscular Dystrophy Foundation (MDF) Board, and our CEO as a member of the MDF executive team. We are excited that our collective Information, Linkages and Capacity Building grant will eventuate in the delivery of The Loop website in 2020.

Our investments into research continue with 3 ongoing projects at Perth Children's Hospital – a focus on nutrition; funding a Spinraza neuromuscular nurse; and the respiratory project. You can read full details in the Research section of this report.

Partnerships have always been a focus for MDWA with our long standing motto of "better together" remaining at the forefront of our thinking.

President & CEO Report continued...

At a state and national level we enhanced our collaboration with numerous other not-for-profits to deliver opportunities for networking, and tangible outcomes for our community.

We would like to thank those individuals at the Telethon Kids Institute, Rare Voices Australia, Spinal Muscular Atrophy Australia, Save our Sons Duchenne Foundation, The Perron Institute for Translational Medicine and the neurological organisations at the Centre for Neurological Support for the continued opportunities in working together.

We extend our gratitude and thanks to our Board members for their support during the year and their ongoing commitment to our community. It is a privilege to have such a skilled and knowledgeable board and their longstanding efforts are valued and appreciated.

We said goodbye to Rob Storey as a member of our Finance Audit and Risk Committee and thank him for his many years of service to MDWA, and we welcomed Neil Hancy as a member of this committee from June 2019.

We wish to thank all of our loyal supporters who gave to the cause during the year. Be it through attending and contributing at fundraising events, pledging donations through various appeals, or through the supply of your corporate services or goods in-kind – we are extremely grateful. As a small charity with no ongoing government funding, your help is invaluable and we cannot do it without you.

To you, our community, we speak on behalf of the Board and the whole team in the office – humbly noting that it remains an absolute privilege and honour to serve you.

Together we will continue to work hard in our commitment to research initiatives, social support, advocacy and provision of other support and services wherever possible – what we call *Support for Life*.

The Board

Elected by the association's members during the annual general meeting, MDWA is fortunate to boast a dedicated board who ensure the association remains focussed on achieving our mission and following our strategic plan.



BRAD GIRDWOOD,
President
Board member since 2014



BRENDAN MURPHY,
Vice President
Board member since 2014



TANVI HARIA,
Treasurer
Board member since 2016



SUSAN TRAHAR,
Member
Board member since 2010



DR PETER W ROWE,
Member
Board member since 2012



JANE EDWARDS,
Member
Board member since 2014



JODIE HATHERLEY,
Member
Board member since 2015



AARON SCHIER,
Member
Board member since 2017



SHANE POWELL,
Member
Board member since 2017



L to R: Piper Marsh, Sarah Williams, Mark Hullett, Emma Kenton, Hayley Lethlean, Cathy Donovan, Mel Dhillon & Brooke McGregor.

Staff, Volunteers & Ambassadors

STAFF

Hayley continued to lead the team towards great outcomes in 2019 as our CEO and advocated for our cause and community along the way. She was supported by Cath in keeping our financials in order.

Our Community Services team of Piper, Sarah and Brooke delivered a mammoth 43 group activities this year, alongside making sure our community were provided with other services and support they need.

Emma, Mark and new recruit Mel pushed our message out to supporters and ran several successful fundraising events, forged stronger links to our community through social media and other communications and increased our engagement with the general public to raise awareness of MD and our organisation.

A small team of 8, we manage to all jump in and get our hands dirty when necessary and continue to support each other when needed.

VOLUNTEERS

Volunteers are essential to MDWA and there are a couple we'd like to especially recognise this year.

Louise Storey joined us as an admin volunteer and helps us out on a weekly basis, alongside our other admin volunteer, Sue Fidock. She is always putting her hand up to do whatever she can at our fundraising events or around the office (including the ever-important task of bringing prosecco to us when we have to get crafty before an event).

Louise is guaranteed to liven up the atmosphere in the office and never fails to get any job done right.

We'd also like to recognise **Jack O'Keeffe** for being a star volunteer in many different capacities. He helped us at a number of the school holiday programs and camp, was part of the Co-design team and also offered some valuable insights into the creation of The Loop national digital project.

AMBASSADORS

Matt Haddon joined our Ambassador squad this year after advocating and volunteering for us time after time. He first became involved with us in 2016 when he was in his final year at Hale School.

He introduced MDWA to the school's charity portfolio and became one of the founding members of the Hale Mates program after he saw the need for his peers to learn more about people living with conditions that limit them physically and to learn and appreciate the additional challenges they face.

Matt also identified the need for adolescents in the MDWA community to be socially engaged and form meaningful connections with people from all walks of life.

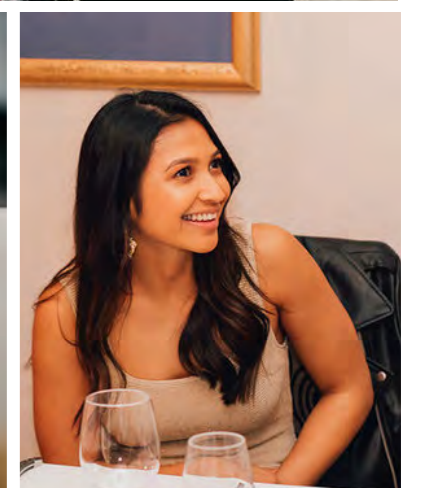
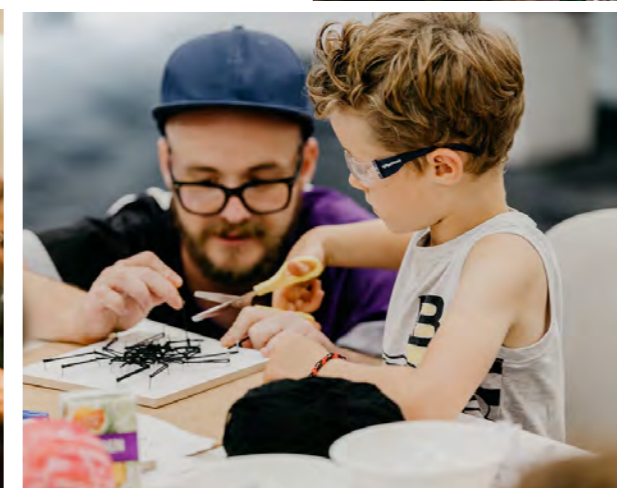
He has been a long-time fundraiser for us, frequently participating in events like HBF Run for a Reason and Dwellingup 100. He also helps tirelessly at our school holiday programs, camp and fundraising events.

Simon Beaumont, our MC extraordinaire, continued to wow our crowd of supporters at our events throughout the year.

His ability to read the room and advocate for us makes it difficult for anyone to walk away without being impacted by our cause.

Ross Wallman continued to play a huge role in leading our Hale Mates program, ensuring both the Hale mentors and MDWA community remained closely connected.

And WA cricketing legend **Adam Voges** was a guest speaker at our Kailis Club event, was present at the MDWA Ambassador's Dinner in the Glass Room at Kailis Bros and represented us at the Salt Sixes Cricket Tournament and he also donated a WACA coaching clinic as an auction item.



MUSCULAR DYSTROPHY WA (MDWA) IS A SMALL ORGANISATION
 MAKING A BIG IMPACT. WE ARE PASSIONATE ABOUT IMPROVING
 THE QUALITY OF LIFE FOR PEOPLE LIVING WITH NEUROMUSCULAR
 CONDITIONS. WE WORK WITH HUNDREDS OF FAMILIES, HELPING
 THEM GET THE BEST SUPPORT AND SERVICES THEY NEED AND
 CONNECTING THEM TO OTHERS WITH SIMILAR CONDITIONS,
 ENABLING THEM TO LEAD FULL LIVES...

...WE CALL IT



Treasurer's Report

On behalf of the Board I am pleased to present the 31 December 2019 Annual Financial Report, which includes the Financial Statements and Independent Audit Report.

The Statement of Comprehensive Income shows a small surplus prior to research grants for the year of \$10,427 compared to last year's surplus prior to research grants of \$69,096.

Total income increased by \$87,169 (compared to 2018) largely due to gain on investments and sale of shares, off-set by a plateau in general donations and no bequest income received during the year. Total income was off-set by an increase in total expenditure of \$145,839 (compared to 2018) primarily due to increased expenses in salaries and wages due to staff resignations, redundancies and additional staffing for fundraising.

Whilst low interest rates on bank deposits and general lower economic and market conditions continue to prevail, our investment strategy continues with a responsible and long-term investment perspective in targeting equity markets. This is reflected in the closing balance of financial investment of \$1,885,854, an increase of \$314,582. This provides us with better

short-term income by way of fully franked dividends and managed fund income distributions with the long-term view to higher capital growth in future years. Our long-term view remains at a minimum three to five years.

Closing cash balance of \$1,000,417 reflects the investment in additional financial assets and the net increase in expenditure noted above.

Finally, the net assets of the association decreased during the year from \$2,298,232 to \$2,221,119 as at December 2019, after the research grants and scholarships a net deficit of \$77,113 compared to last year's deficit of \$84,115.

Overall, the financial position of the association remains strong.

I would like to extend a vote of appreciation to our Chief Executive Officer Hayley Lethlean and her dedicated staff and team of volunteers for their remarkable dedication and commitment during the year.

I thank the Board, members and community for their continued support.

Tanvi Haria, Treasurer

\$560

provides a suite of 8 counselling services to a newly diagnosed family

5.2%

administration expenses in respect to annual turnover

\$2,221,119

Total Accumulated Funds

\$557,500

investment into the community & programs

\$11,040

provides one of our community members with the provision of an E70 CoughAssist™ Machine, maintenance, insurance & support

\$87,540

funds invested into research projects, scholarships & initiatives

\$627,433

total fundraising & donations income

\$29,955

Empower funds granted



Community Services Program



2019 was a record-breaking year for the Community Services Team (CST). We delivered 43 group activities, all the while planning and preparing for a state-wide conference.

The biggest increase in our service provision occurred in two areas: providing support to people moving through the NDIS process; and providing education sessions to a variety of groups.

In 2019, we attended 22 NDIS meetings and received 55 enquiries on this topic. This figure increased from the eight meetings and 36 enquiries we received in 2018. This tells us that more people are planning and preparing for the NDIS, a great outcome for our community.

We provided a total of 16 education sessions to 281 health professionals, students, teachers and community groups. This is an increase on five sessions to 88 people in 2018, which equates to a massive increase of 220%. It is clear from these results that more people are keen to learn about MD within their sector.

We also introduced a number of new initiatives including the Ignite Program, a self-development program for our young community members and Co-design, a process where our community are working with us to develop services and activities in equal partnership.

The CST would like to thank everyone who has played a role in our record-breaking year, including the neuromuscular community, volunteers, supporters, sponsors, staff, schools and the many individuals. Without their support we would not have achieved such success.

Social Programs

SCHOOL HOLIDAY PROGRAM (SHP)

The CST's service provision for 2019 commenced with a 2-day SHP program in January where 19 community members attended. We welcomed activities from PLAYworks with their incredible art concepts, WA Disabled Sports Association with their accessible and inclusive activities and Aus Ark Education for sharing with us information on our native animals.

We continued this for the July SHP with activity providers Ksquared Kreative providing the opportunity to think about design concepts for delicious cupcakes, PLAYworks for their creative art and RoboLab, and to Urban Indigenous for helping us to understand and appreciate NAIDOC week.

A special thank you to all the wonderful volunteers who participated in these programs as your support ensures the SHP is safe, interactive and fun.

CAMP

In October we hosted our annual 3-day camp program at Ern Halliday campsite with 17 campers and 10 volunteers. Camp was jam-packed with activities including WESA and their ever-popular electric wheelchair sports; PLAYworks helped campers create glow in the dark paintings and lanterns; Scitech ran an "Element of Surprise" activity; WADSA carried out adapted activities using their modified equipment; and Rosie O Face painted the kids' faces. The activity which stole the show was by the Duncraig Fire Station who donated their time to demonstrate the capabilities of their fire truck before having to rush off to an emergency with their lights and sirens on.

We'd like to say a big thank you to Telethon and Lotterywest for supporting this vital program for our school aged kids.

YOUNG ADULTS SOCIAL GROUP (YASG)

Six YASG events were hosted throughout 2019. This included a Fringe Festival show, dinner and quiz night at the Rosemount Hotel; an evening of misbehaving with "Miss Behave Gameshow" at Freo Social; movie night at Girls School Cinema; an afternoon of cheese tasting at The Cheese Barrel; and a gathering at The Camfield to end a busy year.

YASG provides a fun environment which encourages our community to increase their social interactions and connect with other young adults living with a neuromuscular condition.

ADULTS WITH AN NMC

In April, 12 of our adults group enjoyed an afternoon of wine and cheese tasting at MyattsField Vineyards for the second year in a row.

19 then took to the seaside in September where they went fishing with the help of Fishability, who generously volunteered their time, followed by lunch at the Breakwater in Hillarys.

MALE CARERS

The first Male Carers event in 2019 was a quiz night in March at the Civic Hotel, where eight men battled it out. In September, 13 participants went out to sea for a spot of fishing followed by lunch. A very special thank you to Mandurah Offshore Fishing and Sailing Club and dedicated Honorary Life Member Des McLean for donating their time, knowledge and boats.

FEMALE CARERS

In May, 11 female carers participated in 'Bubbles and Brush' hosted by PLAYworks. There was lots of laughter as painting skills were put to the test whilst enjoying some sparkling wine.



Rounding out the year, the ladies dined for lunch and enjoyed stunning ocean views at Bib and Tucker.

Our adults events allow us to link people with MD, parents, partners and family members to others experiencing similar circumstances.

HALE MATES

Eight community members and 12 Hale school mentors formed the 2019 Hale Mates program. The group got together every fortnight during the school terms, helping them form a close bond over several successful activities such as running experiments in the science labs, gaming competitions, cooking afternoons, art classes and WESA ran a wheelchair sports activity which saw all mentors and participants get involved in the electric wheelchairs.

The year also saw an increased focus on delivering the Resilience Doughnut program through Hale Mates. The program looks to support the Hale Mates participants and mentors as they develop resilience through the achievement of the "Doughnut Moments" they set for themselves.

The 2019 Hale Mates program wrapped up with a game of laser tag, thanks to Combat Adventures. Our mentors, participants and volunteers all teamed up and went head-to-head on the battlefield.

The CST would like to thank Hale School, the 2019 Hale Mentors, Wendy Keene, Matt Haddon, Ross Wallman and Telethon for making this program a success.

FAMILY DAY

In April, 43 community members attended our annual Family Day at The Maze in Bullsbrook. The day was filled with adventures through the mazes, up-close encounters with native animals, games on the lawn and a delicious BBQ lunch.

Family Day provides the opportunity for families with young or school aged children with a neuromuscular condition to relax and spend time with others, giving and receiving much-appreciated support.

ANNUAL COMMUNITY DAY

The 2019 Annual Community Day was held in the Wild Flower Pavilion set amongst the beautiful Botanic Gardens of Kings Park. 131 valued community members, volunteers, staff and supporters enjoyed a buffet brunch while sipping on MyattsField wine and playing some old fashioned lawn games. A big thank you to Lotterywest for once again supporting this end-of-year event.

Community Day is a great opportunity for everyone who has played a vital role in MDWA and the neuromuscular community to connect, relax and reflect on the year that was.

DUKE OF EDINBURGH INTERNATIONAL AWARD & IGNITE PROGRAM

We currently have two Duke of Edinburgh International Award (DOE) participants who are working hard to complete their Bronze and Gold Awards. The DOE encourages participants to develop skills focussed around self-belief, self-confidence, community engagement and personal challenges.

During October we welcomed Scott Green, a DOE participant from NSW, to work with us in completing his residential project as part of his Gold Award.

We also introduced the Ignite Award which is a challenging program of self-discovery for 10-18 year olds. It provides a framework to learn valuable skills, be physically active, assist others in the community and experience adventures. We now have three very enthusiastic participants who are working hard to achieve their personal goals.

COFFEE MORNINGS

In 2019 we held nine Coffee Mornings (CMs) with an average of five people attending each time. CMs are a good chance for people in the community to come together and discuss whatever is on their mind. In December Ambassador Ross Wallman and NOVA 93.7 donated a limo ride for our regular CM attendees, who went cruising around Perth and enjoyed morning tea at Matilda Bay.

Professional Development

The Community Services Team participated in a number of professional development opportunities to ensure we are always able to provide safe, quality assured services and accurate, up-to-date information. Sessions we attended included a number of different workshops focused on the NDIS and quality and safeguarding, Ignite Award training, First Aid training, Mental Health First Aid training and Assisting with Medication training.

The team also travelled to Sydney to attend the Australian Patient Organisation Network and Australian Neuromuscular Network events.

Empower Fund

In 2019 we conducted three rounds of Empower Grants, with one extraordinary round in July. There were nine successful applicants who received support via funding a number of items, including accessible vehicle hire, a hoist sling commode for school, vehicle modifications, flight and tournament costs for Australian Powerchair Football, overseas travel support and a laptop for home.

Thank you to everyone who donated to the Empower Fund – it provides our community with the opportunity to reach their dreams.



MD 2019 Conference

105 community members and health professionals from across WA gathered for two days in November to hear international speaker Dr James Poysky, national speaker Prof. Monique Ryan and a host of local health professionals who provided information on an array of topics as an update for the neuromuscular community.

A huge thank you to conference sponsors Lotterywest, Perron Institute, Biogen, Sarepta, Phillips Respironics, the Independent Living Centre, Facilitatrix, MyattsField Vineyards and all the speakers and chairs, who made the conference possible and successful.

Co-design

In early 2019, we were awarded an ILC Organisational and Capacity Building grant from the NDIS. We are using this grant in two ways:

Organisational Capacity Building – we wanted to build the organisation's capacity to ensure we are able to meet the changing requirements of WA's neuromuscular community.

The grant allowed us to learn about co-design, a process where service provision is developed by both MDWA and members of the neuromuscular community in equal partnership.

Our inaugural Co-design Team was made up of community members Brianna O'Donnell, Jack O'Keeffe, Rebecca Evans, Sarah Kerr, Peter Hopps and Zy Phillips. Hayley and Sarah were the MDWA representatives on the team.

Individual Capacity Building – the grant assisted us to develop and deliver a number of strategies designed to increase the personal capacity of individual members. The first activity occurred in November when 43 community members participated in a self-management information session.

More capacity building activities will be delivered during 2020.

Funded by the National Disability Agency.

189
hours of education
sessions provided -
equating to 5 weeks of
non-stop education

95%
increase in contact
with our community:
from 267 to 523

24.5%
increase in
face-to-face meetings
from 53 to 66 in the
past year

650
hours provided by
volunteers to assist
in CST-provided
services

220%
increase in
education
sessions

Community Services Program proudly supported by:



Fundraising, Marketing & Communications



OUR PARTNERS:



Fundraising & Partnerships

The 2019 calendar year was jam packed with a range of different events hosted by our small team at new and old haunts. We are extremely fortunate to have a loyal band of supporters, some of whom love to get outdoors and take on physical challenges, while others prefer to mix fine wine with the very best of WA produce. Whatever the event might be, we simply enjoy watching people smile and have a heap of fun in everything we put on for them in the name of fundraising for us.

Across all events, campaigns and appeals, we ran our expenses at less than 25% of revenue. This reduction in costs is a direct result of the generosity displayed by our sponsors, ambassadors and partners who provided us with venues, food, beverages, entertainment, auction items and valuable time purely through full donations or in some cases at heavily reduced prices.

We thank each and every one of you who has helped along the way.

TOYOTA MUSCULAR DYSTROPHY GOLF CLASSIC

Our first major fundraiser to kick off the year was once again generously supported by Toyota WA, Toyota Autoparts and Toyota Financial Services. The ever popular Toyota Golf Classic featured 30 teams of four at Joondalup Resort Golf Course.

We decided to host our presentation function in the golf clubhouse after a few years in the hotel marquee, which proved popular as more guests stayed and were treated to plenty of cocktail food and drinks. The function was again hosted by MDWA Ambassador Simon Beaumont who interviewed guest Glen Jakovich and kept the crowd entertained.

Following from the success of the 2018 Golf Classic, we finished the event with a net gain of \$66,559 which brings the total raised, with the help of the Toyota WA family over the past 12 years, to a figure of almost \$500,000.

SUPPORTER RUN EVENTS

We have a long established involvement with outdoor adventure events, from our 11-year association with the Dwellingup 100, to an alignment with Triathlon WA and the SunSmart Ironman 70.3 Busselton and more recently having a team of dedicated people participate and fundraise through the HBF Run for a Reason.



This year we added the Salt Property Sixes Cricket tournament to the list, with the event netting \$3,065 for us.

These and other supporter-run campaigns, where a team or individual performs a challenge and seeks donations, or runs their own event for us, are very significant in our event calendar. Across 2019, this peer-to-peer fundraising delivered gross income of \$62,979 and we can't thank our dedicated supporters enough.

DWELLINGUP 100

MDWA has a long involvement as aligned charity with the Dwellingup 100, having been associated with the event since its inception in 2009.

In 2019 MDWA stepped up to the plate and took on the role as Event Manager which was a significant task, given the size of our team and our event calendar. With the help of Tony Tucknott, we were able to deliver another incredible event with a challenging set of trails on September 7th.

Our team grew by one when we added an Event Manager with extensive major event experience who worked tirelessly with the rest of our team to deliver an incredible experience for WA mountain-bike and trail running enthusiasts.

The event saw 1,078 participants take part on a cracking day across several distances, while we welcomed several four-legged friends who joined in the new Doggie Dash leg created for the 2019 event. We are truly grateful to the 40 people who took on the added challenge of fundraising for MDWA and successfully raised over \$40,000 for our organisation.

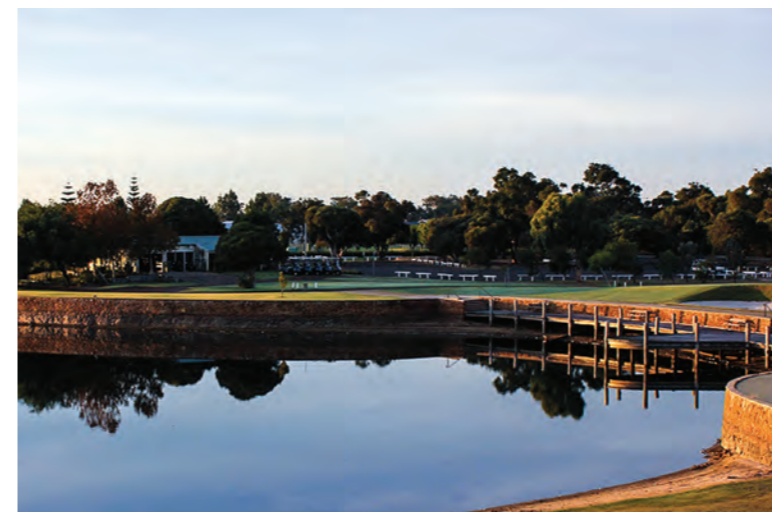
The highlight of the day was the 37 members from our MD community who turned up to show their support for us and the event, easily surpassing attendance in previous years. They were treated to live music, food and drinks in the track-side marquee and courtyard. Bringing our community together and raising awareness for them is one of the major reasons we love being involved in events like the Dwellingup 100.

We also thank our sponsors Facilitatrix, Tourism WA, Global Diagnostics, Koda and Budget 4WD for their support in helping us deliver the 2019 Dwellingup 100, while Coast FM and Wave Radio provided in-kind radio and digital promotional coverage pre-event and on the day.

TRUFFLES FOR MUSCLES DINNER

Stephen Clarke and his team run one of WA's finest restaurants, which was the chosen venue for the newly formatted Truffles for Muscles Dinner held on June 26th.

With an intimate gathering of 45 guests, the seated event moved away from the traditional cocktail setting at Kailis



Bros. Leederville and was a resounding success. Guests were treated to a delightful menu and matched wines provided by MyattsField Vineyards, with their iconic Row 38 going under the hammer for the princely sum of \$14,000 to an excited consortium of bidders.

First-of-the-season Manjimup Truffles were auctioned alongside amazing hospitality experiences and two sets of 5 specially-made Double Magnums of wine.

We thank the team at Clarke's of North Beach who hosted us and our guests, ensuring that everything ran smoothly.

Our ever-present Ambassador Simon Beaumont added to the atmosphere by compering the event. Simon spoke with Vanessa Sanford, a member of our community, who stole the show with such an honest and open conversation about the challenges faced by a young family living with MD. We also give thanks to renowned Perth real estate auctioneer Tom Esze who kept our guests engaged and knocked down all of our items during a lively auction.

Our first ever Truffles for Muscles dinner generated \$50,750, proving to be a success whilst providing an entertaining evening for our valued supporters in a beautiful setting.

KAILIS CLUB EVENT

The cocktail function hosted by Theo and his wonderful team at Kailis Bros, Leederville has been an integral part of our fundraising calendar for the past six years and pays homage to 40 years of seafood auctions and raffles hosted by the Kailis family.

Moving this event to later in the year on August 30th introduced us to a fresh audience, while many of our long-time supporters joined the crowd, making it 85 strong.

Guests were welcomed with a cocktail made by Josh and Rachael Davenport of MyattsField Vineyards followed by espresso martinis which were kindly donated by the Engine Room Espresso family. They also indulged in freshly shucked oysters and sampled fine food produced by the chefs at Kailis Bros.

Newly announced MDWA Ambassador Matt Haddon spoke of his keen involvement with our organisation and how we can each make a great difference in the lives of others. MC Simon Beaumont has become synonymous with this event and stitched the evening together wonderfully.

Gregarious auctioneer Tiny Holly wielded his gavel and threw in some trademark gags to keep our bidders on their toes. A stay in the Pyrenees French House and a guided tour of the SASR Campbell Barracks each fetched \$6,500. The silent auction and wine raffle were both a huge success in an intimate and generous room.

The event generated income of \$52,225. Costs were nominal due to the kindness of our big-hearted partners Kailis Bros, Leederville and MyattsField Vineyards.

BUSSELTON TOYOTA MD GOLF DAY

On November 29th we hosted the 2nd instalment of the regional Golf Day which was once again supported by Laurie Saltarini and Leanne Locke from Busselton Toyota. Through their dedication to see this event succeed we grew our numbers to 72 guests, who enjoyed a spectacular sunny day on course at Dunsborough Lakes.

The club showcased a manicured course which catered to a range of golfing handicaps, whilst the post-golf dinner and beverages helped the players wind down after their 18 holes. The award presentations were held on the outdoor decking and several partners joined in the festivities, participating in a raffle and silent auction.

Due to the generosity of Busselton Toyota, the wider Toyota network and all who attended on the day, we raised just over \$24,000.

MARQUEE DAY

To kick off another spring racing season we hosted 88 guests in the esteemed Director's Lounge overlooking the finishing post at Ascot Racecourse on November 2nd.

Prominent Perth Racing identity, racehorse owner and MDWA community member Amy Evans continued her role as Event Ambassador and completely stole the show with her pre-race tips and style.

An impromptu "fashion show line up" was one of the highlights of the afternoon, with both the ladies and gentlemen dressed to the nines being judged by our youngest Community Ambassador Ari Phillips.

The day was filled with laughter and guests were extremely supportive of the raffle, silent auction and our special table game, Ari's Calcutta, which generated nearly \$3,000 on its own.

We thank our event partners Seafarms, Prof. Sue Fletcher and Community TAB who contributed to the huge success of the event and assisted us to raise \$40,512.

CAROLS AT SCARBOROUGH

Hosted by Scarborough Beach Association, Carols at Scarborough was held on Sunday December 8th on a beautiful but breezy evening.

MDWA was proud to be the charity partner for the third year in a row and the event saw over 4,000 people gather for the evening. The crowd was entertained by MDWA Ambassador and MC Simon Beaumont who kept the Australian Army Choir on track. The evening was filled with Christmas Carols and ended with a spectacular fireworks display over the ocean.

We'd like to thank our team of staff and volunteers who circulated amongst the crowd selling booklets, candles and raffle tickets raising a total of \$8,000.



Marketing & Communications

Our marketing and branding initiatives for 2019 started with the introduction of a new brand tag – *Support for Life*. This new tag replaced what was previously *Empowering full lives* as we wanted to set ourselves apart from other charities that were using the empower reference in their branding.

Our new brand tag epitomises what we do – provide support to our community so that they can live their best life possible, despite the obstacles their condition may present.

We continue to work with a conversational tone in our communications and aim to keep our community and supporters up-to-date through various platforms such as social media, our website and newsletters.



WEBSITE LAUNCH

In February we launched our new website. This was the final chapter in rebranding the organisation and implementing our new brand tag.

All copy throughout the website was rewritten to suit our new conversational tone so that it spoke directly to our community and supporters.

PROMOTIONAL VIDEOS

We spent a significant amount of time interviewing members of our community for a video we showcased at Kailis Club in August. The video shows how each interviewee's connection and affiliation with MDWA has helped changed their lives. It acts as a tool for use to convey to potential sponsors and donors how their support helps our organisation and community.

SOCIAL MEDIA

A fairly significant tool in communicating with our community is social media. Our following continued to grow throughout the year with our followers engaging with the variety of posts published on both Facebook and Instagram.

It was a common trend to see posts which included our community members or events we were hosting gain the most attention and engagement. Throughout the year, our Facebook following increased by 149 people and our Instagram page saw an increase of 316 new followers. This is a large increase particularly when we factor in that MD is a rare condition so not many know of it. We remain incredibly active on both platforms, ensuring we consistently engage with our audience.

BRAND AWARENESS

As part of a brand awareness initiative, we created our very own MDWA branded metal water bottle. The bottle is wrapped in a beautiful piece of artwork which was originally painted by a group of MDWA kids at one of our school holiday programs.

The bottles were initially made for the MD Conference however after seeing interest by several different groups, we decided to add it to our merchandise collection. They can be bought for \$20 each with a \$7 profit from each.

Our very first Papercup Project involvement back in 2018 inspired us to continue the awareness exercise and get on board with Engineroom Espresso and Standby Espresso to deliver more MDWA branded coffee cups to Perth locals. These 100% recyclable cups exhibited the same artwork as the water bottle, which was beautifully created by our kids.

Research Advisory Report



While no new research or scholarships grants were provided, 2019 was a year of consolidation and commitment to research projects already underway.

Throughout the year, we worked closely with the Perth Children's Hospital (PCH) neuromuscular clinic team to develop a long-term plan for gathering patient data for current and future research opportunities and to improve the WA capacity to host clinical trials for neuromuscular conditions in the future.

Of the projects that continued, we included an extension of funding to Dunhui Li to complete his thesis on the application of antisense oligo-induced exon skipping strategies for Duchenne muscular dystrophy and other genetic diseases. Through funding support from our research donors, Oliver was also supported for his travel to Munich, Germany to present his poster.

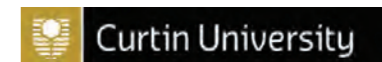
The Nusinersen project funded through TEAM Spencer and MDWA continued to June 2019, enabling the ongoing administration of this medication at PCH.

Other research projects at PCH for 2019 included the continuation of the nutrition project in developing a specialised dietetic service, evidenced-based guidelines for specific conditions and collaboration opportunities with specialists at Royal Children's Hospital in Melbourne.

Our collaboration with Telethon Kids Institute continues now into its 4th year. In 2019, the respiratory project expanded on the pilot with additional lung function and quality of life measures being included in the study, aided by funding through the National Health and Medical Research Council grant. This project expands across the globe in collaboration with the Lucile Packard Children's Hospital and Stanford University in California and we look forward to the outcomes over the next couple of years.

Research cannot be undertaken without collaboration, and MDWA is proud of our partnerships that have been forged to ensure our community can be part of, and contribute to, global research opportunities which will expectantly have beneficial clinical outcomes for all.

RESEARCH PARTNERS:



Harold & Sylvia Rowell PhD Scholarship Recipient: Dunhui Li

MOLECULAR STUDIES ON ANTISENSE OLIGO-INDUCED EXON SKIPPING

Dunhui Li (Oliver) is now in his final year of PhD research and is completing his thesis describing the application of “exon skipping” strategies for Duchenne muscular dystrophy (DMD) and extending this type of therapy to other genetic diseases.

The dystrophin gene contains 79 blocks of information (exons) that carry the genetic message which directs the synthesis of the protein dystrophin. Gene lesions that prematurely stop dystrophin synthesis result in DMD. Dystrophin functions similarly to a shock absorber and this protein binds to specific protein complexes to confer strength and stability to muscle fibres. Some of the binding interactions involve parts of the protein encoded beyond exon 55. In 2019, Oliver evaluated the functions of antisense oligo-induced dystrophin isoforms through a series of experiments. Skipping exons 56 and 57 did not substantially reduce the amount of that dystrophin isoform. It was shown that interactions between the exons 56 and 57 skipped dystrophin isoform and dystrophin binding partners were restored in muscle fibres, indicating that this isoform is semi-functional. Studies in mouse muscle pathology examinations confirmed the functionality of this particular isoform, suggesting some therapeutic potentials. In contrast, the antisense oligomers that induced skipping of dystrophin exons 58 and 59 resulted in an isoform that appeared to be functionally compromised.

The splice switching strategy used in this PhD project to identify dystrophin mutations that could be amenable to exon skipping can also be applied to other neurological or neuromuscular conditions. Oliver has used his experience with DMD to design oligos to potentially address common mutations in the PARK2 gene that cause Parkin-type autosomal recessive juvenile Parkinson’s disease. The application of exon skipping to induce a PARK2 protein missing exons 3 and 4 should reduce the severity of the most common PARK2 mutations. Functional assays of this induced parkin isoform show partial normalization of activity and are encouraging results.

With the financial support from MDWA, Oliver participated the 2019 Annual Meeting of Oligonucleotide Therapeutics Society in Munich, Germany. His poster presentation showcasing the DMD project was acknowledged with a poster award. Oliver submitted a manuscript reporting the DMD project to a premier international journal where it is currently being evaluated for publication. The Parkinson’s work is the subject of a provisional patent and will also be submitted for publication.

Harold & Sylvia Rowell Research Project Grant: Annie Robertson & Melanie Van Der Wilk

IMPROVING NUTRITION IN WA CHILDREN WITH NEUROMUSCULAR CONDITIONS

Senior Dietitians Annie Robertson and Melanie van der Wilk have had the opportunity to develop and implement a specialised neuromuscular dietetic service as part of the neuromuscular clinic at Perth Children’s Hospital (PCH) thanks to MDWA funding. Part of this service involves screening growth parameters for all patients who attend the clinic. Patients are offered a one-on-one appointment with the dietitians if they have a new neuromuscular diagnosis, are starting steroids or are identified as being at nutritional risk (malnutrition or overweight/obese) on their growth screening.

Since the service commenced 18 months ago there have been 210 dietitian screenings carried out across 114 patients. To date 54 patients have been identified as malnourished, overweight or obese (47%). Without the MDWA-funded dietetic position, these patients would not have been identified as at risk or received dietetic services.

The dietitians have developed evidenced based clinical guidelines for the management of Duchenne muscular dystrophy (DMD), spinal muscular atrophy and other neuromuscular conditions (NMCs). They have also developed family resources which have been reviewed by consumers and are in the process of being published.

A research collaboration has been established with the Royal Children’s Hospital in Melbourne to participate in the EAT-DMD project. This is a small research project exploring the attitudes and beliefs about healthy eating and weight in DMD. Another potential future opportunity is collaboration with Murdoch Children’s Research Institute to contribute to a research project exploring energy expenditure in neuromuscular conditions (EEE-NMD study). It aims to explore the relationship between body composition and energy expenditure in children with various neuromuscular conditions and will be the first of its kind. These research projects provide exciting opportunities for PCH’s neuromuscular clinic patients and staff to contribute to the evidence around nutritional management of neuromuscular conditions, which will inform clinical practice in future.

The goal of this project remains to improve the nutrition of all children attending the clinic and demonstrate the need for an ongoing specialised nutrition service for WA children with neuromuscular conditions.

TEAM Spencer MDWA Scholarship Recipient for SMA Research: Dr Adelaide Withers

DEVELOPING CLINICAL PREDICTORS OF DISEASE PROGRESSION IN CHILDREN WITH NMC CONDITIONS - TKI, PCH AND STANFORD UNIVERSITY

The Neuromuscular Research Team at Telethon Kids Institute (TKI) and PCH had a big year in 2019. They welcomed new research members to the team and started the expansion of the pilot project examining predictors of hypoventilation and other markers of respiratory disease progression. The team received additional funding from the National Health and Medical Research Council (NHMRC) in late 2018 which helped expand the pilot study to a 2-year study with additional lung function and quality of life measures. It now also includes an international study site at the Lucile Packard Children’s Hospital in California, in collaboration with Stanford University.

The team focussed on logistics and practical implementation of the study protocols to allow de-identified data sharing between the Perth and California study sites and ensure their measurements are standardised and calibrated correctly. Protocols for recruitment, data collection and clinical assessment have also been developed for use at both sites, and development of the protocols was greatly enhanced by a visit from the Stanford Team to PCH in April 2019. This was an invaluable opportunity to harmonise data collection and build relationships with the neuromuscular community.

The most exciting development the team has been working on is investigating home sleep studies as an alternative to sleep studies at the hospital for children with NMCs. This was highlighted by the neuromuscular community reference group members as a research priority as many families find attending the hospital for sleep studies onerous. Although home sleep studies are not commonly done in children with NMCs, the team has developed a protocol for home sleep studies that includes monitoring of carbon dioxide levels using a Sentec device. Many families have been very eager to participate in their investigation of the validity of home sleep studies, and a number have already been carried out. The first home sleep studies were conducted in 2019 with promising results and the research team are currently exploring options to offer home sleep studies to adults.

The collaboration between the neuromuscular community and the research team continues to flourish, primarily by collaboration with the consumer reference group but also via participation in community events and conferences as invited speaker. The research team remain incredibly grateful for the ongoing support from MDWA and look forward to the continuation of the collaboration between researchers, MDWA, families, patients and the wider neuromuscular community.

TEAM Spencer Project Grant

SPINRAZA TREATMENT FOR SPINAL MUSCULAR ATROPHY PATIENTS AT PCH

Nusinersen (Spinraza) was added to the Pharmaceutical Benefits Scheme (PBS) in June 2018 for the treatment of children with Spinal Muscular Atrophy (SMA).

The availability of this medication was celebrated by health professionals and most importantly by families affected by SMA; however, like all hospital services around Australia the team at PCH were unprepared to be able to make this immediately available.

Funding from TEAM Spencer and MDWA allowed the team at PCH’s Neurology Department to fund the presence of Nurse Jodi Mann to work alongside Paediatric Neurologist Dr Maina Kava in order to start administering this medication in June 2018.

SMA is a rare, genetically inherited condition which affects the spinal motor neurons, resulting in loss of motor muscle function. It can affect a child’s ability to walk, sit, breath and swallow.

Nusinersen is an effective medication for this condition as it is an antisense oligonucleotide which works by helping the body to produce more of the survival motor neuron protein, in turn reducing the loss of motor neuron nerve cells and improving muscle strength.

The team currently have 12 SMA patients receiving Nusinersen at PCH and it remains a very successful program. The secret to the success is not only the dedication of the nursing and medical team behind it but also the children themselves who present to the Day Treatment Unit – always with big smiles on their faces.

One of the great things to come from this funding, apart from the amazing benefits to the SMA patients and families, is the ability for Dr Maina Kava and Jodi Mann to work closely together to deliver approximately 65 lumbar punctures and discuss the future of neuromuscular services to move things in a more positive direction.

Over the past 18 months that this medication has been available to SMA patients, the team have seen some amazing improvements in the childrens' motor function and abilities, as well as overall general health.

This medication has completely changed the natural disease history of SMA patients and the team has also had to adapt to new treatments and clinical practices to keep up the pace.

Hopefully in the near future this medication will be available to all people living with SMA, not only in Australia, but worldwide.

The team remain very grateful to MDWA and TEAM Spencer for their ongoing support.



Muscular Dystrophy Association of WA (Inc) | ABN 49 158 959 834

We'd like to acknowledge that Sarah McCloskey allowed us to use the imagery of the mural she painted in Leederville for our staff and community photos. You can buy some of her beautiful work through her website <https://www.hellosarsar.com/>



**Muscular
Dystrophy WA**

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

FINANCIAL REPORT

FOR THE YEAR ENDED 31 DECEMBER 2019

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

FINANCIAL REPORT

FOR THE YEAR ENDED 31 DECEMBER 2019

INDEX

Board's report	3
Income and expenditure statement	4
Asset and liabilities statement	5
Statement in changes in equity	6
Statement of cash flows	7
Notes to the financial statements	8 - 16
Board members' declaration	17
Independent audit report	18 - 20

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

BOARD'S REPORT

Your Board members submit the financial report of Muscular Dystrophy Association of Western Australia Inc., also known as Muscular Dystrophy WA Inc., for the financial year ended 31 December 2019.

Board members

The names of Board members throughout the year and at the date of this report are:

Brad Girdwood
Brendan Murphy
Tanvi Haria
Susan Trahar
Shane Powell

Jane Edwards
Peter Rowe
Jodie Hatherly
Aaron Schier

Principal activities

The principal activities of the Association during the financial year include advocacy on behalf of and service provision to Western Australians living with muscular dystrophy and neuromuscular conditions and their families. The Association continues to fund research initiatives and projects into improving quality of life for muscular dystrophy and neuromuscular conditions.

Significant changes

No significant change in the nature of these activities occurred during the year.

Operating Results

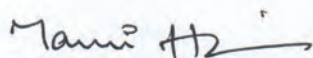
Surplus prior to grant expenses was \$10,427 after granting \$87,540 for research and projects, including a provision for Harold and Sylvia Rowell Scholarships; it results in a net loss of \$77,113.

New Accounting Standard Implemented

The Association has implemented three new Accounting Standards that are applicable for the current reporting period.

AASB 15: *Revenue from Contracts with Customers*, AASB 1058: *Income of Not-for-Profit Entities* and AASB 16: *Leases* have been applied using the cumulative effective method; that is, by recognising the cumulative effect of initially applying AASB 15, AASB 1058 and AASB 16 as an adjustment to the opening balance of equity at 1 January 2019. Therefore, the comparative information has not been restated and continues to be reported under AASB 118: *Revenue*, AASB 117: *Leases* and AASB 1004: *Contributions*. Also to note in relation to AASB 16 is that the Association applied the temporary relief for peppercorn leases under AASB 2018-8 to measure the right-of-use assets at cost on initial recognition. Further information is provided in Note 1.

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



Mrs Tanvi Haria
Treasurer



Brad Girdwood
President

DATE: 5 May 2020

The accompanying notes form part of these financial statements.

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

INCOME AND EXPENDITURE STATEMENT
AS AT 31 DECEMBER 2019

	Note	2019 \$	2018 \$
INCOME			
Fundraising and donations	2	627,433	629,792
Grants income	3	400,150	320,438
Bequest income		-	137,550
Dividends received		27,627	66,452
Interest received		73,583	97,368
Increase in value of investments		86,305	-
Gains on sale of shares		147,958	-
Other income		33,678	57,965
TOTAL INCOME		1,396,734	1,309,565
EXPENDITURE			
Bookkeeping fees		3,600	31,200
Depreciation expense		50,070	47,519
Audit fees		8,000	8,057
Bank charges		228	136
Community expenses		237,477	222,043
Community salaries and superannuation expense		320,023	298,621
Utilities expense		5,654	7,092
Loss on sale of investments		3,512	31,735
Unrealised loss of share valuation		-	66,012
Advertising and promotion expenses		22,018	14,564
Administration expenses		27,334	29,565
Outgoing expense		28,009	27,038
Salaries and superannuation expense		510,640	395,506
Fundraising expenses		169,742	61,381
TOTAL EXPENDITURE		1,386,307	1,240,469
Current year surplus prior to Research Grants and Scholarships Provision		10,427	69,096
Team Spencer Research Grants and Scholarships	4	-	(62,730)
Provision for Harold and Sylvia Rowell Scholarships	5	(87,540)	(90,481)
Net current year (deficit)/surplus after Research Grants and Scholarships paid		(77,113)	(84,115)
RETAINED SURPLUS AT THE BEGINNING OF THE FINANCIAL YEAR		2,298,232	2,382,347
RETAINED SURPLUS AT THE END OF THE FINANCIAL YEAR		2,221,119	2,298,232

The accompanying notes form part of these financial statements.

MUSCULAR DYSTROPHY ASSOCIATION OF WESTERN AUSTRALIA (INCORPORATED)**A.B.N. 49 158 959 834****ASSETS AND LIABILITIES STATEMENT
AS AT 31 DECEMBER 2019**

	Note	2019 \$	2018 \$
CURRENT ASSETS			
Cash on hand	7	1,000,417	1,412,066
Accounts receivable and other debtors	8	31,703	31,875
Prepayments		3,168	3,000
TOTAL CURRENT ASSETS		<u>1,035,288</u>	<u>1,446,941</u>
NON-CURRENT ASSETS			
Financial assets	9	1,885,855	1,571,272
Property, plant and equipment	10	133,434	183,504
TOTAL NON-CURRENT ASSETS		<u>2,019,289</u>	<u>1,754,776</u>
TOTAL ASSETS		<u><u>3,054,577</u></u>	<u><u>3,201,717</u></u>
CURRENT LIABILITIES			
Accounts payable and other payables		20,766	11,271
Grants received in advance (Scholarship & Projects)	3	163,384	111,899
Employee provisions		53,192	61,582
TOTAL CURRENT LIABILITIES		<u>237,342</u>	<u>184,752</u>
NON-CURRENT LIABILITIES			
Provision for Harold and Sylvia Rowell Scholarships	5	576,292	668,954
Empower Funds	6	19,824	49,779
TOTAL NON-CURRENT LIABILITIES		<u>596,116</u>	<u>718,733</u>
TOTAL LIABILITIES		<u><u>833,458</u></u>	<u><u>903,485</u></u>
NET ASSETS		<u><u>2,221,119</u></u>	<u><u>2,298,232</u></u>
MEMBERS' FUNDS			
Current Surplus		(77,113)	(84,115)
Retained surplus		2,298,232	2,382,347
TOTAL ACCUMULATED FUNDS		<u><u>2,221,119</u></u>	<u><u>2,298,232</u></u>

The accompanying notes form part of these financial statements.

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

**STATEMENT OF CHANGES IN EQUITY
FOR THE YEAR ENDED 31 DECEMBER 2019**

	Retained Surplus \$
Balance at 1 January 2018	2,382,347
Comprehensive income	
Loss for the year attributable to members of the entity	(84,115)
Balance at 31 December 2018	<u>2,298,232</u>
Comprehensive income	
Loss for the year attributable to members of the entity	(77,113)
Balance at 31 December 2019	<u><u>2,221,119</u></u>

The accompanying notes form part of these financial statements.

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

**STATEMENT OF CASH FLOWS
FOR THE YEAR ENDED 31 DECEMBER 2019**

	Note	2019 \$	2018 \$
CASH FLOWS FROM OPERATING ACTIVITIES			
Receipts from donations, bequests and raffles		1,051,785	1,043,851
Other receipts		-	57,965
Interest received		72,072	105,751
Dividends received		38,786	55,110
Payments to suppliers and employees		(1,490,461)	(1,298,618)
Net cash (used in)/generated from operating activities	11	<u>(327,818)</u>	<u>(35,941)</u>
CASH FLOWS FROM INVESTING ACTIVITIES			
Payment for plant and equipment		-	(21,158)
Proceeds from sale of investments		591,109	350
Payment for purchase of investments		(674,940)	-
Net cash used in investing activities		<u>(83,831)</u>	<u>(20,808)</u>
Net decrease in cash held		(411,649)	(56,749)
Cash on hand at the beginning of the financial year		<u>1,412,066</u>	<u>1,468,815</u>
Cash on hand at the end of the financial year	7	<u><u>1,000,417</u></u>	<u><u>1,412,066</u></u>

The accompanying notes form part of these financial statements.

MUSCULAR DYSTROPHY ASSOCIATION OF WESTERN AUSTRALIA (INCORPORATED)
A.B.N. 49 158 959 834
NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 DECEMBER 2019

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 [insert name of applicable state/territory Act], the basis of accounting 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 1031: *Materiality* and AASB 1054: *Australian Additional Disclosures*.

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.

(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.

MUSCULAR DYSTROPHY ASSOCIATION OF WESTERN AUSTRALIA (INCORPORATED)
A.B.N. 49 158 959 834
NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 DECEMBER 2019

Note 1: Summary of significant accounting policies (continued)

(f) Cash and cash Equivalents

Cash and cash equivalents includes 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 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

Concessionary leases

For leases that have significantly below-market terms and conditions principally to enable the Association to further its objectives (commonly known as peppercorn/concessionary leases), the Association has adopted the temporary relief under AASB 2018-8 and measures the right-of-use assets at cost on initial recognition.

(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.

(j) Financial assets

Investments in financial assets are initially recognised at cost, which includes transaction costs, and are subsequently measured at fair value, which is equivalent to their market bid price at the end of the reporting period. Movements in fair value are recognised through an equity reserve.

(k) Revenue and other income

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.

The Association has applied AASB 15: *Revenue from Contracts with Customers* (AASB 15) and AASB 1058: *Income of Not-for-Profit Entities* (AASB 1058) using the cumulative effective method of initially applying AASB 15 and AASB 1058 as an adjustment to the opening balance of equity at 1 January 2019. Therefore, the comparative information has not been restated and continues to be presented under AASB 118: *Revenue* and AASB 1004: *Contributions*. The details of accounting policies under AASB 118 and AASB 1004 are disclosed separately since they are different from those under AASB 15 and AASB 1058, and the impact of changes is disclosed in Note 1.

In the current year

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).

MUSCULAR DYSTROPHY ASSOCIATION OF WESTERN AUSTRALIA (INCORPORATED)
A.B.N. 49 158 959 834
NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 DECEMBER 2019

Note 1: Summary of significant accounting policies (continued)

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

The Association publishes and sells books and magazines publications to the general public. Revenue is recognised when control of the products has transferred to the customer. For such transactions, this is when the products are delivered to the customers. Volume discounts could be provided with the sale of these items, depending on the volume of aggregate sales made to eligible customers over every six-month period. Revenue from these sales is based on the price stipulated in the contract, net of the estimated volume discounts. The volume discounts are estimated using historical experience, and applying the expected value method. Revenue is then only recognised to the extent that there is a high probability that a significant reversal of revenue will not occur.

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

MUSCULAR DYSTROPHY ASSOCIATION OF WESTERN AUSTRALIA (INCORPORATED)
A.B.N. 49 158 959 834
NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 DECEMBER 2019

Note 1: Summary of significant accounting policies (continued)

In the comparative period

Non-reciprocal grant revenue was recognised in profit or loss when the Association obtained control of the grant and it was probable that the economic benefits gained from the grant would flow to the Entity and the amount of the grant could be measured reliably.

If conditions were attached to the grant which must be satisfied before the Association was eligible to receive the contribution, the recognition of the grant as revenue was deferred until those conditions were satisfied.

When grant revenue was received whereby the Association incurred an obligation to deliver economic value directly back to the contributor, this was considered a reciprocal transaction and the grant revenue was recognised in the statement of financial position as a liability until the service had been delivered to the contributor; otherwise, the grant was recognised as income on receipt.

The Association received non-reciprocal contributions of assets from the government and other parties for no or nominal value.

These assets were recognised at fair value on the date of acquisition in the statement of financial position, with a corresponding amount of income recognised in the statement of profit or loss and other comprehensive income.

Donations and bequests were recognised as revenue when received.

Interest revenue was recognised using the effective interest method, which for floating rate financial assets is the rate inherent in the instrument. Dividend revenue was recognised when the right to receive a dividend had been established. Rental income from operating leases was recognised on a straight-line basis over the term of the relevant leases.

Revenue from the rendering of a service was recognised upon the delivery of the service to the customer.

New and Amended Accounting Policies Adopted by the Association
Initial application of AASB 16

The Association has adopted AASB 16: *Leases* retrospectively with the cumulative effect of initially applying AASB 16 recognised at 1 January 2019. In accordance with AASB 16, the comparatives for the 2018 reporting period have not been restated.

The Association has recognised a lease liability and right-of-use asset for all leases (with the exception of short-term and low-value leases) recognised as operating leases under AASB 117: *Leases* where the Association is the lessee.

The lease liabilities are measured at the present value of the remaining lease payments. The Association's incremental borrowing rate as at 1 January 2019 was used to discount the lease payments.

The right-of-use assets for equipment were measured at their carrying amount as if AASB 16 had been applied since the commencement date, but discounted using the Association's incremental borrowing rate per lease term as at 1 January 2019.

MUSCULAR DYSTROPHY ASSOCIATION OF WESTERN AUSTRALIA (INCORPORATED)
A.B.N. 49 158 959 834
NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 DECEMBER 2019

Note 1: Summary of significant accounting policies (continued)

The right-of-use assets for the remaining leases were measured and recognised in the statement of financial position as at 1 July 2019 by taking into consideration the lease liability and prepaid and accrued lease payments previously recognised as at 1 January 2019 (that are related to the lease).

The following practical expedients have been used by the Association in applying AASB 16 for the first time:

- for a portfolio of leases that have reasonably similar characteristics, a single discount rate has been applied;
- leases that have remaining lease term of less than 12 months as at 1 January 2019 have been accounted for in the same way as short-term leases;
- the use of hindsight to determine lease terms on contracts that have options to extend or terminate;
- applying AASB 16 to leases previously identified as leases under AASB 117 and Interpretation 4: *Determining whether an arrangement contains a lease* without reassessing whether they are, or contain, a lease at the date of initial application; and
- not applying AASB 16 to leases previously not identified as containing a lease under AASB 117 and Interpretation 4.

Initial application of AASB 15 and AASB 1058

The Association has applied AASB 15: *Revenue from Contracts with Customers* and AASB 1058: *Income of Not-for-Profit Entities* using the cumulative effective method of initially applying AASB 15 and AASB 1058 as an adjustment to the opening balance of equity at 1 January 2019. Therefore, the comparative information has not been restated and continues to be presented under AASB 118: *Revenue* and AASB 1004: *Contributions*.

The Association has elected to apply AASB 1058 retrospectively only to contracts that are not completed contracts at the date of initial application. The adjustment to opening retained surplus on 1 January 2019 was an increase of \$nil with a corresponding decrease in contract liabilities. A classification change occurred which resulted in the deferred income now being classified as contract liability in line with wording used in AASB 15.

MUSCULAR DYSTROPHY ASSOCIATION OF WESTERN AUSTRALIA (INCORPORATED)
A.B.N. 49 158 959 834
NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 DECEMBER 2019

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.

	2019 \$	2018 \$
Collection Boxes Income	2,814	3,609
Annual Golf Day	87,425	90,416
Dwellingup 100	143,141	65,242
Busso Ironman 70.3	10,174	13,728
Truffle for Muscles	42,759	134,651
Empower Funds	29,956	31,765
Marquee Day	40,032	43,730
Supporter Run Events	32,454	32,516
HBF Run for a Reason	7,882	34,702
Double Magnums 4MD	8,000	-
Busselton Golf Day	25,547	26,107
Entertainment Book Sales	1,324	1,298
Mail Appeal Income	70,696	74,503
General Donations	68,121	61,664
Christmas Carols at Scarborough	4,883	15,861
Kailis Club	52,225	-
TOTAL FUNDRAISING AND DONATIONS	627,433	629,792

Note 3: Grants, Scholarship & Project income

The Association attains grant income from government agencies, corporate bodies and private organisations which are allocated to Community Projects, Events, Scholarships and Research Projects. The Scholarships and Projects grants relate in particular to Team Spencer Research Grants and Scholarships income, Harold and Sylvia Rowell Scholarships income and Empower Funds donations.

	2019 \$	2018 \$
Lotterywest and Telethon Grants	152,220	117,634
Local Government Grants	27,000	20,000
Scholarship & Projects Grants	113,750	140,000
Commonwealth Grant	48,240	-
Other Grant income	58,940	95,304
Total Grant income	400,150	372,938
Less		
Unexpended Scholarship & Projects Grants	(32,500)	(52,500)
NET GRANT INCOME	367,650	320,438

MUSCULAR DYSTROPHY ASSOCIATION OF WESTERN AUSTRALIA (INCORPORATED)
A.B.N. 49 158 959 834
NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 DECEMBER 2019

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 dedicate themselves 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: Harold and Sylvia Rowell Scholarships

In 2012 the Association received a bequest from the Estate of the Late H Rowell OAM and the Board resolved to utilise the bequest to fund annual research scholarships and research initiatives. It is expected the bequest will enable to provide funding for scholarships for ten years.

Note 6: Empower Funds

In 2017, the Board approved the Empower Fund Grants to provide funding to our community for initiatives that cannot ordinarily be fully funded or supplied via other agencies or funders. The Empower Fund Grants Board 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 to the Empower Fund Liability Account and carried forward to be expended in the following year. The Board endeavours to expend the annual Empower Fund budget as determined by the previous year's income. Costs associated with administering and promoting the fund will be included within the budget.

	2019	2018
	\$	\$
Note 7: Cash on hand		
Cash at bank		
- Unrestricted	876,730	1,273,063
- Restricted	123,687	139,003
	1,000,417	1,412,066
	1,000,417	1,412,066
Note 8: Accounts receivable and other debtors		
Trade Receivables	12,905	3,429
Other debtors	18,798	28,446
	31,703	31,875
	31,703	31,875
Note 9: Financial assets		
Non-current		
Investments in listed corporations at fair value		
- Unrestricted	1,433,249	1,194,167
- Restricted	452,605	377,105
	1,885,854	1,571,272
	1,885,854	1,571,272

MUSCULAR DYSTROPHY ASSOCIATION OF WESTERN AUSTRALIA (INCORPORATED)
A.B.N. 49 158 959 834
NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 DECEMBER 2019

	2019 \$	2018 \$
Note 10: Plant and equipment		
Furniture & fittings	20,107	20,107
Less accumulated depreciation	(20,107)	(20,107)
	<u>-</u>	<u>-</u>
IT assets	24,483	24,483
Less accumulated depreciation	(24,483)	(24,483)
	<u>-</u>	<u>-</u>
Medical support equipment	513,567	513,567
Less accumulated depreciation	(430,248)	(392,706)
	<u>83,319</u>	<u>120,861</u>
Telephone equipment	5,655	5,655
Less accumulated depreciation	(5,655)	(5,655)
	<u>-</u>	<u>-</u>
Website	62,644	62,643
Less accumulated depreciation	(12,529)	-
	<u>50,115</u>	<u>62,643</u>
Total plant and equipment	<u><u>133,434</u></u>	<u><u>183,504</u></u>

Note 11: Right of use asset
Peppercorn Lease

During the current year, the Association entered into a 1 year peppercorn lease from 1 July 2019 with the option to renew the lease for the further three years with a local health department for the exclusive use of the office to provide services to Western Australians with muscular dystrophy and neuromuscular conditions. The Association may not use this space for any other purpose during the lease term without prior consent of the local health department. The lease payments are \$nil per annum. Only outgoings are payable on monthly basis.

This lease is measured at cost in accordance with the Association's accounting policy as outlined in Note 1.

The Association is dependent on this lease to further its objectives. Without this peppercorn lease, it would be unlikely for the Association to service this area due to high market rates in this area. More information on the concessionary leases are available as described in Note 1.

MUSCULAR DYSTROPHY ASSOCIATION OF WESTERN AUSTRALIA (INCORPORATED)

A.B.N. 49 158 959 834

**NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 DECEMBER 2019**

	2019 \$	2018 \$
Note 12: Cash flow information		
Reconciliation of cash flows from operating activities with net current year surplus		
Net current year loss	(77,115)	(84,115)
Non-cash flows in current year surplus:		
- Depreciation and amortisation	50,070	47,519
- Unrealised loss/ (gain)	(86,305)	66,012
- Loss on sale of property, plant and equipment and investments	(144,446)	31,735
Changes in assets and liabilities		
- Decrease/ (increase) in accounts receivable and other debtors	172	15,612
- Decrease/ (increase) in prepayments	(168)	98
- Decrease/ (increase) in accounts payable and other payables	(61,637)	(129,835)
- Increase in provisions	(8,389)	17,033
	<u>(327,818)</u>	<u>(35,941)</u>

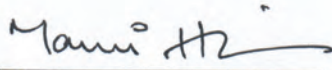
MUSCULAR DYSTROPHY ASSOCIATION OF WESTERN AUSTRALIA (INCORPORATED)
A.B.N. 49 158 959 834

BOARD MEMBERS' DECLARATION

The board members of the registered entity declare that, in the board's opinion:

1. The financial statements and notes, as set out on pages 1 to 11, are in accordance with the Associations Incorporation Act 2015 (Western Australia) and:
 - a. comply with Australian Accounting Standards; and
 - b. give a true and fair view of the financial position of the registered entity as at 31 December 2018 and of its performance for the year ended on that date.
2. There are reasonable grounds to believe that the registered entity will be able to pay its debts as and when they become due and payable.

This declaration is signed in accordance with Associations Incorporation Act 2015 (Western Australia).



Mrs Tanvi Haria
Treasurer



Mr Brad Girdwood
President

Dated: **5 May 2020**

Perth, Western Australia

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

INDEPENDENT AUDIT REPORT
TO THE MEMBERS OF
MUSCULAR DYSTROPHY ASSOCIATION OF WESTERN AUSTRALIA (INCORPORATED)

Qualified Opinion

We have audited the accompanying financial report, being a special purpose financial report, of the Muscular Dystrophy Association of Western Australia (Incorporated). This report comprises the Board's report, assets and liability statement as at 31 December 2018, the income and expenditure statement for the year then ended, statement of changes in equity and statement of cash flows for the year then ended and notes to the financial statements, including a summary of significant accounting policies and board members' declaration.

Cash donations are a significant source of fundraising revenue for Muscular Dystrophy Association of Western Australia Inc. Muscular Dystrophy Association of Western Australia Inc. has determined that it is impracticable to establish control over the collection of cash donations prior to entry into its financial records. Accordingly, as the evidence available to us regarding fundraising revenue from this source was limited, our audit procedures with respect to cash donations had to be restricted to the amounts recorded in the financial records. We therefore are unable to express an opinion on whether the recorded cash donations of Muscular Dystrophy Association of Western Australia Inc. are complete.

In our opinion, except for the possible effects of the matter described in the above paragraph, the accompanying financial report presents fairly, in all material respects, the financial position of the association as at 31 December 2019 and of its financial performance for the year then ended in accordance with the accounting policies described in Note 1 to the financial statements and the requirements of the Associations Incorporation Act 2015 (Western Australia).

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 ethical 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

We draw attention to Note 1 to the financial report, which describes the basis of accounting. The financial report has been prepared to assist the association to meet the requirements of the Associations Incorporation Act 2015 (Western Australia). As a result, the financial report may not be suitable for another purpose. Our opinion is not modified in respect of this matter.

Responsibilities of the Board for the Financial Report

The Board is responsible for the preparation and fair presentation of the financial report in accordance with the financial reporting requirements of the Associations Incorporation Act 2015 (Western Australia) and for

such internal control as the Board determines is necessary to enable the preparation and fair presentation of a financial report that is free from material misstatement, whether due to fraud or error.

In preparing the financial report, the Board is responsible for assessing the association's ability to continue as a going concern, disclosing, as applicable, matters relating to going concern and using the going concern basis of accounting unless the Board either intends to liquidate the association or to cease operations, or has no realistic alternative but to do so.

MUSCULAR DYSTROPHY ASSOCIATION OF WESTERN AUSTRALIA (INCORPORATED)

A.B.N. 49 158 959 834

**INDEPENDENT AUDIT REPORT
TO THE MEMBERS OF
MUSCULAR DYSTROPHY ASSOCIATION OF WESTERN AUSTRALIA (INCORPORATED)**

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 the 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 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 the Board.
- Conclude on the appropriateness of the Board'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 the Board 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.

Owen & Plaistowe

Certified Practising Accountants



Hugh M E Plaistowe
Partner

Dated: 6th May 2020

Perth, Western Australia