



Muscular  
Dystrophy WA

## 2017 ANNUAL REPORT

**MUSCULAR DYSTROPHY WA 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.**



## MESSAGE FROM THE PATRON

50 years is a fine achievement and one that deserves celebrating.

While I am incredibly proud to see Muscular Dystrophy WA reach this wonderful milestone, what is most remarkable to me is the lasting impact this important organisation has on the muscular dystrophy community.

In 2017, my family and I had the opportunity to attend all three 50th Anniversary events. What became very apparent was the overwhelming sense of friendship, spirit and community – everyone was gathered together for the same reason – all connected by muscular dystrophy and all willing to make a difference, truly embodying Muscular Dystrophy WA's belief that together we are better.

I am truly privileged to have been the Patron for the past 30 years to such a passionate organisation that aims to improve the quality of life and wellbeing for those living with muscular dystrophy and their families. I thank Muscular Dystrophy WA for awarding me Honorary Life Membership in 2017 - it is an honour to assist you.

Muscular Dystrophy WA continues to provide benefit to their community; be it through research or through practical support to improve their quality of life. I am so pleased to see the organisation reaching and impacting more people with neuromuscular conditions than ever before.

I congratulate them on reaching their 50th milestone achievement and remaining committed to their mission of empowering full lives.

**Mr Stan Perron AM CitWA**

# MEET OUR BOARD



**Brad Girdwood**  
**President**  
BEng M  
More than 10 years of business management  
3 years' Board service



**Dr Peter W Rowe**  
**Member**  
MB BS FRACP  
Paediatric Neurologist with a dual appointment at Princess Margaret Hospital (PMH) & the State Child Development Centre, Perth (SCDC)  
6 years' Board service



**Tanvi Haria**  
**Member**  
FCPA  
Over 25 years of broad commercial & general management experience  
2 years' Board service



**Brendan Murphy**  
**Vice President**  
BEng (Mining), MFin, GAICD  
Senior site management positions in global & local mining companies both in Australia & overseas  
3 years' Board service



**Susan Trahar**  
**Member**  
LLB (Hons), GDLP  
20 years' experience in Allied Health practice & management as well as 18 years of legal practice  
7 years' Board service



**Aaron Schier**  
**Member**  
MBA (to be awarded June 2018)  
Customer Solutions Specialist & Autonomous Haulage Project Manager in the Mining Technology Industry plus 5 years volunteering with MDWA  
Board member since October 2017



**Geoff Woods**  
**Treasurer**  
BBus, FCPA, CTA  
Providing taxation advice since 1990, prior to then worked as an accountant in public practice, merchant banking & the building industry  
15 years' Board service



**Jane Edwards**  
**Member**  
PgCertBusAdmin, MPubRel  
Background in public relations, marketing & communication  
3 years' Board service



**Shane Powell**  
**Member**  
MHRM, GradDipBusHRM, Grad CertBusHRM, DipMgt, CertIVCSP, CertIVTAA  
Human Resources management  
One year Board service



**Jodie Hatherly**  
**Member**  
GM Legal, BA LLB  
Over 22 years as a corporate lawyer in private & public organisations, specialising in oil & gas  
2 years' Board service

# MEET OUR STAFF



**Hayley Lethlean**  
Chief Executive Officer  
Since January 2015



**Piper Marsh**  
Community Services Manager  
Since May 2014



**Brianna O'Donnell**  
Communications Manager  
Since April 2005



**Mark Hullett**  
Partnerships & Fundraising Manager  
Since May 2013



**Jessica Crute**  
Community Services Officer  
Since April 2016



**Emma Kenton**  
Brand Awareness & Engagement  
Since January 2016



**Toby Gummer**  
Administration & Information Systems Manager  
Since January 2013



**Cathy Donovan**  
Bookkeeper  
Since June 2011



## PRESIDENT'S REPORT

2017 was a year of pride and joy as we united together to celebrate 50 wonderful years of this organisation and reflected often on the past to acknowledge all those who have come before us, giving selflessly for decades to position us to be able to truly make a difference.

I wholeheartedly thank our founder, Professor Byron Kakulas, for his vision and commitment to our cause. From humble beginnings, his discovery of muscle regeneration in the quokka, to 50 years of

commitment to our community, Prof Kakulas has continued in his quest to find a cure and treatment for muscular dystrophy. We honour and thank him and we know that without him and the handful of dedicated parents back in 1967, Muscular Dystrophy WA would not be here today.

I respectfully acknowledge that Prof Kakulas was surrounded by so many great champions during those early years and it was such an honour to reflect and pay respect to them at our breakfast celebration in April. It was my privilege on behalf of the Board and members at the AGM to honour one in particular, our 30 year Patron Mr Stan Perron, with Honorary Life Membership of the Association. He is creating an enduring legacy within the neuromuscular community.

I also acknowledge and thank the Board for their time and efforts during 2017. Their professionalism and diverse range of skills has once again been complemented by new members Shane Powell and Aaron Schier. With backgrounds in human resources, business, technology and project management, our Board's talent and diversity sees us well positioned to continue serving our community to the highest level possible.

Despite it being yet another tough year economically, we still achieved our fundraising targets as well as hosting three additional 50th Anniversary events. The Garden Gala in early September was an elegant and fun evening showcasing our wonderfully diverse community. It also celebrated the ongoing commitment of our long term donors, partners and supporters who provide us with a strong foundation for sustainability.

Our long-standing partnership with the West Perth Rotary Club continued through a generous three year funding arrangement. They have once again demonstrated their commitment and investment into muscular dystrophy research and the translation of this into outcomes for our community. I am very proud to say we have embarked on a clinical trial readiness project for WA which should see new treatments available in the foreseeable future.

Our 50th year is a milestone worth celebrating and I sincerely thank each and every one of you for your contribution to date. To the Honorary Life Members, volunteers, donors and partners, we remain forever grateful. In particular I acknowledge our 50th Anniversary partners who dug deep and gave extra - The Stan Perron Charitable Trust, Toyota WA, MyattsField Vineyards, Prof Sue Fletcher, Abbie and Peter Adams, Arlec Australia and Add Energy.

Through our Vice President Brendan Murphy and CEO Hayley Lethlean, we have continued collaboration at a national level with the Muscular Dystrophy Foundation. While many MDF matters were deferred in 2017, the close collaboration of the CEOs facilitated some national change and progress.

I thank our staff for their continued service, positive commitment and hard work to deliver all of the anniversary events. It was a busy and exciting year and the Board acknowledge all of your extra efforts. I speak on behalf of all board members in saying it is simply a pleasure to work with such a dedicated and loyal team of staff and volunteers.

In closing, my sincere thanks goes out to the community we serve. For 50 years we have had a strong focus - we truly are dedicated and motivated to support you.

**Brad Girdwood, President**





## CEO'S REPORT

*"There is no power for greater change than a community discovering what it cares about"* - Margaret Wheatley

I am unbelievably proud to play a role in serving our wonderful community, who for 50 years have not faltered in the quest to change the path and impact of muscular dystrophy. The past 12 months have enabled us to reflect, acknowledge and celebrate the champions who have dedicated much of their life to raising awareness and advancing research, and we have also paused to remember all of those loved ones lost along the journey.

Our community expands well beyond those living with muscular dystrophy, and includes parents, siblings, extended family, carers and friends. Our ability to link our community with solutions to meet their needs continues to grow.

The Community Services Program now delivers well beyond anything we thought possible. The various reports included clearly demonstrate the growth in programs, the increase in participation numbers and the influential connections we have made. There is still a lot to be done, but we are on the right path and progress is certain.

I thank the Board for their direction and their commitment to expanding our resources which allows the community to remain our focus. I thank our staff for their efforts and enthusiasm to make it happen. You can all be proud of the work that you do and the difference you make! I also thank the volunteers who work with us, side by side.

One of the biggest challenges we face as an organisation is getting the balance right between present or future, support or cure, practical help or research. We are part of many local and national conversations that have an impact on research and clinical care outcomes. Stronger national partnerships with our counterparts in other states and organisations like Rare Voices Australia, Centre for Community Driven Research and SMA Australia have seen some big wins in 2017.

Local partnerships with the Telethon Kids Institute, Hale School, Save Our Sons Duchenne Foundation, Murdoch University, and Princess Margaret Hospital have seen direct benefit to our community in 2017. Through these partnerships we continue to take small actions every day, which we know over time will lead to big results. We recognise that our successes would not happen without the generosity and hard work of the many individuals driving these partnerships and I thank you all for your commitment.

We are so proud to be associated with some very generous corporate partners who have stood by us, put trust in us and supported the work we do, enabling us to do what we do best - providing our community with the support and services they deserve. Toyota WA, The Stan Perron Charitable Trust, Kailis Bros, Myattsfield, Telethon and the West Perth Rotary Club are organisations who have all contributed to the sustainability of our organisation for decades. To each and every one of you, thank you.

This year has been an exciting one and as we continue to create opportunities we will continue to fill gaps that unfortunately exist within society but that we hope to overcome.

We care and we are a power for change. We remain steadfast on building a groundswell of awareness to create even greater change for the next 50 years.

**Hayley Lethlean, Chief Executive Officer**





## TREASURER'S REPORT

I am pleased to present the Association's 31 December 2017 Annual Financial Report, which includes the Financial Statements and Independent Audit Report.

The Statement of Comprehensive Income shows a surplus prior to research grants for the year of \$258,502. Last year, there was a surplus prior to research grants of \$107,244.

The increased surplus was due to the excellent effort put in by all for our 50th Anniversary and additional bequest income compared to last year.

The Perth economy has continued to struggle but despite this it has been good to see that the Truffles for Muscles Auction improved exceptionally this year and the Annual Golf Day is continuing to generate consistent income for the Association. The 50th Anniversary events also created some fantastic results generating \$175,917 for the year. This is something everyone should be proud of for the support they provided during the year.

With continuing low interest rates on bank deposits, our investments in Growth Equities and Managed Funds in the last 12 months have grown modestly after some reinvestment to 31 December 2017 to a total market value of \$1,669,369 which at the end of 2016 was a total of \$1,502,666. Our investment strategy continues with confidence in the equity markets with the view of them being a good long term investment option, whilst in the process giving the Association better short term income by way of fully franked dividends and Managed Fund income distributions with higher capital growth in future years.

Finally, the Net Assets of the Association increased slightly during the year from \$2,205,727 in 2016 to \$2,382,347 at the end of 2017, after the research grants and scholarships of \$81,882 compared to last year's \$103,191.

Once again I would like to thank the Association's dedicated staff and volunteers for their wonderful work ethic and professionalism throughout the year.

Finally, I would like to thank Tanvi Haria for taking over my role of Treasurer at the end of the AGM and I wish her, the Board, the muscular dystrophy community, and the Association staff and volunteers all the very best in the future. I look forward to continuing to be part of this community as a supporter, very part-time golfer and volunteer in the years to come.

**Geoff Woods, B.Bus. FCPA CTA, Treasurer**



# STATISTICS

**\$436**

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

**6.8%**

administration expenses in respect to annual turnover

**\$2,382,347**

Total Accumulated Funds

**\$434,786**

investment into the community & programs - a 15% increase on last year

**\$10,151**

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

**\$81,882**

funds invested into research projects, scholarships & initiatives

**\$772,181**

total fundraising & donations income

**\$175,917**

donations & funds raised during the year relating to our 50th Anniversary

**\$33,024**

Empower Grants funds raised



## COMMUNITY SERVICES PROGRAM

2017 will go down in history as a bumper year for the Muscular Dystrophy WA Community. For the Community Services Team this is not just for the fact that MDWA celebrated its 50th year but because of the sheer number of community services activities and record number of people attending our programs.

This highlighted to us that we were moving ever closer to filling the gaps identified in the state-wide 2015 community services review.

On top of the programs the team delivered, there were a number of further initiatives that supported our community to live empowered lives including the NDIS Expo, NDIS Booklet, Advocacy Plan and participation at Telethon.

Finally, Jess and I would like to thank the MD Community for continuing to support our community services events, for your willingness to provide us with feedback and for being a great support to each other. You are truly inspiring people.

**Piper Marsh, Community Services Manager**

### NDIS EXPO

Muscular Dystrophy WA's commitment to ensuring our community is fully prepared for the NDIS commenced with our first ever NDIS Service Provider Expo. Delivered in conjunction with Save Our Sons Duchenne Foundation, the expo showcased the range of service provider options for people within the neuromuscular community. 26 service providers and 41 community members attended this event. Feedback from both the community members and service providers who attended highlighted how important events like this are to ensure people have greater choice and control.

### NDIS BOOKLET

As part of the NDIS Peer Support Program, MDWA joined forces with Save Our Sons Duchenne Foundation to produce the Practical Planning Guide for the NDIS. This booklet provides advice on preparing and planning for the National Disability Insurance Scheme. On receiving feedback from the community this booklet is now available as a printable form on our website.

### ADVOCACY PLAN

Over recent years the demand for MDWA individual advocacy services has increased. There are a number of reasons for this, including the changes and confusion brought on by the rise of the NDIS. 2017 saw the development of a formal Advocacy Plan to guide MDWA in our efforts to ensure people requiring support are receiving it in a timely manner and from the most appropriate source. Since the instigation of this plan, community services staff have attended eight NDIS planning meetings and assisted in advocacy for accommodation, planning, transport and education.



# COMMUNITY SERVICES PROGRAM

## TELETHON

For the first time the Telethon child was nominated by Muscular Dystrophy WA. Maddox Ball, a young boy who lives with Duchenne muscular dystrophy, represented MDWA and our community spectacularly in the lead up to and during the Telethon weekend. Maddox was able to shine a light to the people of WA on what living with a neuromuscular condition is like. This was an unexpected, yet wonderful, addition to MDWA's 50th celebrations.

## SUPPORT FOR LIFE

The Telethon-funded Support for Life program continued its development. This resource aims to gather the collective knowledge of the muscular dystrophy community on a range of topics beyond medical management. A big thank you to all the members of our community who provided their valuable time and input during the development of this resource. It is hoped that this resource will provide a range of funding and support information regardless of where a person is on their MD journey. MDWA looks forward to launching the Support for Life website in 2018.

## SCHOOL HOLIDAY PROGRAM

The 2017 School Holiday Program delivered day programs during the April and July school holidays and a three day camp during October.

The April School Holiday Program saw 29 participants attend across the two days, where they undertook a number of activities including a scavenger hunt, photography workshop, Bricks4kids workshop and a Scitech show.

In July, 24 participants attended across the two days and participated in a puppet workshop, magic show, Animal Ark and Street Art.

The October camp saw a record number of participants and volunteers; 17 and 14 respectively. Activities included a robotics workshop, Master Chef Challenge and a quiz night. 2018 will see a change in venue and format for camp which will allow for a different range of activities for our campers.

*"I like the fact that the kids can interact with others with similar conditions and it gives them a sense of belonging. I like the fact that the activities that are organised are out of the everyday normal for our family so it makes it even more enjoyable"* – parent of SHP participant.

*"I like being with everyone and the carers are really nice and fun to be with"* – participant of SHP.

## EMPOWER FUND

At the 50th Anniversary Garden Gala guests were given the opportunity to pledge to the Empower Fund. This potentially life-changing new initiative will enable members of the muscular dystrophy community to live more empowered, full lives through the provision of practical financial support.

The fund will provide financial opportunities to our community in situations that cannot ordinarily be fully covered or supplied via other agencies or funding bodies with the aim that grants have a long-term impact. The Empower Fund Grants Committee (EFGC) will provide advice and recommendation to the Board of Muscular Dystrophy WA and will oversee the distribution of grant funding.



# COMMUNITY SERVICES PROGRAM

## HALE MATES

The first Hale Mates peer mentoring session commenced in February 2017. The program links eight school-aged children with 15 Hale School peer mentors. This vital program aims to increase social interactions for our Hale Mates participants and in doing so, decrease the social isolation that often occurs in children with neuromuscular conditions.

Activities undertaken during 2017 included drone flying, a FIFA competition, a drama workshop and a virtual reality session, culminating in the end of year Christmas party and celebration.

2018 will see further development of this program when resilience training is added to the core activities.

The Hale Mates team would like to say a final goodbye to an inaugural Hale Mate – Jordan Rogers (2006 – 2017).

*“Thank you for organising this program. It is giving him a sense of belonging to a group and he is growing in leaps and bounds” – parent of Hale Mate.*

*“I enjoyed meeting new people, I was accepted and welcomed. I felt like I belonged and I have fun every time. Even though I was the only girl for most of the year I never felt out of place or awkward. I felt I was cool just because I am me” – Hale Mates participant.*

## YOUNG ADULTS SOCIAL GROUP

Due to participant rates across 2016, MDWA increased the number of YASG events to six, representing an increase of 100% on 2016. A total of 118 people attended, which equates to an event average of 20 people. Activities included quiz nights, a Kings Park picnic, a Murder Mystery Night and High Tea.

*“Thanks MDWA for running the YASG events. If it weren't for you running these events I would have never met a great group of new friends and would have never found out about electric sports” – YASG participant.*

## MALE AND FEMALE CARERS

2016 saw changes in the provision of our carer social support program including the introduction of the Male Carers Program. 2017 was therefore a year to focus on increasing participant attendance and gaining a greater understanding of what our carers want within this program. We are pleased with the event responses.

### Female Carer Events

- > 16 attended the Sparkling High Tea
- > 10 participated in the Tai Chi and Laughter Yoga workshop

### Male Carer Events

- > 8 attended the East Fremantle FC v Swan Districts FC lunch
- > 8 attended the Whipper Snapper Distillery tour

*“Thank you for conducting these sessions, it is always wonderful to catch up with our families and I really enjoy participating in activities I normally wouldn't” – female carer.*



# COMMUNITY SERVICES PROGRAM

## ADULTS WITH MD

On a chilly Friday night, 25 people attended the Christmas in July 3 course feast. The atmosphere was jovial and the Christmas quiz increased the social interaction.

2018 will see an increase in the number of adult activities.

*"What a wonderful night. We really appreciated yours and your mum's effort in making us feel welcome. Plus it was great to catch up with friends"* – adult with MD.

## DUKE OF EDINBURGH AWARD

MDWA's three Duke of Edinburgh International Award participants continued on their Award journeys.

Anthony Ambrosini, MDWA's first Gold Award participant, completed both his Adventurous Journey to Sydney for National Electric Wheelchair Sports and his Residential Project where he documented his travel to New Zealand, and in doing so produced a resource on travelling with MD.

Noah Ryan focused on his skill, drone photography, and went on an Adventurous Journey to Margaret River.

Logan Bayley utilised his Instagram account "@logansjourney" to raise awareness of Duchenne muscular dystrophy and gave people an insight into what life is like living with DMD.

2018 will see both Noah and Logan achieve their Bronze Award.

## EDUCATION PROGRAM

The Community Services Team delivered a record number of education sessions with 132 people attending 11 sessions. Sessions were delivered on a range of topics including cough assist machines, types of muscular dystrophy and planning for the NDIS. These sessions were delivered to health professionals including physiotherapists and nurses, school staff and students, and community members. Three sessions were conducted in Albany and surrounds.

Another first occurred when MDWA was invited to present 'Enabled Living in WA' at the Australasian Annual Myology and Scientific Meeting, which was held in Singapore. This was an exciting opportunity for MDWA to showcase MD service provision in Western Australia.



# COMMUNITY SERVICES PROGRAM

620

requests for  
information or  
assistance -  
an increase on  
2016 of 117%

53

home & hospital  
visits to community  
members -  
a 65% increase  
on 2016

948

hours of volunteer  
work - up 13.6% from  
834 in 2016

630

people attended  
our social &  
education activities -  
35.7% up  
from 2016



Community Services Program proudly supported by:





## RESEARCH ADVISORY REPORT

I am pleased to present the Research Advisory Committee (RAC) Report for 2017.

This year marked the 50th anniversary of MDWA and our ongoing commitment in supporting world class research in muscular dystrophy and related neuromuscular conditions. Effective treatments and even a cure remain our ultimate goals, and we continue to strive for a collaborative environment where research progress across the globe will positively influence the lives of Western Australians living with muscular dystrophy.

Following the AGM, Dr Peter Rowe, paediatric neurologist at the State Child Development Centre and Princess Margaret Hospital (PMH) offered his ongoing commitment to the committee and we welcomed new member Jane Edwards. With links through a number of universities and PhD scholarships and with Jane's lived experience of muscular dystrophy, she offers valuable input.

During the year the RAC met on five occasions and much discussion focused on current research trends and some gaps facing our local community, a key one being access to local clinical trials. 2017 saw no new scholarship recipients, however three of our current PhD students continued with their studies. The committee utilised the year for consolidation and reflection of our current investment study areas and set about planning for future research initiatives.

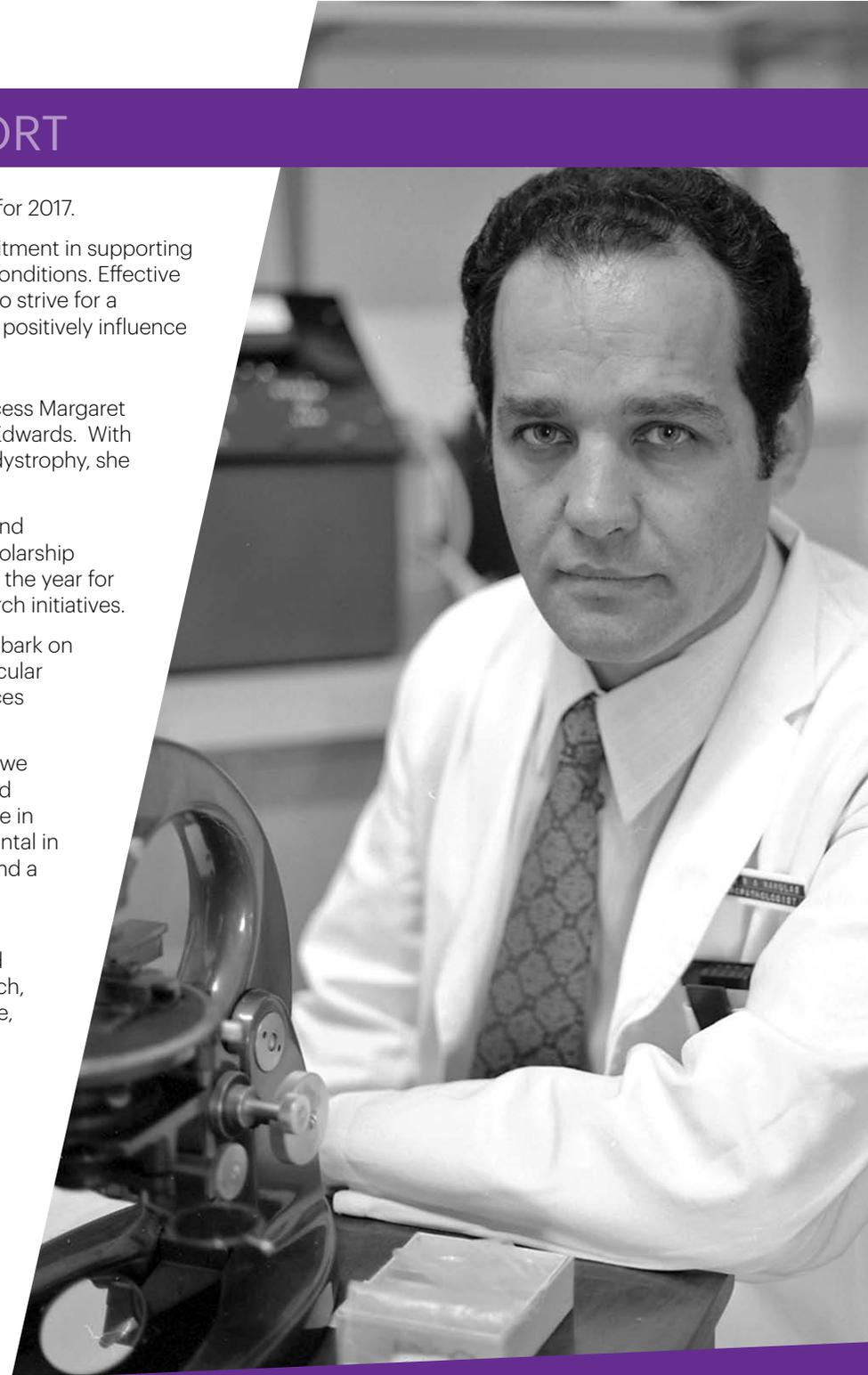
We want to ensure that we harness opportunities for our local community benefit and 2017 saw MDWA embark on a three year partnership with West Perth Rotary Club in a joint funded effort to investigate the current muscular dystrophy clinical trial capacity in WA. This has brought about opportunities of collaboration with Rare Voices Australia, Telethon Kids Institute and the neuromuscular clinical department at PMH.

In March, thanks to the generous support of Murdoch University's Prof Sue Fletcher and Prof Steve Wilton, we hosted a community breakfast with Christine McSherry, founder of the USA charity The Jett Foundation and Board Member of International Duchenne Alliance. Christine spoke at length about her firsthand knowledge in advocating for the Duchenne community to Pharma, the FDA and the government. Christine was instrumental in bringing together a coalition of more than 1,000 families and patients to advocate for greater support to find a cure for DMD.

2017 was a big year for national patient advocacy and a community voice for submissions to the Pharmaceutical Benefits Scheme (PBS) in regards to the SMA treatment SPINRAZA (nusinersen) developed by Biogen. Through strong collaboration with SMA Australia and the Centre for Community-Driven Research, we facilitated the opportunity for the WA SMA community to provide input into the SMA Patient Experience, Expectations and Knowledge (PEEK) study. This patient and family input was extremely valuable and in November, the Therapeutics Good Administration (TGA) approved this drug as the first treatment for SMA registered in Australia.

A key goal within our research strategy is sharing knowledge and this year Hayley Lethlean joined the Patient and Carer Support Organisation (PCSO) Standing Committee. This national committee is hosted by the Centre for Community-Driven Research and they consider and make recommendations to health stakeholders on matters of strategic importance relevant to the Australian health system, that relate to patient and carer engagement in health policy, with a specific focus on Health Technology Assessment. A seat at this table enables us to have a voice for our community on future policy-related initiatives.

**Susan Trahar, Chair of the Research Advisory Committee**



# RESEARCH ADVISORY REPORT

## HAROLD & SYLVIA ROWELL PhD SCHOLARSHIP RECIPIENT, DUNHUI LI MOLECULAR STUDIES ON INDUCED ALTERNATIVE SPLICING

Dunhui Li (Oliver) is now in the second year of his PhD research and looking at modifying dystrophin gene expression with the aim of making different variants. The goal is to see if some of the variants are functional and if so, then our exon skipping technology can be applied to cure Duchenne causing mutations. With the arrival of new compounds from Sarepta, we can now induce dystrophin isoforms missing exons 56+57 and 58+59 in cultured cells.

Another aspect of the work is to look at small molecules, in some cases drugs already approved by the Food and Drug Association (FDA) and see if they can enhance the potency of our exon skipping compounds. Riluzole, an FDA approved neuro-protective drug for Amyotrophic lateral sclerosis (ALS) is being assessed to modulate the efficacy of antisense oligonucleotides (AOs) induced exon skipping.

Research into Becker muscular dystrophy indicated that not all dystrophin exons are necessary for protein functions. Oliver is studying other genes associated with human diseases PARK2. It appears that a disease-causing mutation is the deletion of exon 3. Evidence suggests that the loss of PARK2 exons 3 and 4 is associated with milder/slower progression disease. Hence, we are trying to induce another isoform of the PARK2 product to restore the protein function. A patent is being prepared.

As the US FDA approval of splicing switching compounds Exondys51® and Spinraza®, for the treatment of Duchenne muscular dystrophy and Spinal Muscular Atrophy, AOs are showing great therapeutic potential to treat inherited diseases. Although there is an unequivocal increase in dystrophin after treatment, there is still room for improvement. For this part of his research project, he is exploring combinatory therapies with small chemicals that are known to interfere with global splicing and gene expression. If these compounds can be used in conjunction with specific exon skipping agents (ie AOs), it may be possible to enhance the exon skipping efficiencies. Riluzole and SRPIN340 inhibit the two main splicing kinases, i.e. CDC like kinase and SR protein kinase 1 and he is now assessing the combination of Riluzole or SRPIN340 with AOs in vitro.

Oliver has presented his work as posters at the AGCTS conference in Sydney (May 2017) and CBSM conference in Perth (August 2017).



# RESEARCH ADVISORY REPORT

## TEAM SPENCER MDWA SCHOLARSHIP RECIPIENT FOR SPINAL MUSCULAR ATROPHY (SMA) RESEARCH, DR ADELAIDE WITHERS

### LONGITUDINAL PULMONARY FUNCTION IN PAEDIATRIC NEUROMUSCULAR DISORDERS

Our Respiratory Neuromuscular Research team continues to investigate the impact of paediatric neuromuscular disorders (NMD) on respiratory health, pulmonary function testing and quality of life. In addition to funding support from MDWA, Telethon Kids Institute are proud to announce that we have been granted further research funding from the Dutch Duchenne Parent Project.

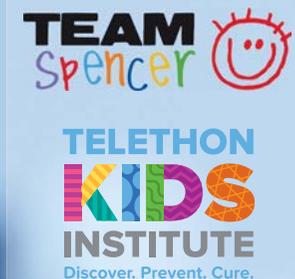
The primary aim of our research is to determine whether alternative methods to sleep study such as lung function testing, symptom scores, quality of life indicators or motor function assessment can better predict the onset of respiratory failure so we can initiate treatment earlier, delaying the onset of respiratory failure and death. Our secondary aim is to use the findings from our longitudinal cohort study to document and describe the natural history of respiratory disease in these disorders, allowing us to construct clinical guidelines for monitoring respiratory function and determine relevant respiratory outcome measures for future clinical trials.

Recruitment for our research is ongoing, and we have collected initial data for a number of patients. After receiving additional funding to specifically examine patients with Duchenne muscular dystrophy, we have amended our initial study protocol to include more potential outcome measures. We have established a Neuromuscular Community Reference Group to obtain a consumer perspective.

Preliminary research to support our study design has been completed. Retrospective review of pulmonary function tests in our paediatric NMD patients and well as those from Stanford have been examined in detail, allowing us to design the most appropriate protocol for our study. Our preliminary findings suggest that Slow Vital Capacity (SVC) is the lung function test most strongly associated with clinical progression in paediatric NMD (as evidenced by loss of ambulation and/or commencement of non-invasive ventilation). We are the first group to publish results of longitudinal pulmonary function testing in children with NMD, and our future findings will allow construction of evidence based guidelines for clinical management and determination of appropriate respiratory outcome measures for use in clinical trials.

We also investigated which variables measured during sleep study give the highest accuracy in diagnosing hypoventilation, and were surprised to find that our results were different to the only published, recommended guidelines from the American Academy of Sleep Medicine. We are the first centre to ever conduct this type of research, and will soon be submitting our findings for review and publication. We hope to publish our findings as guidelines for use specifically in Australia, but are hopeful that our recommendations may be adopted throughout the world.

Our team is extremely grateful for the ongoing funding and support we have received from MDWA, as well as all of the patients and family members who have given their time to assist with our research.



# RESEARCH ADVISORY REPORT

## TEAM SPENCER MDWA SCHOLARSHIP RECIPIENT FOR SPINAL MUSCULAR ATROPHY (SMA) RESEARCH (PREV.), LOREN PRICE

After four and a half years of research, I was finally able to submit my PhD thesis for examination in November 2016. Undertaking this marathon was the hardest thing I have ever done. I know I would not have reached the finish line if not for the support of the people around me, including my family, colleagues and most importantly, my supervisors, Professors Steve Wilton and Sue Fletcher. In June 2017 I finally received the eagerly awaited email to say that my thesis had been approved and accepted by the University, a massive relief!

My research was focused on the use of antisense oligonucleotides (AOs) to design a therapy for spinal muscular atrophy. Through this work we have gained valuable knowledge about AOs, how they function, and how their applications can be adapted to target a wide variety of genes and conditions. I have continued working with Prof Steve Wilton and Prof Sue Wilton, further investigating the use of AOs in treating SMA, as well as applying the knowledge gained to treating other diseases.

While this journey was certainly a difficult one, I am so grateful to have been given this opportunity. This would not have been possible if not for the generous support from Rick and Ruth Stevens and Muscular Dystrophy WA in providing me with the Team Spencer MDWA Scholarship for SMA Research. I would like to take this opportunity to thank Rick and Ruth Steven as well as Hayley Lethlean, John Gummer, and the whole MDWA team for making this possible. I am so proud to be associated with such fantastic organisations and people who selflessly campaign to better the lives of those living with neuromuscular conditions and to support scientific research.

To undertake a PhD is no small task, it is a full time job with a lot of overtime and barely enough time to clean your house and see your family, let alone find the time to generate an income. By providing much needed funding for PhD scholarships, we can continue to support ground breaking research that will not only benefit the Perth scientific community, but the wider muscular dystrophy community as well, bringing hope for the future.



# RESEARCH ADVISORY REPORT

## **HAROLD & SYLVIA ROWELL PhD SCHOLARSHIP RECIPIENT (PREV.), VIVIENNE TRAVLOS**

### **THE MYLIFEMYVOICE TEEN NMD STUDY**

I'm in the final stages of writing up a thesis exploring the health status and well-being of youth living with a neuromuscular disorder who are wheelchair users. The MyLifeMyVoice study recruited (38) youth aged 13-22 years old and their parents from across Australia and New Zealand.

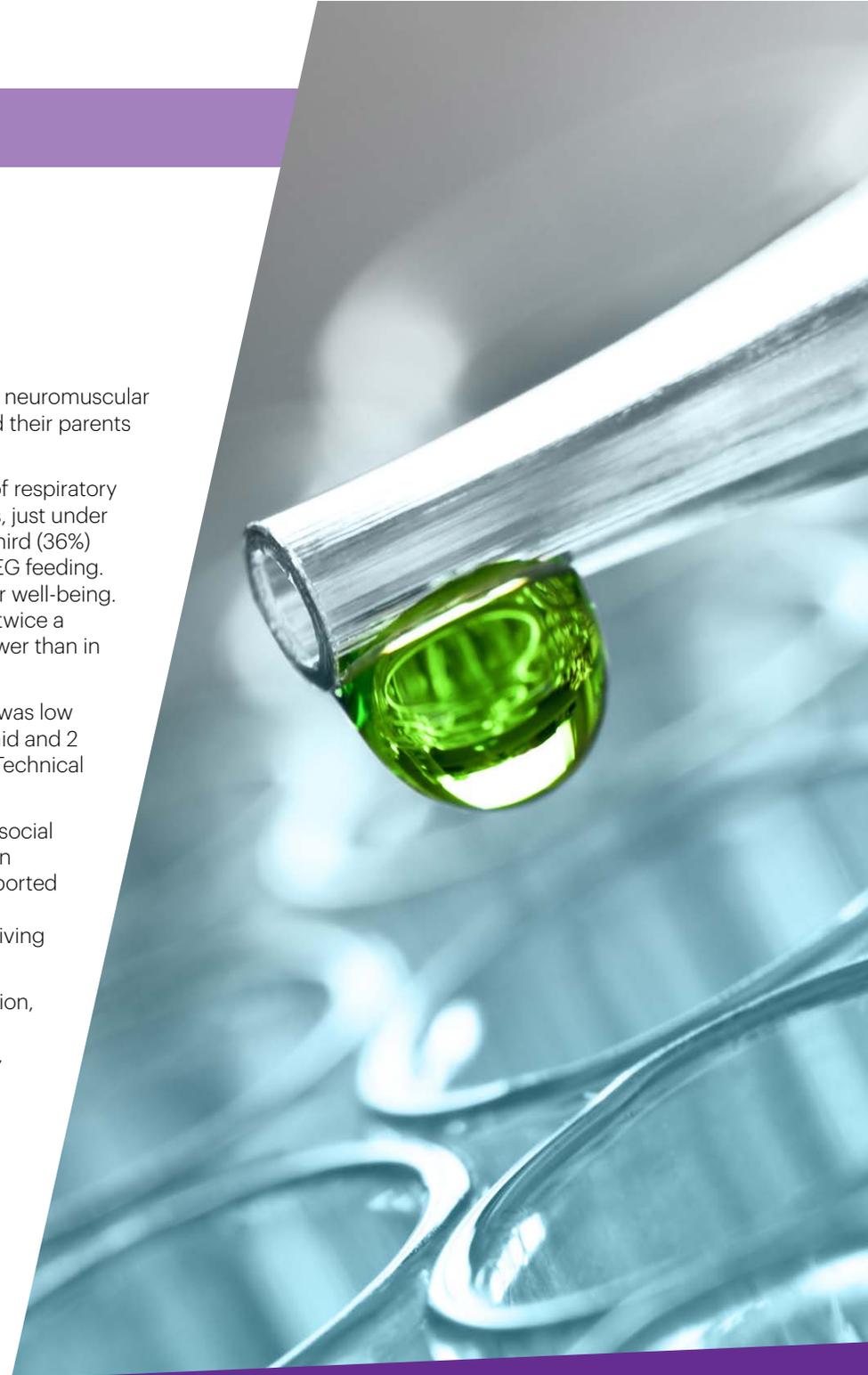
Youth in our study reported severe health issues across body systems. Reassuringly, knowledge and care of respiratory health was good: despite two-thirds of youth (66%) needing ventilator support for weak breathing muscles, just under two-thirds (58%) reported no respiratory illness requiring antibiotic use over the previous 12 months. One third (36%) did not know their cardiac status. Least knowledge was reported about nutritional supplementation and PEG feeding. Daytime fatigue, a higher number of fractures and sleep discomfort were individually associated with lower well-being. 89% of youth reported sleep discomfort, which was highly correlated with parents attending to their child twice a night or more (45% of parents). These parents' Adult Carer Quality of Life scale scores were significantly lower than in parents who did not need to attend to their child at night.

We also measured youths' participation compared to young people in general. Frequency of participation was low across life areas, highest in 'school or university life' and lowest in 'work life'. Only four were employed (2 paid and 2 volunteer), each for less than 10 hours per week. None of the five youth who had completed university, or Technical and Further Education held a formal job.

We used a statistical model to explore how the combination of individually associated physical health and social variables impacted on mental well-being. We found that none of the physical health issues nor participation frequency impacted mental well-being in youth who were above average academic achievers and who reported high perceived family support. Previous studies also found that youth with NMD who were high academic achievers reported higher well-being. Families' capacity to provide support despite the complex issues of living with NMD cannot be explained by this research and is deeply humbling.

Our data helps reassure that despite severe physical health co-morbidities and low frequency of participation, mental well-being can be equal to or even greater than that of typically developing youth. The greatest impacts on youth's mental well-being may be made by: greater attention paid to sleep for the whole family, clinic coordination that addresses management of the multiple health issues while minimising impact on school or learning time (academic achievement), the quality rather than the quantity of participation and through strong family support.

Vivienne is extremely grateful to the Rowell and extended families for their support that helped share the voice of this group of resilient youth living with NMD.



# OUR PARTNERS

Theodore Kailis and his amazing crew at **Kailis Bros**, Leederville have been unwavering partners of Muscular Dystrophy WA for over 40 years. They are now the key pillar in the delivery of the Truffles for Muscles Charity Auction, generously hosted at their famed Oxford Street premises. This evergreen relationship was founded upon the Kailis' family connection with Prof Byron Kakulas.

MDWA's 50th year coincided with the 10th instalment of the ever-growing Golf Classic, consolidating the ongoing commitment of **Toyota WA**. Over this decade, Toyota WA staff, dealerships and their associated businesses have truly embraced the muscular dystrophy community. As MDWA undergoes significant change and an organisational rebrand, Toyota WA Managing Director Mark Lauren has gone further to provide MDWA with a fully maintained vehicle; a mobile billboard which truly showcases the partnership.

Without any hesitation, long-term event supporter **Arlec Australia** adopted a "\$50k for 50 Years" partnership, providing annual funding across a wide range of campaigns and initiatives. Beyond pure financial support, the Trahar family lent their event expertise and networking presence to the Association during a landmark year.

**Professor Sue Fletcher** has dedicated much of her career into muscular dystrophy research. Sue is an integral part of our relationship with Freeth House, generating awareness whilst encouraging young Guildford Grammar students to support MDWA. Always generous with their time, Sue's lovely family have regularly volunteered, and attended camps and fundraising events. Sue went the extra mile to ensure the success of our 2017 celebrations by becoming a key partner in our "\$50k for 50 Years" program.

With the support of **Telethon** in 2017, we delivered an early intervention program for adolescents and children living with neuromuscular conditions. Components of this offered a resilience training program to improve confidence, develops self-advocacy skills and increase decision making capacity. Our relationship with Telethon dates back to the late 1960s. We are so grateful that they recognise the importance of our Community Services Program and research projects.

**Lotterywest** shows unwavering support of the Community Services Program. Without their support, we would not be able to deliver new and diverse programs at little or no cost to our community.

**MyattsField Vineyards'** owners and vigneron, Josh and Rachael Davenport, have shown enduring support of Muscular Dystrophy WA for over ten years through the provision of wine, venue and event partnerships. These wonderful people truly go the "extra mile", riding their mountain bikes, playing golf and attending events for the cause. Josh and Rachael were acknowledged for their commitment with induction as Life Members of the Association this year.

**Scarboro Toyota** once again attended the Toyota WA Muscular Dystrophy Golf Classic, and supplemented their generosity to our community and cause by providing Muscular Dystrophy WA with full-time use of a branded Toyota RAV4.

**The Perron Group** and the **Stan Perron Charitable Foundation** have demonstrated unfailing support of the muscular dystrophy community, and are instrumental in the ongoing success of the Toyota WA Muscular Dystrophy Golf Classic. In late 2016, our Patron Mr Stan Perron very kindly provided a cheque for \$100,000 to help launch our "\$50k for 50 Years" fundraising campaign.



P E R R O N G R O U P

# POWER FROM THE PEOPLE

With one of our biggest beliefs being that we are better together, our partnerships and events are where the magic happens. Not only does it facilitate the recognition of our partnerships, it also brings together our community and connects so many people to each other.

This year was a bumper year with the extraordinary 50th Anniversary celebrations on top of our usual events and happenings.

## TOYOTA WA MUSCULAR DYSTROPHY GOLF CLASSIC

**28 MARCH, 2017**

There could be no better way to celebrate three major milestones than with a day out on the fairways and greens of the stunning Joondalup Resort Golf Course. Less than a month before our 50th Birthday, and 30 years since Mr Stan Perron commenced his role as Patron of MDWA, we celebrated 10 years in concert with Toyota WA as the Naming Partner of our Golf Classic.

There was terrific patronage from our corporate community, whilst the Toyota network embraced the anniversary and helped to fill the event with 27 teams. The golfing Gods smiled, the weather was kind and the course was in tip-top condition as Mark Lauren and his team from Toyota WA took their own crown to win the Ambrose tournament.

Some amusing golf was witnessed, and served as an entrée before the presentation dinner which was hosted by Joondalup Resort in the wonderful poolside marquee, with the event generating \$81,626.

## SUNSMART IRONMAN 70.3 BUSSELTON

**5-7 MAY, 2017**

Triathlon WA and the SunSmart Ironman 70.3 Busselton event once again played generous host to our committed team of triathletes who are dedicated to TRIumph over muscular dystrophy.

In near-perfect Busselton conditions, our significant crew of staff, volunteers and competitors were hard to miss on-course over the weekend, with the purple army never far from the action.

Muscular Dystrophy WA was warmly acknowledged as the aligned charity in the event magazine, whilst being regularly touted by the event announcers over the loud speakers. With a live audience of over 10,000 people, this recognition and awareness is so precious for our brand and community.

We thank our wonderful event Ambassador Renee Baker for her tireless efforts, and the man on the microphone, Simon Beaumont, for his persistent and knowledgeable description of the work of MDWA. The purple army once again went the extra mile to swim, ride, run and fundraise their way to a team tally of \$34,138.



# POWER FROM THE PEOPLE

## TRUFFLES FOR MUSCLES CHARITY AUCTION

29 JUNE, 2017

The 4th annual Truffles for Muscles Charity Auction generated \$123,646 and saw some spirited bidding on the freshest and largest new-season offerings from Manjimup Truffles, paired with amazing hospitality experiences and a row of grapes to call your own.

We are deeply indebted to Theodore from Kailis Bros Leederville, Josh and Rachael from MyattsField Vineyards and Al Blakers from Manjimup Truffles, whose generosity enabled Muscular Dystrophy WA to launch the 2017 truffle season with a bang.

The 100-strong VIP crowd were treated to a delectable truffle croquet monsieur put together by Event Ambassador Chef, Russell Blaikie of Must Winebar. Guests dined on delicious Kailis Bros seafood, while being entertained by MC Simon Beaumont and his roaming mic.

The auction highlights included MyattsField Vineyards' famous Row 38, which sold under the hammer of auctioneer Tiny Holly for \$17,000. The winning bidder plays winemaker with their own row of grapes and all that they produce for the year. This bespoke experience grows in popularity every year.

New to the event in 2017 was artist-in-residence 'Shakey', aka Jacob Butler, who painted an iconic Manjimup Truffle scene featuring WA's Truffle King himself, Al Blakers. Not only did Mr Blakers donate 1.5kg of the freshest Manjimup black truffle for the night, he also outbid the room to take home his painting.

The event saw the launch of our Camp Pledge and it was truly heart-warming to see 27 individuals contribute \$1,000 or more, totalling \$37,000, straight to the heart of our community and helping to send a child to camp. This is so much more than just a camp for the children. The barriers that may exist during a typical school camp are eliminated as all activities are accessible and they have the opportunity to engage with other young people who truly understand what they are going through.

## TRAIL DAY FOR MDWA

19 AUGUST, 2017

The 2017 instalment of the Act-Belong-Commit Dwellingup 100 represented the eighth year where MDWA has been the official Aligned Charity Partner of the event. Significantly in our 50th year as an ever-evolving organisation, 2017 saw the introduction of a new trail run, exposing the event to a far wider audience and helping gain greater traction, if you pardon the pun.

The original mountain bike challenge is still available across several distances, while a new wave of participants are now able to trek the hills and valleys of Dwellingup on foot if cycling isn't their thing. All team members were presented with a commemorative event jersey, with the pre-race team photos and on-course sea of purple a thing to behold.

Our partnerships with TriEvents and the Perth Mountain Bike Club continue to develop, with both providing wonderful event support and advocacy for our Trail Day Team and the Muscular Dystrophy WA organisation and community. Our committed team of riders and runners once again raised vital funds for the cause, generating \$69,238.



# POWER FROM THE PEOPLE

## 3 OCEANS CAROLS AT SCARBOROUGH 10 DECEMBER, 2017

Muscular Dystrophy WA was delighted to be the aligned charity of the iconic 3 Oceans Carols at Scarborough on Sunday 10 December, thanks to the Scarborough Beach Association.

This joyous community event attracted over 3,000 people who celebrated the spirit of Christmas by singing along with the Australian Army Band and the Australian Army Pipes and Drums.

Through the sale of candles and song books, Muscular Dystrophy WA raised \$4,000 before developer and naming rights partner, 3 Oceans, generously matched the funds taking the total fundraising to \$8,000.

We are most grateful for the support of 3 Oceans, City of Stirling, Metropolitan Redevelopment Authority, Lotterywest, Scarborough Beach Association, the Far East Organization and the many Scarborough businesses that supported the evening. We look forward to growing this event with the Scarborough Beach Association for many years to come.

## 50-FOR-50 PARTNERS

In celebration of the 50 Year Anniversary of Muscular Dystrophy WA serving the needs of our community, we embarked on a capital campaign where partners were encouraged to contribute to recognise 50 wonderful years.

We often emphasise that we are better together. These partnerships are organic in nature and tailored to provide unfettered access to events, many showcasing the history of MDWA. Where we have come from is every bit as significant as where we are going.

We thank the following organisations and people for their commitment and unwavering support: The Stan Perron Charitable Foundation, Arlec Australia, Professor Sue Fletcher, Abbie and Peter Adams, Toyota WA, Myattsfield Vineyards and Add Energy.

## VOLUNTEER RECOGNITION

One of the greatest gifts people give us is their time. We could not do what we do without the work of our dedicated team of volunteers. We know we are better together and are able to deliver more services through our Volunteer Program. What is heart-warming is the rapport our volunteers build with members of the MDWA Community as well as the relationships they build with one another.

We love the relationship that has been built between three of our devoted volunteers. Tanika Bennell joined the program in 2014, a few years later we welcomed Rebecca Singleton and then Ilan Eldad in 2016. We threw them together at an event and friendship blossomed. Tanika, Rebecca and Ilan have continued to work together, giving countless hours of their time to help with community activities and fundraising events. They are the first to respond and are always there when we need them, creating their own fun wherever they go.

And while we don't always have all of them at the same time, they are each important to us in their own right and we couldn't be without them.



# HONORARY LIFE MEMBERS

Honorary Life Membership is awarded for exceptional service and long lasting contribution to our Association.

The MDWA Board unanimously agreed to formally present the 2017 Honorary Life Memberships as part of the 50th anniversary breakfast event. This provided an opportunity to recognise the contributions of those key people who have given so much to our Association and to our community.

Dr Patricia Kailis, our longest-standing Honorary Life Member, presented the awards alongside our President, Brad Girdwood. Dr Kailis was awarded her Honorary Life Membership in 1975.

## CONOR MURPHY

An Honorary Life Membership Award was posthumously awarded to Conor Murphy. Conor was a member of Muscular Dystrophy WA from a young age. In his early teens he took on numerous Ambassadorial roles where he demonstrated commitment to the wider community and to raising awareness for the cause.

Despite limitations in his physical ability, Conor achieved in both the academic and the sporting arenas. He was a vocal advocate for disability reform and a supportive and respected mentor. His legacy will continue to benefit the community for many, many years to come.

Conor's parents, Lesley and Maurice Murphy accepted his Honorary Life Membership Award.

## JOSH AND RACHAEL DAVENPORT

Next we acknowledged husband and wife team Josh and Rachael Davenport. In 2006 Josh and Rachael stamped their commitment to our community by becoming the official wine sponsor of the Association with their renowned wines from MyattsField Vineyards.

In addition to the many thousands of bottles of wine they donate, they continue to demonstrate passion and commitment by volunteering, participating and sponsoring events and generating significant funds for our organisation.

They have personally connected with many of our community members and supporters and have built true friendships across many generations.



# HONORARY LIFE MEMBERS

## THEODORE AND MICHAEL G KAILIS

Another duo is father and son team, Theodore and Michael G Kailis. The Kailis Bros partnership was founded upon their family relationship with Professor Byron Kakulas.

Michael G Kailis of Canning Vale Fish Markets ran the Annual Charity Auction between 1972 and 2013. Together we have held 40 successful Christmas Auctions in conjunction with Kailis Bros, generating thousands of dollars for the Association.

This partnership continued with Theodore taking the reins from his Dad in hosting a good number of the Annual Charity Fish Auctions. Our ongoing partnership with Theodore now enables us to deliver the prestigious Truffles for Muscles Charity Auction.

Theodore was one of three early adopters of Truffles for Muscles, ensuring the concept became a reality. Theodore continues to take a keen and genuine interest in what we do and remains a genuine partner and supporter of our cause.

## ROB STOREY

Rob became involved with Muscular Dystrophy WA in 2006 through a business networking group. Having supported family friends affected by muscular dystrophy for many years ago, Rob instantly made a connection with our Association and threw his support behind the Community Services Program prior to becoming a Board Member.

Rob took on the role of President in 2011 and remained in that role until 2016. Rob was, and always has been, ever-present – representing us at countless functions, advocating for us, fundraising personally and professionally through his business and last but not least, attending camps and cooking barbeques for our community.

He is very much loved by our community, our Board and staff and we will always be indebted to him for his contribution in the past and ongoing.

## STAN PERRON AM CitWA

Our final inductee for 2017 was Mr Stan Perron, a long-standing supporter who has shown commitment and dedication towards research, and to our community, for more than 40 years.

Mr Perron became our Patron 30 years ago and during those years has remained focused and directly involved, personally and philanthropically, through his charitable foundation, The Stan Perron Charitable Foundation.

Mr Perron was integral in creating the partnership between MDWA and Toyota WA, which celebrated its 10th anniversary in 2017 and has raised over \$360,000 in total.

Mr Perron remains a humble, fair and private person, demonstrating humility within a business environment through his philanthropic giving.



# 50th ANNIVERSARY CELEBRATIONS

In 2017, Muscular Dystrophy WA celebrated 50 years of funding research and supporting the Western Australian Muscular Dystrophy Community.

The focus for the year was threefold – recognition, acknowledgement and awareness.

Founded in 1967, Muscular Dystrophy WA was founded by Professor Byron Kakulas in conjunction with a small group of parents from the Rotary Club of West Perth.

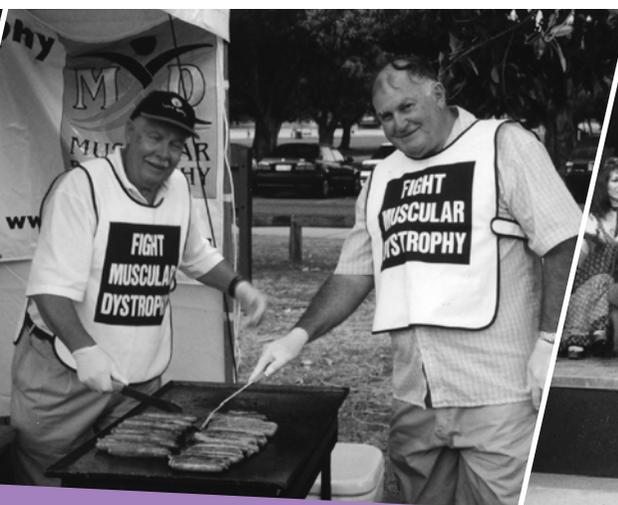
Making the momentous discovery that a paralytic disease affecting the Rottnest Island quokka could be treated for vitamin E deficiency, Professor Kakulas demonstrated the potential for muscle diseases to be treated that were previously thought incurable.

Along with stimulating worldwide research, Professor Kakulas worked with the Rotary Club and other committed community members to gain funding to provide social support for those living with muscular dystrophy.

While Muscular Dystrophy WA's pillar of strength has been our commitment to world-renowned research, our crucial aim today is to provide practical help to improve the quality of life of people living with muscular dystrophy.

We celebrated our Anniversary with three key events.

Perhaps most remarkable of all is the sense of genuine connection, spirit and community that existed at all three Anniversary events. It is a testimony to the heart and soul of our organisation and is the key driver that has guided us for the past 50 years, and will see us still standing strong in another 50.



# 50th ANNIVERSARY CELEBRATIONS

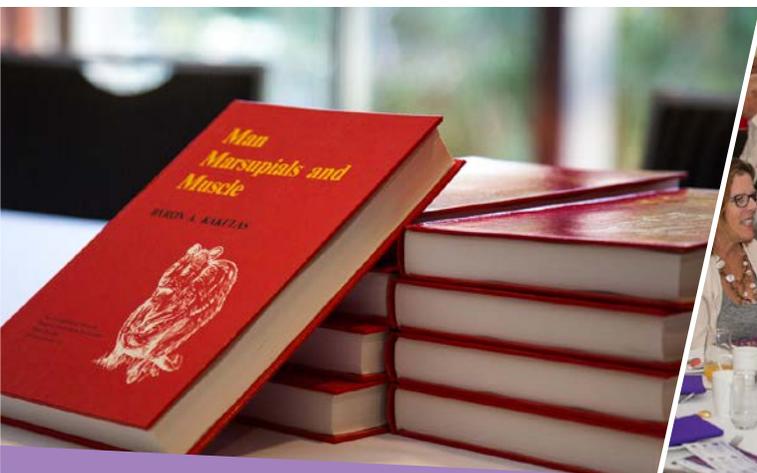
## 50th ANNIVERSARY BREAKFAST CELEBRATION

On April 13, 236 past and present supporters gathered at Fraser's State Reception Centre for breakfast to celebrate Muscular Dystrophy WA's 50th Birthday. Following in the footsteps of our founders who gathered to form our Association 50 years earlier to the day, together we celebrated, recognised and reflected on the past five decades.

We celebrated what has been achieved so far, the many scientific advances and welfare support across many facets of our community. Not the least of these has been our very successful Carrier Detection and Genetic Counselling Program which has helped so many families.

We highlighted just how far we've come in connecting communities, families and care, and providing practical help to improve the quality of life for people living with muscular dystrophy today.

We recognised the people, efforts and supporters that have got us to where we are today – the volunteers, Honorary Life Members, partners, sponsors and of course our muscular dystrophy community. We also took time and reflected on those who are no longer with us but have been part of the journey by way of a moving ceremony.



# 50th ANNIVERSARY CELEBRATIONS

## 50th ANNIVERSARY GARDEN GALA

Spring had definitely sprung on Saturday 2 September, when lavish floral blooms and sparkling chandeliers greeted guests at Muscular Dystrophy WA's 50th Anniversary Gala.

253 guests packed into the Pan Pacific Golden Ballroom for the special occasion, hosted by Today Tonight's Monika Kos. The room was turned into a garden oasis and brought to life by Wedstyle.

A pre-dinner Pimms pop up bar and freshly shucked oysters by Andy Grljusich set the tone for an evening full of surprises. Guests were treated to a spine tingling performance by Indi Singer/ Songwriter Bernardine, a centre stage show by aerobatic artist Miss Gail Force and a live painting by artist in residence, Jacob "Shakey" Butler.

Shakey painted a majestic white peacock which represented society's ability to find beauty in nature's flaws. The white peacock is born with a genetic mutation and we see this as unique and beautiful, such as those with muscular dystrophy. Shakey's message was about accepting and celebrating our flaws and differences.

Our great friend Tiny Holly led a spirited auction assisted by fellow Ambassador, Simon Beaumont.

Some of the most popular auction items were stunning digitised artworks painted by children in the muscular dystrophy community.

Guests were also given the opportunity to pledge to the new Empower Fund. This potentially life-changing new initiative will enable members of the muscular dystrophy community to live more empowered and full lives through the provision of practical financial support.

Once the formalities were over, we kicked up our heels as Proof the Band kept everyone on the dancefloor until midnight.



# 50th ANNIVERSARY CELEBRATIONS

## 50th ANNIVERSARY BIRTHDAY BASH

Our community is our reason and for that very reason we decided to throw a Birthday Bash to celebrate them!

On Sunday 26 November, 148 friends, family and supporters joined with us to celebrate an amazing year, to pay tribute to the past 50 years and recognise there is still so much we can achieve together.

Perth City Farm's Art Room made the ideal setting with a warm, rustic, relaxed and friendly environment. We were treated to the most amazing bountiful grazing table by the Perth Catering Co, whilst listening to relaxing tunes from Why Georgia and sipping on some fine drops from MyattsField Vineyards.

Guests also indulged in the delicious cake created for us by Sugar & Floss Cake Design and chatted the afternoon away with new and old friends.

Special thanks to Lotterywest for their support of this event and to our event suppliers.



# OUR STORY & OUR PEOPLE

Muscular dystrophy is a genetic neuromuscular condition where muscles slowly degenerate and weaken. It affects more than **20,000 Australians** and currently **has no cure**. With more than 70 types of muscular dystrophy identified, the severity of deterioration of muscle strength and function varies, making the task of **treating the condition even more difficult**.

Muscular Dystrophy WA is built around the community we serve.  
**We are in it for them.**

We start with people: their ambition, life and personality, and work with them to further their own goals. **We know that their condition does not define them.**

Being a member of the Muscular Dystrophy WA Community means people have the services and support beyond medicine to live a life they love.

Our mission is to be a **leader** in the support of those living with muscular dystrophy and neuromuscular conditions and to be part of a national voice in achieving and **maximising quality of life** for them.

**No matter a person's abilities, their right to live a full, rich life that they love should always be championed**



We'd like to say a big  
**THANK YOU**  
to everyone who has  
been there for us,  
with us and behind us  
over the last 50 years



Empowering **full** lives



Muscular  
Dystrophy WA

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