



MUSCULAR DYSTROPHY  
WESTERN AUSTRALIA

# ANNUAL REPORT 2015

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## MESSAGE FROM THE PATRON



**In my 29th year as Patron of Muscular Dystrophy WA, I welcome you to the 2015 Annual Report.**

**Muscular Dystrophy WA continues to strive for new and innovative opportunities to raise funds to empower the community to reach their full potential and throughout the year have shown outstanding commitment to enriching the lives of Western Australians living with muscular dystrophy and neuromuscular conditions.**

**I congratulate the Staff, Board, volunteers and supporters on another successful year.**

**MR STAN PERRON AM CITWA**



## OUR MISSION

**To enrich the lives of Western Australians living with muscular dystrophy and neuromuscular conditions.**

## WE DO THIS BY:

- Providing individualised support services
- Linking our people with appropriate personalised support services
- Supporting multidisciplinary research aimed at muscular dystrophy and neuromuscular conditions
- Raising awareness and strengthening community bond

## OUR VISION FOR 2020

**To be an organisation at the forefront in the support of Western Australians living with muscular dystrophy and neuromuscular conditions.**

**To be part of the national voice in achieving and maximising quality of life for the Australian muscular dystrophy community.**

## OUR GOALS FOR 2020

- 1 We are the first choice of support for the Western Australian muscular dystrophy community
- 2 We have a service model linking our community with appropriate personalised services
- 3 We have a diverse and sustainable funding base
- 4 We support relevant muscular dystrophy and neuromuscular research
- 5 We have national collaboration with a united voice for Australians living with muscular dystrophy and neuromuscular conditions
- 6 We have contact with all Western Australians living with muscular dystrophy and neuromuscular conditions of which the majority are actively engaged

## OUR VALUES

INTEGRITY

COMPASSION

INNOVATION

RESPECT

COMPETENT

# MEET OUR BOARD



**Rob Storey**  
**President**

Graduate Diploma in Banking & Finance  
Diploma in Financial Planning  
Certified Financial Planner  
10 years Board service



**Des McLean**  
**Member**

Served 27 years in the RAAF, retired as Squadron Leader  
Previous President & Deputy President of the Shire of Murray  
23 years Board service



**Susan Trahar**  
**Vice President**

B App Science (Speech and Hearing)  
LLB (Hons)  
Graduate Diploma (Legal Practice)  
5 years Board service



**Brad Girdwood**  
**Member**

Bachelor of Engineering  
10 years of Business Management  
Board member since April 2015



**Geoff Woods**  
**Treasurer**

Bachelor of Business Degree  
Fellow of CPA Australia  
Chartered Tax Adviser of The Tax Institute  
13 years Board service



**Jane Edwards**  
**Member**

Background in Public Relations, Marketing & Communication, Post Graduate Certificate in Business Administration  
Master of Public Relations  
Board member since April 2015



**Dr Peter W Rowe**  
**Medical Director**

Paediatric Neurologist with a dual appointment at Princess Margaret Hospital (PMH) & the State Child Development Centre, Perth (SCDC)  
4 years Board service



**Brendan Murphy**  
**Member**

BEng, Mining Engineering (Hons)  
Graduate Diploma, Banking and Finance  
Senior site management positions in global & local mining companies both in Australia & overseas  
Board member since April 2015



**Libby Oldershaw**  
**Member**

Freelance Journalist  
Over 25 year's Journalism experience  
Board member since April 2015

# MEET OUR STAFF



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



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



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



**Rob Kerr**  
**Project Support Officer  
- The Duke of Edinburgh's  
Award Program**  
Since October 2014



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



**Cathy Donovan**  
**Bookkeeper**  
Since June 2011



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

## WE REMEMBER

With sadness we acknowledge the loss of Western Australian Muscular Dystrophy Community Member, Tighe Mullane. We were deeply saddened by Tighe's passing and continue to extend our heartfelt condolences and support to his family.

# PRESIDENT'S REPORT



I am delighted to report that for the first time in more than a decade, we have a full complement of Board Members. In April 2015 we welcomed four new Board Members to Muscular Dystrophy WA (MDWA) - Jane Edwards, Brad Girdwood, Brendan Murphy and Libby Oldershaw. Each brought a diverse and unique set of skills, together with a personal link to the Muscular Dystrophy Community. It is extremely encouraging to see that we have keen interest from highly skilled people seeking to contribute to the growth of the organisation.

In addition to our core responsibility of setting the framework for the operation of MDWA, the Board has focused on three key deliverables; the development of a new five-year Strategic Plan, reviewing the priorities and structure for enhanced community support, and lastly, comprehensive governance and policy improvements.

In April we embarked on the development of a new Strategic Plan. It was essential that during the planning phase we sought input and feedback directly from our Community and key stakeholders. Face to face and online surveys were undertaken with our Community and all information was collated to gain a clear understanding of the community needs. With the help of an external facilitator, the Board and Staff undertook a thorough assessment of our purpose and core business.

Following the six month plan development, I'm confident to report that the 2016-2020 Strategic Plan is targeted and measured, and sets a clear direction for the next five years. All Staff will be held accountable for delivering on the outcomes and as a Board, we will monitor this progress on a regular basis. Key focus of this plan includes collaboration and unity across the country, linkages, individual and family support, and targeted support into multi-disciplinary research. A more detailed copy of the new plan is included on page 20 of this report.

The Board reaffirmed the importance of MDWA's role in improving the quality of life for the Muscular Dystrophy Community. It is refreshing to see that the Board has strongly aligned our purpose to ensure programs and initiatives deliver real outcomes to families and individuals affected by muscular dystrophy and neuromuscular conditions.

One key challenge and opportunity within the disability sector is the potential roll out of the National Disability Insurance Scheme. For WA in particular, we have an added layer of complexity with the alternative WA NDIS MY Way trial underway in the State. Both future models of support to the disability sector with the individual at the centre of care is long overdue, and offers great opportunity for our Community. The theme of NDIS and WA NDIS MY Way has been topical at the Board table throughout the year and we will continue to explore and monitor how MDWA can operate to support our Community through the NDIS and/or WA NDIS MY Way.

As a Board we are committed to ensuring the governance of our organisation is appropriately managed and that policy review and development remains a common thread throughout meetings. The Board implemented a number of Terms of Reference for Board subcommittees. As a priority, we updated the Board Code of Conduct and introduced a Charter of Business which guides our decision making principles and responsibilities. Formal induction process for all new Board Members has been introduced and we continue to develop robust succession planning. As a Board we believe performance evaluation is central to good governance. Regular evaluation is undertaken at management and operational levels. This will now go hand in hand with Board evaluation to purposefully improve performance across all levels of the organisation.

As I prepare to step down from the Board after 10 years, I would like to personally thank all of the Staff, Board and our Community as a whole who have made my role so much easier. In particular I thank past President Des McLean, who has relentlessly served the Muscular Dystrophy Community over 28 years and who is also preparing to stand down. This will leave only one Board Member from when I started all those years ago - Geoff Woods. Geoff's contribution to the Board as Treasurer and a member of the Finance and Audit Review Committee has been exceptional.

Des and I step down with confidence in the quality and experience of the Board and Staff, knowing the Muscular Dystrophy Community is in safe hands.

**ROB STOREY**  
PRESIDENT



**“THE BOARD HAS STRONGLY  
ALIGNED OUR PURPOSE TO  
ENSURE PROGRAMS AND  
INITIATIVES DELIVER REAL  
OUTCOMES”**

# CEO'S REPORT



In writing this report I have taken time to reflect on what we have done to make a difference. Working within the charitable sector, it is vital that we are accountable for the funds we raise, for the service we deliver and most importantly that we are actively responsive to our Community needs.

In the President's Report, Rob highlighted the importance of having sound leadership and good governance as a cornerstone of driving a successful organisation. After a year at the helm, with the leadership of the Board and a year of reassessment and redefining our core purpose, I am confident that we are set in a targeted direction for the next five years.

Our ability to strengthen community bonds is essential. Not only does this mean providing a targeted service to members of the Muscular Dystrophy Community that are actively engaged with MDWA, but also ensuring that we capture the needs of those not engaged with MDWA. 2015 saw us pro-actively forge partnerships across other not for profit organisations and the health and disability sector which in turn, will positively influence outcomes for the neuromuscular community.

Acknowledging long term donors, committed volunteers and corporate partnerships is integral in recognising who we are and why we exist. Our long standing partners - Toyota WA, Kailis Bros, MyattsField Vineyards, Perron Group and TriEvents again showed their commitment to our cause and for this we are forever grateful.

Prioritising initiatives that deliver maximum benefit for our Community, remains one of our key challenges. We are acutely aware our work here is far from done! Taking into consideration the challenges within the health and disability sector, it's critical that we are innovative, visionary and agile with our Community need at the centre of all considerations. Planning and project development in 2015 was reflective of this and while we may not fill all service needs, we are committed to ensuring we link our Community with services that will support their needs.

Our promise to support multi-disciplinary research is demonstrated through the ongoing TEAM Spencer and Harold and Sylvia Rowell Scholarship Programs. 2015 saw progress of Vivienne Travlos' PhD study and the allocation of a new scholarship to Dr Adelaide Withers, as part of a study with PMH and the Telethon Kids Institute. An equipment grant was awarded to Dr Jessica Terrill from UWA and more detail of these initiatives are highlighted in the Research Advisory Report.

Collaboration and having a voice both at state and federal level is vital for raising awareness and gathering momentum in the neuromuscular space. This is a key directive from the Community and Strategic review. Although our fundraising events are held to generate income to support our Community, they do assist with raising awareness. In a tough economic climate, where individuals and organisations are having to tighten their belts, we hope our supporters and the public can differentiate our cause from the many others.

# A YEAR IN REFLECTION

It is an honour and privilege to work alongside a great team who passionately support our Community. This extends beyond our team of dedicated Staff and I am encouraged by the willingness to share resources and information across the whole of Australia. Working collaboratively with State CEO counterparts has delivered tangible outcomes including a new national database for more qualitative data collection, collaboration for a new visual identity, development of the 2016 Building for the Future Neuromuscular Conference and national advocacy for people with neuromuscular conditions with the National Disability Insurance Agency (NDIA).

I acknowledge the hard work of the Board and the drive of the Staff in 2015, in particular their combined efforts in setting new direction and objectives for the 2016 – 2020 Strategic Plan. I also take the opportunity to thank our volunteers, partners and members for their commitment and contribution, working with us to support our Community.

To conclude, I personally thank Rob Storey who steps down after 10 years on the Board, the last six as President. I could not have asked for a more dedicated mentor to support me in my first year as CEO. Rob is a passionate, forward thinking person who has showed commitment across every aspect of the organisation. Rob has always been present and has actively participated in many fundraising events, he attends most community activities and has passionately advocated for unity across the country ensuring the voice of the Muscular Dystrophy Community is heard. Rob, you are an integral part of the organisation's history and you can retire knowing your influence has left the organisation financially sound and with clarity of purpose.

Thank you for the opportunity to serve the Muscular Dystrophy Community and together we look forward to successfully meeting the challenges of the future head on.

**HAYLEY LETHLEAN**  
CHIEF EXECUTIVE OFFICER



# To enrich the lives of Western Australians living with muscular dystrophy and neuromuscular conditions.

**SUPPORTING RESEARCH**

**PROVIDING SUPPORT SERVICES**

**STRENGTHENING BONDS**

**RAISING AWARENESS**

**LINKING WITH SERVICES**

We achieve our mission by balancing these four perspectives of our work

**Community & Stakeholders**

## Improve outcomes & satisfy community

Enhance the quality of life of our Community

Support advances in MD research

Systemically advocate to support our Community needs

Develop a strong interface with clinical environments

**Internal Processes and Operations**

## Develop new and innovative processes

Become a recognised and understood brand

Utilise reliable data to make informed decisions

**People, Knowledge and Innovation**

## Increase training and development

Attract, engage, develop and retain effective people

Identify, develop and establish internal and external partnerships

Achieve operational excellence using performance measurement and management practices

**Financial Sustainability**

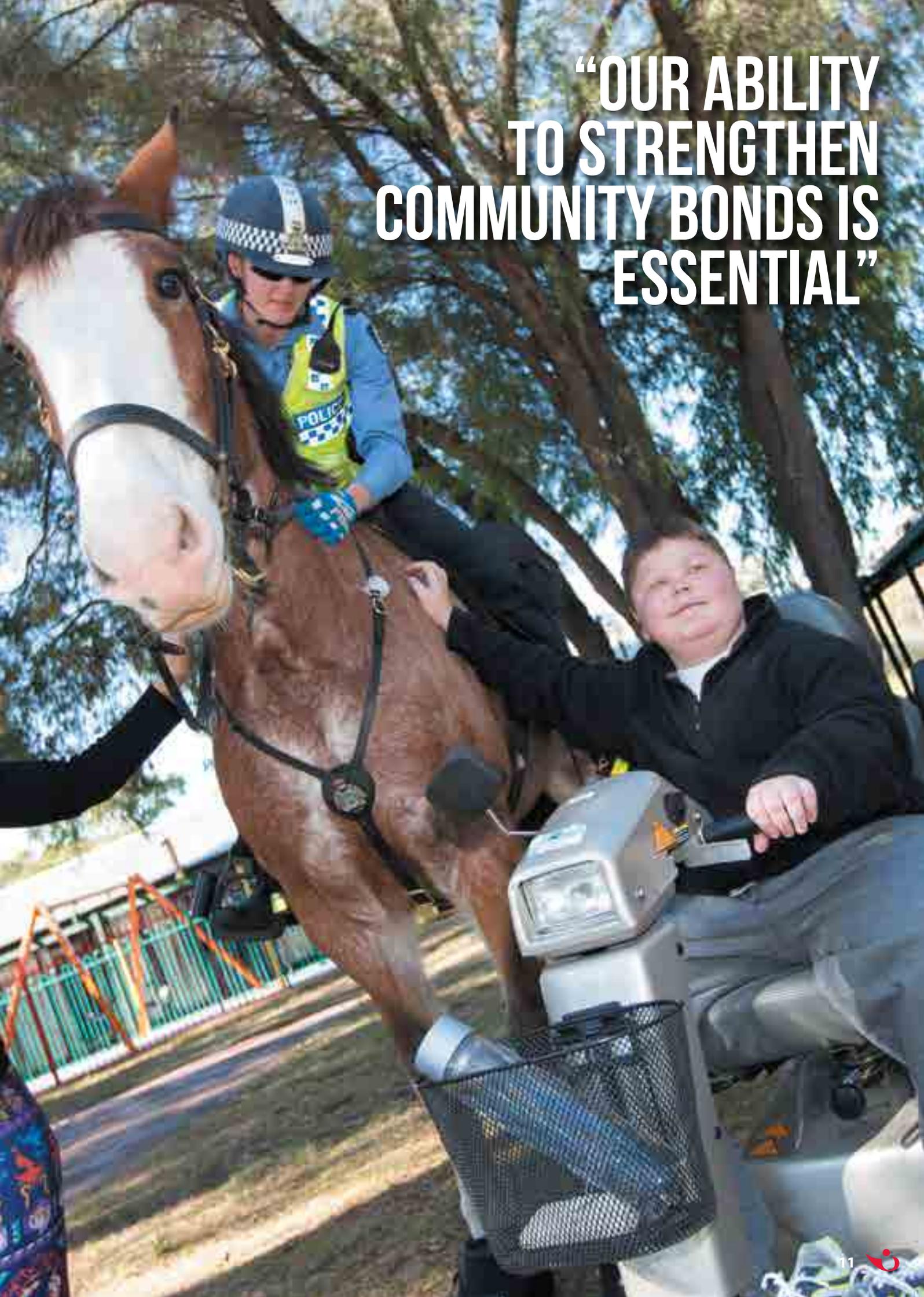
## Grow revenue streams and donor base

Investment in our strategic priorities

A diverse and sustainable funding base

Continuous improvement of resource use and cost efficiencies

**“OUR ABILITY  
TO STRENGTHEN  
COMMUNITY BONDS IS  
ESSENTIAL”**



# TREASURER'S REPORT



I am pleased to present the Muscular Dystrophy Western Australia's 31 December 2015 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 \$116,945. Last year, there was a surplus prior to research grants of \$370,999. The reduced surplus was due to reduced grant and bequest income.

It has been reassuring to see that three of our more recent fundraising projects the Toyota WA Golf Classic, Ride for Someone Who Can't and the Truffles for Muscles Auction have now consolidated and are generating consistent income for our organisation, a total of \$235,414 from all three for 2015. Our newest fundraising initiative being the Marquee Day at Ascot has generated \$43,312 in its first year which is a fantastic first up result.

I am happy to report that due to the current very low interest rates on Bank deposits the Board has increased our investments in Growth Equities and Managed Funds in the last 12 months to 31 December 2015 from a total market value of \$853,722 at the end of 2014 to a total of \$1,428,937 at the end of 2015 after minor growth of \$3,665 for 2015. These investments have been increased to give the Association better short term income by way of fully franked dividends and Managed Fund income distributions but also to take advantage of the falling markets with the long term view to higher capital growth in the coming years. The long term view we have for holding these investments is a minimum of three to five years.

Finally, the Net Assets of the Association increased during the year from \$2,177,499 in 2014 to \$2,201,675 in 2015, after the research grants of \$66,920 compared to last year's \$126,268 of research grants.

Once again, I would like to thank our dedicated Staff and Volunteers for their wonderful work ethic and professionalism throughout the year. It has been a pleasure working with our new Board Members and I look forward to continuing our work together in 2016.

**GEOFF R WOODS** B.BUS. FCPA CTA  
TREASURER



Research Grants allocated:

**\$66,920**



Total Accumulated Funds:

**\$2,201,675**



Community Support Expenses:

**\$274,470**



Net surplus position 2015:

**\$24,176**



Ride For Someone Who Can't:  
(biggest individual fundraiser)

**\$107,397**



Total Fundraising  
& Donations income:

**\$510,469**

# MEDICAL DIRECTOR'S REPORT

2015 has been a year of consolidating some of the work already achieved in finding treatments and pursuing new and other innovative therapies for neuromuscular conditions.

Reproducibility and persistent benefits from treatments for Duchenne and Becker muscular dystrophy, such as eteplirsen seem to be moving slowly towards FDA approval. Affected families and individuals would understandably just like to access potential treatments now. Their frustration has been heard and echoed.

In recent years national coordination of research has benefited from the establishment of the Centre for Research Excellence in Neuromuscular Disorders (CRE-NMD). Western Australia is represented by Professor Nigel Laing AO - Head of Neurogenetics at the Harry Perkins Institute of Medical Research. Development of national and international research collaborations allow access to a broader cross section of the target population (neuromuscular conditions) and make clinical trials and development of treatments more achievable and accessible.

The continued opportunity offered from the Harold and Sylvia Rowell PhD Scholarship is greatly appreciated. The 2014 recipient Vivienne Travlos presented her progress thus far to the Muscular Dystrophy WA Board in 2015, which was received with enthusiastic response. This research engages directly with young people with neuromuscular conditions. The support from the Rowell family will be kindly extended to pre-clinical research for 2016.

I am grateful to be part of the Muscular Dystrophy WA Research Advisory Committee and would direct your attention to the Committee's Report prepared by Chair, Susan Trahar.

Internationally effort is being made to be trial ready. This is evidenced in recent reports for some neuromuscular conditions where profile raising has occurred. This is an imperative step in advance of available therapies.

Aside from trial readiness, one of the main things parents ask when they come to the Neuromuscular Clinic at PMH is "Are you following the guidelines?". A very useful set was published in 2010, with involvement of Professor Katie Bushby (who subsequently visited Perth for the 2012 World Muscle Society Meeting). Development of Guidelines has extended to those recently published for Facio-Scapulo-Humeral muscular dystrophy (FSHD).

Exon skipping technology - which has been supported by Muscular Dystrophy WA in provision for Prof Steve Wilton and Prof Sue Fletcher research team - has evolved in other directions with a number of more recent developments including IONIS SMNRx.

Development of effective treatments are urgent for the most common and severe form of Spinal muscular atrophy Type 1 (SMA1) - the leading genetic cause of death for infants. Sadly 97% die by two years of age. The SMN protein is essential for the formation of motor neurones. Absence of SMN1 is partially compensated for by SMN2, which produces enough SMN protein to allow for relatively normal development in cell types other than motor neurons. However, SMN2 cannot fully compensate for loss of SMN1 because, although SMN2 is transcribed at a level comparable to that of SMN1, a large majority of SMN2 transcripts lack exon 7, resulting in production of a truncated, less stable SMN protein.

This therapy is one of a number being developed that have some evidence to support an improvement in motor function. Early access is required and there are many issues to sort out. The numbers who would benefit are small - perhaps two to four per year in WA. This research is aimed at trying to establish just how much of a difference can be made. The issue of when this and other treatments can be made available is very important and it is hoped that Muscular Dystrophy WA will play a significant role in championing the needs of Western Australians in this evolving area.

The Neuromuscular Clinic at PMH is looking forward to moving to the new Perth Children's Hospital later in 2016. Planning meetings about clinic organisation have been most promising and we hope to have reasonable access to walking and stair climbing tests. Access to the respiratory laboratory and cardiology is also planned.

Muscular Dystrophy WA continues to develop as an organisation whose structure aims to improve focus on individuals with neuromuscular conditions and their families. I'm greatly encouraged about the future of our organisation and its relevance to Western Australian families.

**DR PETER W ROWE** MB BS FRACP  
PAEDIATRIC NEUROLOGIST, PRINCESS MARGARET HOSPITAL  
AND STATE CHILD DEVELOPMENT CENTRE

# COMMUNITY SUPPORT PROGRAM

Proudly supporting the  
Muscular Dystrophy WA  
Community Support Program



2015 was a year of reflection and review for the Community Support Team. After a number of years of service provision, the team felt that it was time to have a look at the programs and support provided, to see if any changes were required. The process commenced formally through the Community Services Review but continued on for the rest of 2015, as the team questioned and considered everything that we did.

Our 2015 program offerings were well received both in terms of participation rates and feedback. We made a number of changes one being the new Young Adults Social Group. This was a direct outcome from the Community Services Review and demonstrates our key focus to build a Community Support Program aligned to the Muscular Dystrophy Community's needs.

A significant amount of time is dedicated to both individual client needs and systemic advocacy. We cannot underestimate the importance of providing holistic support for our Community and strengthening bonds with government, allied health and other not for profit service providers.

Thank you to everyone who provided feedback throughout the year, we will ensure your voice is heard.

Piper Marsh and Rob Kerr

## COMMUNITY SERVICES REVIEW

The Community Services Review considered the state-wide service provision for people living with muscular dystrophy and those who care for/support someone with muscular dystrophy. This included feedback from people in both the metropolitan and regional areas of WA.

This highlighted that there were currently a few gaps within the disability sector regarding support for people with muscular dystrophy. These gaps include:

- The importance of a coordinated care approach throughout the sector for those with muscular dystrophy
- Support to those newly diagnosed
- Systemic advocacy both at a state and national level ensuring closer collaboration
- Support to those in transition between paediatric and adult care
- Young adult social support and social support for fathers
- Widespread awareness of the condition and the Muscular Dystrophy WA brand



In 2016 we plan to build upon and further develop our Community Service Program by adding new initiatives as well as expanding on the existing provision. This will help to ensure we continue to better meet the needs of our Community in 2016 and beyond.

# COMMUNITY SUPPORT PROGRAM

## 2015 CAMP

The July school holidays saw eight children spend four wonderful days at Landsdale Farm School. Highlights included the Animal Ark Roadshow, a visit from the WA Mounted Police, the graffiti art workshop and the highly anticipated 2015 Master Chef Challenge. We thank our volunteers who supported camp, the WA Mounted Police, the students from Freeth House - Guildford Grammar and the Staff of Variety WA who cooked our campers a Mexican feast.



In 2016, we are looking to provide even more activity opportunities for school aged children with muscular dystrophy and neuromuscular conditions.



## MOTHERS' RETREAT

Thanks to the support of Carers WA, we held our mothers' retreat in Mandurah in September. The weekend included a number of activities designed to give mums some well-deserved rest and relaxation. In 2016 we plan to revitalise the weekend format with a series of social events for mothers, grandmothers, guardians, wives and carers, that will span the entire calendar year.

## ANNUAL COMMUNITY DAY AT MYATTSFIELD VINEYARD

Over 120 people attended Muscular Dystrophy WA's Annual Community Day. The name change from the Annual Family Picnic was to reflect what this day is all about - a celebration of everyone involved in the Muscular Dystrophy Community. One of the most important elements being that everything is provided, making it a hassle free afternoon and easy for participants to attend.

Thanks again go to MyattsField Vineyards and Lotterywest for their ongoing support of one of the most popular events on our Calendar.



*"It was another beautiful day at MyattsField. Thank you to MDWA for making us feel welcome and special".*

(Member of Muscular Dystrophy WA)

# COMMUNITY SUPPORT PROGRAM

## COUGH ASSIST PROGRAM



A key component of MDWA's Cough Assist program in 2015 was the Telethon funded Cough Assist Outreach program. This program was highly successful and saw:

- MDWA increase its stock of CoughAssist™ machines by 9, making a total of 61 machines
- 53 people with muscular dystrophy, their carers and health professionals educated on the use and care of the CoughAssist™ – in both metropolitan Perth and regional WA
- The development of a new loan agreement and provisioning guidelines

None of these results would be possible without the generous and outstanding support of the Channel Seven Telethon Trust. We thank them for their contribution to this vital program.

*"We are so grateful to have the E70 CoughAssist Machine on loan from Muscular Dystrophy WA. Our daughter Mackenzie (9) has Spinal muscular atrophy Type 2, and her respiratory health is a key concern for us. Using the E70 is part of our daily routine, like brushing teeth - every morning and night Mackenzie is able to practice her coughing and put positive pressure into her lungs, which helps them to expand and stay flexible. If she is sick, the E70 clears any build-up or secretions she has in her airway.*

*We think it is a life-saver! Mackenzie has not been hospitalised with any respiratory issues in the last five years, or indeed experienced any significant cold/flu symptoms in that time either.*

*We especially love the portability of the E70 machine. Being in the country, we travel to Perth a lot for medical appointments. With the new machine being as compact and light as it is, we travel with it as hand luggage and are able to continue Mackenzie's respiratory care away from home. It also gives us the confidence to holiday for extended periods, like other families can do, knowing that Mackenzie's respiratory health is not compromised and we have help at hand if needed. The E70 has even travelled to Bali with us!*

*Once again, we would like to thank MDWA for allowing us to be part of the Cough Assist program. It is an essential service for people living with muscular dystrophy and neuromuscular conditions, and we really benefit from it".*

The Crane Family, Karratha, WA



# COMMUNITY SUPPORT PROGRAM

## YOUNG ADULTS SOCIAL GROUP

In 2015 we launched our first ever Young Adults Social Group. The group sees our members aged 17 and older come together for the chance to socialise, make new friends and build networks.

Held at various locations across the metropolitan area, this program is all about enabling young adults to hang out and have fun.

Our 2015 activities included a game day, a tour of the Special Air Service Regiment at Swanbourne and a night at the Kwinana Motorplex, where participants tested themselves and their chairs against the reaction clock.

We acknowledge the support of the Special Air Service Regiment, Kwinana Motorplex and the Centre for Comparative Genomics. Together your support ensured this trial program was a great success and will continue in 2016.



*"This program was very necessary as it provided an avenue for our son to get out and about and he really enjoyed it. We can't wait for the next one".*

*(Mother of a participant)*

## NDIS/MY WAY PEER SUPPORT SESSIONS



In partnership with the Duchenne Foundation, Muscular Dystrophy WA have been providing peer support sessions designed to assist people's readiness for either the National Disability Insurance Scheme (NDIS) or WA NDIS My Way. A number of muscular dystrophy families are already involved in trial sites, however national research has shown that people who become involved in the planning process prior to entering a trial site are better prepared and have better outcomes during the process.

Fifteen people have attended these sessions which have included topics such as planning, goal setting and crisis management. Sessions will continue to be held throughout 2016.

## THE DUKE OF EDINBURGH'S INTERNATIONAL AWARD

Three participants were involved in the Muscular Dystrophy WA Duke of Edinburgh's International Award. Aiden Jones and Sarah Kerr joined the program and worked towards their Bronze Awards, while Anthony Ambrosini undertook his Silver Award, our first participant to do this.



All participants worked hard during the year and celebrated their success at a number of events including the Mandurah Fishing Adventure, the Dukie Recruitment Day and the Ride for Someone Who Can't launch.

The participants and MDWA acknowledge and thank Rob Kerr, Project Support Officer, for his work and ideas during 2015.



# COMMUNITY SUPPORT PROGRAM



**417**

people participated in our programs in 2015



**62 COMMUNITY MEMBERS AND 4 ORGANISATIONS**

provided input into the Community Services Review



We received

**135**

requests for information.



Service enquiries was the top reason for contact with

**300+ CALLS**



**20%**

of calls are regarding CoughAssist machines



**10%**

of calls are from new members



**OVER**

**1200 HOURS**

of respite provided in 2015

## VOLUNTEER ACHIEVEMENT - HONOURING DES MCLEAN

We nominated Des McLean for the 2015 WA Volunteer Service Awards where he was honoured for 27 years of voluntary services provided to Muscular Dystrophy WA (MDWA).

In 1988 Des McLean was asked to become the President of the Mandurah branch of the then Muscular Dystrophy Research Association (now MDWA). Several years later Des was invited to join the Board of MDWA in Perth. From 2005 until 2011, Des was President of our organisation.

There are not adequate words to express our appreciation and love for Des; he is an important part of our Community. Des is the first to lend a hand, to say he will be there and goes out of his way to build and foster genuine relationships with the WA Muscular Dystrophy Community.

Des has so much knowledge of our history, he has seen where we have come from and even though he will officially step down from the Board in 2016, he still plays a big part of where we will go. We are so lucky to have you Des, you're one in a million!





**“WE RISE BY  
LIFTING OTHERS”**

**ROBERT INGERSOLL**



# RESEARCH ADVISORY REPORT



I am pleased to present the inaugural Research Advisory Committee (RAC) Report. The RAC is a formal subcommittee of the Board of Muscular Dystrophy WA.

When needed, the RAC calls on external professionals to provide advice and contribute where the business under consideration requires further expertise or investigation. The RAC acts as the principal advisory committee in relation to matters of strategic research initiatives, policy and regulation pertaining to research scholarships, research performance, scholarship appointment and assessment.

In 2015 the RAC set clear Terms of Reference, with the intent of setting some key research objectives to provide input into the MDWA Strategic Plan for 2016 and beyond. A formal Research Policy will guide future decisions around research funding allocation. In 2015 the RAC reviewed and approved the applications for two grants.

## **SUSAN TRAHAR**

VICE PRESIDENT AND CHAIR OF THE RESEARCH ADVISORY COMMITTEE



# RESEARCH ADVISORY REPORT

## TEAM SPENCER – MUSCULAR DYSTROPHY WA SCHOLARSHIP FOR SPINAL MUSCULAR ATROPHY RESEARCH



### **DR ADELAIDE WITHERS - DEVELOPING CLINICAL PREDICTORS OF DISEASE PROGRESSION IN CHILDREN WITH NEUROMUSCULAR DISORDERS**

**PRINCESS MARGARET HOSPITAL, TELETHON KIDS INSTITUTE & STANFORD UNIVERSITY  
SCHOOL OF MEDICINE, USA**

CHIEF INVESTIGATORS - DR ANDREW WILSON AND PROF GRAHAM HALL

Children with neuromuscular disorders (NMD) develop muscle weakness that can have significant impact on health and in many cases, results in premature mortality. Neuromuscular disorders involving the respiratory muscles (e.g. Duchenne muscular dystrophy, Spinal muscular atrophy) result in impaired breathing, poor oxygenation and increased carbon dioxide levels (termed hypoventilation).

If not identified and treated, hypoventilation progresses from occurring during sleep to also occur during waking hours and finally, respiratory failure. Hypoventilation can be treated effectively with non-invasive ventilation, and dramatically improves survival and quality of life in these conditions. Symptoms of hypoventilation are non-specific and when they become obvious, respiratory failure and irreversible lung damage may already be present.

The primary aim of this study is to identify objective outcomes, such as lung function, that accurately predict the onset of hypoventilation. The secondary aim is to develop a longitudinal cohort to describe the natural history of respiratory disease in these patients. The study will measure lung function, clinical symptoms, quality of life and overnight sleep studies to characterise and track disease progression over a 12 month period in children and young people with neuromuscular disorders. This will take place at Princess Margaret Children's Hospital, Perth and the School of Medicine at the University of Stanford, California, USA.

While respiratory failure is the leading cause of death in neuromuscular disorders, the care of children with these conditions is currently not able to be advanced due to the inability to perform clinical trials in paediatric patients. As such, it is critical that relevant parameters for monitoring the onset and progression of hypoventilation in children and young people with NMD are identified. MDWA look forward to the outcomes of this study and sharing this with the Muscular Dystrophy Community. We wish Dr Withers and the team at PMH all the best with the progress of their research.

# RESEARCH ADVISORY REPORT

## MDWA EQUIPMENT GRANT



### **DR JESSICA TERRILL – PRECLINICAL TESTING OF TAURINE FOR REDUCING DYSTROPATHOLOGY IN THE MDX MOUSE MODEL OF DUCHENNE MUSCULAR DYSTROPHY**

**SCHOOL OF CHEMISTRY AND BIOCHEMISTRY, UNIVERSITY OF WESTERN AUSTRALIA**

**CHIEF INVESTIGATORS – DR PETER ARTHUR AND PROFESSOR MIRANDA GROUNDS**

Dr Terrill is currently undertaking research through an NHMRC grant testing the efficacy of three repurposed pharmaceutical compounds in the mouse model of the dystrophy (mdx). Repurposed pharmaceutical compounds may offer a readily available, cost effective and expedient potential treatment option for Duchenne muscular dystrophy.

The team has identified taurine as the preferred candidate for further testing because it improves muscle function without the side effects observed for the other two compounds. The focus of the research has now shifted to rigorously testing taurine in animal models of dystrophy to ascertain whether there is likely to be benefits to patients with dystrophies. Part of this testing involves understanding how increasing intake of taurine affects taurine content in the body and whether there is increased loss of taurine in urine. The equipment funded by the MDWA grant will enable the team to undertake this aspect of the research.

MDWA is delighted to be in a position to support this research through the provision of an equipment grant. We look forward to the outcomes of this study and sharing this with our Community. We wish Dr Terrill and the team at UWA School of Chemistry and Biochemistry all the best with the progress of their research.



# RESEARCH ADVISORY REPORT

## PAST SCHOLARSHIP RECIPIENTS

### **LOREN PRICE - 2012 - 2015 TEAM SPENCER MUSCULAR DYSTROPHY SCHOLARSHIP FOR SPINAL MUSCULAR ATROPHY (SMA) RESEARCH**

#### **APPLICATIONS OF ANTISENSE OLIGONUCLEOTIDES (AO) IN SPLICE INTERVENTION FOR TREATING INHERITED DISEASES**

COORDINATING SUPERVISORS – PROFESSOR STEVE WILTON AND PROFESSOR SUE FLETCHER

Loren Price has now concluded her research and is currently preparing her PhD Thesis for production in 2016. Loren's research utilised the exon skipping principals (Antisense oligonucleotides (AOs)) created by Professors Steve Wilton and Sue Fletcher for Duchenne muscular dystrophy. It is noted that their prior exploration within this area, facilitated a much speedier process of theoretical application for the potential treatment of Spinal muscular atrophy.

The AOs were designed to target and manipulate the retention of a missing exon within the Survival motor neuron gene to enhance the amount of functional protein. The study tested over 100 AOs in SMA patient cells. Loren noted that the concept underlying the use of AOs has much broader applicability to a range of genetic conditions. Some of these conditions include Cystic Fibrosis, the Collagenopathies and adult onset Pompe's disease to name a few.

Loren has been extended opportunities to present the progress of her research at a number of international symposiums and conferences. MDWA is delighted to report that Loren is currently engaged for a full-time 12 month contract with the Centre for Comparative Genomics at Murdoch University. Here she will continue with the progression of certain elements of her PhD research which demonstrated some promising results.



### **VIVIENNE TRAVLOS - 2014 HAROLD AND SYLVIA ROWELL SCHOLARSHIP RECIPIENT**

#### **MY LIFE MY VOICE TEEN NMD STUDY**

COORDINATING SUPERVISORS - ASSOCIATE PROFESSOR SHANE PATMAN AND DR JENNY DOWNS

Vivienne Travlos is now in her third and final year of gathering research data as part of the MyLifeMyVoice Teen NMD Study. The project sets out to review the current health and wellbeing of 14-19 year olds living with a neuromuscular disease (NMD) in Australia and New Zealand.

The study further seeks to give teenagers a voice in scientific research by exploring their thoughts about health, wellbeing and engagement. This research aims to support understanding of the varied functional abilities of teenagers living with NMD. We look forward to the results this study will offer towards the end of 2016.



# EVENT AND CAMPAIGN SUCCESS

## TOYOTA WA MUSCULAR DYSTROPHY GOLF CLASSIC – 10 APRIL, 2015

The Golf Classic, held at the stunning Joondalup Resort, was another outstanding success. With the continuing support of Naming Partner Toyota WA, the day was attended by a near capacity field of 19 teams, who enjoyed the wonderful setting.

The presentation lunch featured more hilarious work on the gavel by Tiny Holly, and the event secured in excess of \$40,000.



## SUNSMART IRONMAN 70.3 BUSSELTON – 1 MAY, 2015

Team numbers and awareness grew in the second year of our alignment with Triathlon WA and the SunSmart Ironman 70.3 Busselton. We were treated to excellent conditions and it was wonderful to look out at the sea of red event polo shirts for the team photo at the iconic Busselton Jetty.

Our sincere thanks again go to Rob Storey and his team, daughter Ellen and ex-MDWA-staffer Emma Pass, who raised nearly \$9,000 towards an overall team tally of over \$40,000.



## TRUFFLES FOR MUSCLES CHARITY AUCTION – 11 JUNE, 2015



The second instalment of Truffles for Muscles was generously hosted by long term partner of Muscular Dystrophy WA - Kailis Bros, Leederville. MyattsField Vineyards and Manjimup Truffles also supported the event, which generated in excess of \$75,000.

Approximately 100 guests enjoyed seafood canapés, a truffle cooking demonstration by Russell Blaikie, great wines from MyattsField Vineyards and a spirited auction of fresh new-season truffles.



# EVENT AND CAMPAIGN SUCCESS



## RIDE FOR SOMEONE WHO CAN'T — 5 SEPTEMBER, 2015

Our largest ever team of 68 riders were entered into the 2015 Act-Belong-Commit Dwellingup 100 event, for the sixth instalment of the Ride for Someone Who Can't (RFSWC).

The event was seamlessly organised by TriEvents and Perth Mountain Bike Club, who are both great advocates of the RFSWC Team and Muscular Dystrophy WA.

These tough-terrain treadly warriors rode through mud, sweat and gears for the cause, pushing their fundraising efforts to well-over \$100,000.



## MARQUEE DAY FOR MUSCULAR DYSTROPHY WA — 23 OCTOBER, 2015



With the weather set fair, we were treated to a spectacular day of racing at Ascot. The ladies wowed in their fascinators and hats for the launch of the hottest new fundraising event for Muscular Dystrophy WA.

We thank Naming Partner add energy group for their continued support. Event MC Eamon Murphy kept the capacity crowd entertained, along with special guest Ambassadors Renee Baker and Andrew Embley, and auctioneer extraordinaire, Simon Beaumont.

This event, which generated gross income of more than \$43,000, is destined to become a fixture on the Muscular Dystrophy WA calendar for years to come.



## CORPORATE FUNDRAISER ACKNOWLEDGEMENT - PERTH WELLNESS CENTRE



Six years ago, the Perth Wellness Centre started a Christmas Fundraising Initiative after the passing of Dr Neil Brodie's business partner, Dr Philip Horner.

Dr Horner had held many Christmas food drives, so in remembrance of him, Perth Wellness Centre started their Christmas Charity event. The practitioners donated their time between Christmas and New Year with the patients paying by their choice of donation and 100% of those

funds being given to charities. It was supposed to be for one year but it was so successful and well received, that they have continued each year and are now approaching \$60,000 funds raised in total.

Muscular Dystrophy WA has been extremely fortunate to receive a significant proportion of these funds. To date \$28,141 has been received from Perth Wellness Centre. It is the continued support of businesses like the Perth Wellness Centre that assist us in achieving our mission of enriching the lives of Western Australians living with muscular dystrophy.

# EVENT AND CAMPAIGN SUCCESS

## SUPPORTER RUN FUNDRAISER – PETER RASH

Peter Rash became familiar with the staff at Muscular Dystrophy WA and our broader Community through our charity alignment with Triathlon WA. In December 2015, Peter participated in the SunSmart Ironman Busselton, raising in excess of \$4,000.

Peter is an employee at Inpex who have been supporting MDWA since 2012, through staff participation in the TRI For Someone Who Can't and Ride For Someone Who Can't initiatives.

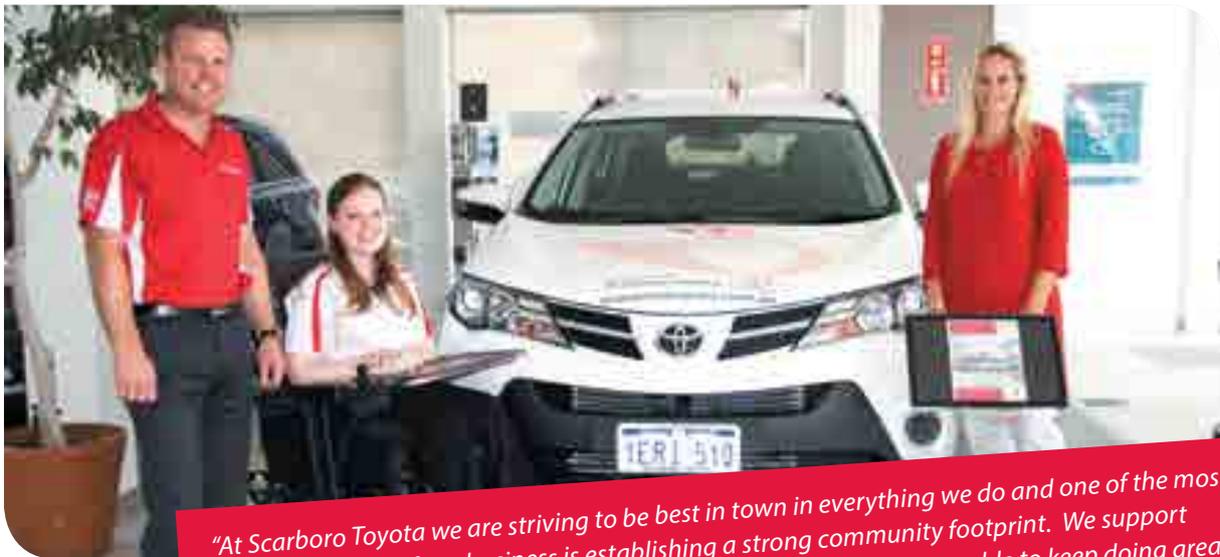
Peter is a passionate bee keeper and is 'powered by honey'! Those who supported Peter, were thanked with a jar of his honey. After 11.57.59 hours completing the 3.8km swim, 180km ride and 42km run, Peter crossed the finishing line in his bee keeper suit, carrying our flag. We are quite sure this would be a world first!



## SCARBORO TOYOTA PARTNERSHIP

In January, 2015, Muscular Dystrophy WA acquired the use of a brand new Toyota Rav4, courtesy of Scarboro Toyota. The fully branded Rav4 has been instrumental in providing event delivery and vital community support services.

Scarboro Toyota promises quality, innovation and safety – ideals Muscular Dystrophy WA share in improving the quality of life for those with muscular dystrophy, assisting innovation by funding world leading research and providing safety in education and support for those with muscular dystrophy, their carers and families.



*"At Scarboro Toyota we are striving to be best in town in everything we do and one of the most important areas of our business is establishing a strong community footprint. We support and help great organisations like Muscular Dystrophy WA so they are able to keep doing great things. Through the provision of a Rav4, MDWA are able to actively service the community. This in turn is hugely beneficial for major events such as the MDWA Golf Classic and the Ironman 70.3 Busselton. For us, it's not about what we give, but simply how we give it".*

Michael Beros - Scarboro Toyota General Manager

GREENFIELDS

## John rides to raise disease awareness

GREENFIELDS (continued) John Halford will take his BMW for Summers Who Can't in Dwellings on September 5.

The 65-year-old will join a group of 65 mountain bikers who will cover 50km of bush trails collectively.

Mr Halford hopes to raise \$10k for the event.

The ride raises funds to help people with dystrophy.

"I've been riding for about four to five years," Mr Halford said. "I saw something about the Ride for Summers Who Can't and thought it was a good cause and signed up."

He will be riding for 17-year-old Dylan Stewart, who has a form of muscular dystrophy.

To donate visit [dwellings2018.rvry.net/summers-who-cant](http://dwellings2018.rvry.net/summers-who-cant) or [john@halford.com](mailto:john@halford.com)



### MUSCULAR DYSTROPHY

■ Muscular dystrophy is a neuromuscular condition that results in the progressive deterioration of muscle strength and function.

■ Individuals with muscular dystrophy don't have the luxury of being able to compete in a mountain biking event, and often as a result of this are confined to an electric wheelchair.

■ This challenges independent activities.

## No holding back for Brianna

DISEASE DOES NOT SLOW HER DOWN

By Ian Brown



It's a beautiful day in the park, and Brianna is out on her electric wheelchair, smiling broadly. She's wearing a grey hoodie and a scarf, and she's looking towards the camera. Next to her, another woman is riding a bicycle, dressed in a full Batman costume, including a mask and cape. They are on a paved path, and the background shows trees and a clear sky.

Brianna is a 25-year-old woman with Duchenne's muscular dystrophy, a condition that causes muscle weakness and wasting. She's been using an electric wheelchair for several years, but she's always been an avid cyclist. In fact, she's been riding for over 10 years, and she's always been a fan of the Batman franchise.

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NEWS

## Family on bikes for charity

STONELAND (Continued) The family will be riding for the charity who can't in Dwellings on September 5.

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Hayley, Lewis, Jerry and Matthew Griffiths. Photo: John Smith

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## Long triathlon Storey

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Rob and Ellen Storey took part in the Dunnetton triathlon event.



# IN THE PRESS



Aloeece Edmunds, Lara Diepeveen, Matt Thomson, Claire Anderson, Emily Hunt and Elesha McFarlane. Picture: Matt Jelonek

## Physios give charity a run for the money

FIVE local physiotherapists and their seven members will make their way to Rottnest Island later this month as they participate in the Rottnest Path Run.

The group will run to raise awareness for muscular dystrophy after being inspired by Town of Victoria Park councillor Claire Anderson who has facioscapulohumeral muscular dystrophy (FSHD).

Physiotherapist Emily Hunt said she was inspired by some of her special clients, including Ms Anderson.

### DETAILS

Brooks Rottnest Marathon and Fun Run  
Rottnest Island  
October 25

"They work hard to live their lives to the full even with this debilitating condition. If I can help in any way to make their lives easier or support research for muscular dystrophy then I will," she said.

Ms Anderson was diagnosed with FSHD when she was 14.

It is a genetic muscle disorder in which the muscles of the face, shoulder blades and upper arms are among the most severely affected.

The term muscular dystrophy means slowly progressive muscle degeneration.

The team aims to raise more than \$1000, which will contribute to supporting people living with the condition through Muscular Dystrophy WA's provision of services, programs and funding research.

www.everydayhero.com.au/event/RUNFSWC



### What a feeling for local charity

Summer Toyota's Max van der Merwe and Emma O'Sullivan with Muscular Dystrophy WA's Alan Blakers. Picture: Ali Trahar

Toyota's Max van der Merwe and Emma O'Sullivan have donated a new white Toyota Hilux to Muscular Dystrophy WA to help fund research and support for people living with the condition.



### Truffles for Muscles Charity Auction

Muscular Dystrophy WA's latest fundraising charity auction raised the magic of the night with a special Truffles for Muscles Charity Auction. The event was held at the Raffles Hotel in Perth on the 11th of June.



### Third time's the charm for fundraiser

UPHOLSTERER and local business Howard is selling copies of her book to raise funds for Muscular Dystrophy WA.



Suzanne Howard is selling books of her poetry to help Muscular Dystrophy WA. Picture: Matt Jelonek

8 ♦ MANJIMUP-BRIDGETOWN TIMES

www.manjimup.com.au

## Truffles go under hammer for muscles

A COVETED Lower South West product will again go under the hammer in Perth to raise money to help find a cure for muscular dystrophy.

Manjimup Truffles owner Al Blakers has donated his biggest truffle this season for the second annual Truffles for Muscles Charity Auction.

All proceeds will go toward funding Muscular Dystrophy WA's research into a cure.

Mr Blakers said he was proud to be part of an event that was working toward such a good cause.

"It's for the kids and it's a good cause," he said.

"It was a terrific night last year - we raised a lot of money."

Mr Blakers said several great



Manjimup Truffles owner Al Blakers with Harley Whitcombe, Boatshed Market owner Michael Porter and 2014 event ambassador Andrew Embley. PICTURE: ALI TRAHAR

chefs were lined up for this year's event on June 11, which features a select number of luxury auction items.

More than 20,000 Australians have muscular dystrophy, for which there is neither treatment nor cure.

## Dad's Ride is very personal

...and it's a very personal story. It's about a father who lost his leg in a military accident and now he's back on his feet. It's about a father who lost his leg in a military accident and now he's back on his feet. It's about a father who lost his leg in a military accident and now he's back on his feet.



Leaving their love very personal. ...and it's a very personal story.

## Doing the ride thing

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## Mountain of passion for ride

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## Beau's new challenge

RETIRED West Coast Eagle Beau Waters, right, has teamed up with triathlete Renee Baker to support Muscular Dystrophy WA.



The pair are ambassadors for the 2016 TRI For Someone Who Can't as part of the SunSmart IRONMAN 70.3 Busselton Ironman which matches a triathlete in the event with a person who has muscular dystrophy.

Baker and Waters will swim 1.9km alongside the historic Busselton Jetty, cycle 90.1km and finish with a gruelling 21.1km run along the Busselton coastline.

For more information or to TRI For Someone Who Can't in 2016 contact [tri@mdwa.org.au](mailto:tri@mdwa.org.au).

## More reason to tri



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## 'Sisters' pedal for charity

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# ORGANISATIONAL PARTNERS



# EVENT AND CAMPAIGN PARTNERS



Andrew Embley | Co-Op Dining | Eventing in the Park | LeBelvedere  
 Leeuwin Estate | Nervana Chiropractic | Salt Property Group  
 Toyota Financial Services | Spices Catering | Ventou



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