



2015/2016 Annual Report





Vision

A world without neuromuscular conditions by 2050

Purpose

Muscular Dystrophy South Australia exists to provide supports and services to people living with a neuromuscular condition and their families and to support research to find a cure and improved clinical practice.





Tim Anderson President

The Muscular Dystrophy SA Purpose is "to provide supports and services condition and their families, and to improved clinical practice."

In response to fulfilling our purpose the Muscular Dystrophy SA Board committed to a major transformation the overarching Muscular Dystrophy project, implemented by the Muscular SA Vision of the world without Dystrophy SA Management team, in the past financial year to focus on increasing client services and research The Muscular Dystrophy SA Board is supported through new and enhanced committed to working at a strategic fundraising initiatives and mutually beneficial corporate and research the needs of our clients and being partnerships.



MD Mafia

As highlighted by Professor Allan Bretag, Director of Research, in detail in his following Research report, I am delighted to confirm the research partnership that Muscular Dystrophy SA has established with the University of South Australia. This partnership is commencing through the Research Agreement between Muscular Dystrophy SA and the University of South Australia for the initial Muscular At all times, we are guided by fulfilling Dystrophy SA-funded project, led by highly respected University of South clients, striving towards reaching Professor Leanne Dibbins, and titled and meeting the needs of you, our "Identifying New Genetic Causes of Neuromuscular Disorders".

neuromuscular conditions by 2050.

and organisational level to best serve mindful and responsive in the dynamic, constantly changing and evolving environment in which we work. This particularly includes, for example, capitalising on opportunities and meeting the challenges arising through the National Disability Insurance Scheme.

It is pleasing to see the continued successful implementation of our client related strategic objectives which are based on client needs.



Multicultural Feast

the service requirements for our Australia senior researcher, Associate the Muscular Dystrophy SA Vision members.

In closing I acknowledge and thank to people living with a neuromuscular This active research partnership and all our members, clients, volunteers, inaugural research project coupled Muscle Team fundraisers, donors, support research, to find a cure and with our joint focus and intent for corporate partners, staff, Phil further collaboration through more Martin and other members of targeted research projects and joint the Management team and Board commercialisation of intellectual colleagues for your continued property that arises, is all aligned with support and commitment to Muscular Dystrophy SA.



Adventure Challenge Bali

CEO's Report 2015/2016

CEO's Report 2015/2016



Phil Martin Chief Executive Officer

I am pleased to advise that through the 2015/2016 financial year we continued to make significant progress in the implementation of our strategic initiatives and our 2020 vision to be: 'An organisation driven by client needs that supports people with muscular dystrophy, and other neuromuscular conditions, to participate in and enjoy community life and equips them with resources they require to support them in a dignified manner; and, a leader in the not-for-profit disability sector - respected for the quality and breadth of its client services, research initiatives and the effectiveness of its fundraising activities'

As can be seen from the more detailed reports each team within the organisation has significantly progressed initiatives towards these



outcomes. In addition we commenced work to transform the organisation to maximize opportunities to generate more services and supports to more people living with a neuromuscular condition and to fund research to assist in finding a cure.

Our Client Services team is in the second year of a five year set of initiatives to increase the range of supports in conjunction with needs and aspirations of our clients that were identified through client and family consultations. The initiatives are occurring in conjunction with the roll out of the National Disability Insurance Scheme and continue to of respiratory infections, improving create great opportunities.

We are currently supporting 748 clients and family members in a range As you will see in Professor Bretag's of services. These outcomes are achievable through opportunities dynamic advances in Neuromuscular created as the National Disability Insurance Scheme is progressively corresponding increase in clinical trials implemented in South Australia and as we seek a cure. Through the terrific through the generous support of our work of our research committee we are sponsors and supporters.

young adults continues to grow in to contribute to this worldwide popularity and has become so popular research for ways to prevent, treat or that we are now looking at ways to cure neuromuscular conditions. This through more camps. The camp in our strategic priorities and our vision provides learning, developmental and for 2050 of a world without muscular fun activities for 5-25 year olds as well dystrophy and other neuromuscular as a much needed break for parents.

the number and focus of support Australian Neuromuscular Network groups in conjunction with client and our close work through the requests.

Kids and Philips Respironics and in and implemented a highly successful



State Electric Wheelchair Sports team

conjunction with the Women's and Children's Hospital we were successful in increasing the availability of cough assist machines for our client group. Research in England and Australia indicates that these machines significantly assist in the reduction quality of life and reducing hospital admissions.

research report it has been a year of Disorder (NMD) research and a thrilled to have been able to progress a collaborative research initiative The annual camp for children and with University of South Australia address future demands perhaps represents a significant advancement conditions.

The team has successfully increased Through our membership of the Muscular Dystrophy Foundation (MDF) and in conjunction with Muscular With the generous support of Dystrophy New South Wales and Variety Children's Charity, Cops for Duchenne Foundation we planned

national conference in Sydney 'Building for the Future'. This three day conference brought together researchers and clinicians from throughout Australia and New Zealand to update the significant progress in research and clinical practice. The conference also provided clients and progress of the National Disability Insurance Scheme and how to ensure they can gain access to the emerging benefits of the scheme.

In the first half of the financial year we undertook a major project designed to transform the organisation as we work to increase services and research within a significantly changing external environment. Thank you to all the clients, families, supporters, volunteers, staff and members who contributed to the project and to the Board for their commitment to implementing key aspects of the recommendations.

We continue to work to introduce a range of fundraising activities to complement and ultimately match returns from our lottery program. When combined with our work to streamline internal practices and to seek efficiencies through economies of scale, these activities will provide a significant growth platform for services and research.

Throughout the year our Marketing and Fundraising team continued to conduct events to increase revenue and raise public awareness about muscular dystrophy. The success of these activities is due largely to the commitment and energy of the team as well as the fantastic support of the public.

Thank you to all of our supporters

who purchase lottery tickets. Your support enables us to continue to provide much needed supports and services to our clients and families.

Through the 2016/2017 financial year we will continue the transformation work to re-position Muscular families an opportunity to learn about Dystrophy South Australia as a growing and sustainable business. This involves careful review of our fundraising and lottery activities' calendar to allow increased focus and support to our many fundraising supporters and sponsors as well as continued growth in service delivery and research initiatives.

> We are committed to raising our public profile and community awareness about neuromuscular conditions, and we will achieve this through executing a robust communication strategy and delivering mutually beneficial, valueadding corporate partnerships to complement the high quality support services.

> My thanks go to our staff, supporters and volunteers for their considerable work undertaken to ensure the continued success of our Association. particularly acknowledge the considerable work and commitment of our Board members who work tirelessly to ensure we continue to be responsive to client needs and leading quality service and research initiatives.







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Client Services Report

Client Services Report



Amber Pyle Client Services Manager

Where did we start?

Client Services started the financial year with an intent to build and strengthen current and recently implemented services. The challenge faced by the department was ensuring staffing levels continued to meet client need and the demand and expansion of services. It was apparent that to ensure services remained responsive and programs were fully supported to develop in line with client needs, that an increase in Client Services staffing year largely due to an overestimated hours was required.

vear the client services team started out with 3.1 FTE of staff with additional funding allocated to roll out a part time Client Services Coordinator position. This reflected the organisations strong



Client Christmas Party

Client Services department despite restraints in budget outcomes.

The new position was allocated to focus support on programs such as the Duke of Edinburgh Award, Hydrotherapy, website updates and management, client focused social media and support group coordination.

In July of 2015 Client Services faced one of its biggest challenges upgrading to a new National Client Database. With increased database to update files and details and the use, roll out of the National Disability Insurance Scheme (NDIS) and higher expectations for more detailed data, significantly assist in future advocacy a new Client Database was essential. The database started out with 721 individuals registered including clients Client Services has worked hard to living with a neuromuscular condition and some carers, family members and siblings.

Significant delays in the roll out of the NDIS were identified over the financial number of participants registering for the scheme. Despite this, Muscular At the commencement of the financial Dystrophy SA continued to progress with involvement and knowledge of the scheme and its impact and benefit for clients. It is important to note that current organisational funding received from the State Government focus to increase supports into the will progressively transfer over to the NDIS as clients register for the scheme.

What did we do?

Roll out of the new Client Services Coordinator position started in Database. The Client Services Team contributed a significant amount of time to get the database uploaded



Big Red Ride & Run

with all available state data. The increased capacity of this database to record more information resulted in ongoing contact with many clients development of a nationwide user manual template. This information will for funding and provision of services.

update many of the client specific sections of the organisational website and whilst this process is ongoing there has been many changes to the information provided on the site.

The team continued to provide quality services and supports to clients including Camp Capacity, Grown Ups Getaway, support groups, therapies, counselling, advocacy, equipment loans, information provision and NDIS planning support. Many services offered received an increase in client participation. Below are a few results of these successful achievements.

Camp Capacity 2016 reached record numbers with 37 participants and additional 6 day visitors. 43 carers were required to ensure Camp September 2015 which coincided Capacity was fully supported. Camp with the launch of the National Client reached maximum capacity with these numbers prompting discussions on how to address future expansion of the event.

Approximately 70 participants about their condition.

Where did we finish?

22 new clients diagnosed with a neuromuscular condition registered with the organisation. This Through closed the financial year with a total of 748 active clients, plus family members Red Ride & Run an additional Cough and carers. The Client Services team Assist machine was purchased to To date Muscular Dystrophy SA has has worked hard to improve internal be allocated to adult clients for use been successful in receiving funding via communications and build collaborative through a program developed in participants NDIS plans for attendance engaging relationships with supporters conjunction with the Royal Adelaide at Camp Capacity. The Client Services and sponsors alongside the Marketing and Fundraising teams. This has been an incredibly rewarding and beneficial Muscular Dystrophy SA was also services offered to clients and this will process for both internal and external successful in receiving a grant from roll out over the 2016/17 financial year networks.

attended Muscular Dystrophy SA A milestone achievement for the facilitated support groups, which is Client Services department was the a great outcome, with planning for approval of an application for \$71,200 new groups in place for the 2016/2017 by Variety Children's Charity for ten financial year. Many of the groups Cough Assist Machines in late 2015. meet monthly and provide great These machines are clinically proven to opportunity for our Clients to learn reduce recurrent respiratory infections, whereby reducing hospital admissions and improve quality of life for children and young adults living with a the amount of \$9,150 towards the neuromuscular condition

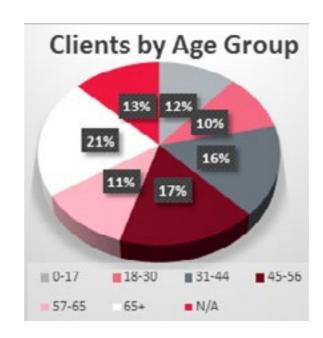
> participants in the Association's Big Hospital.

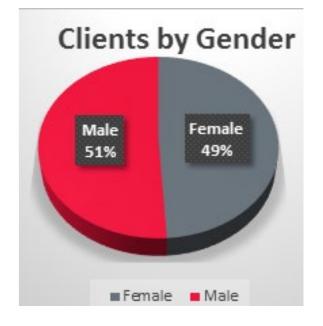
> the Coopers Brewery Foundation for



2016 Grown Ups Getaway. This was gratefully received and contributes dedicated fundraising towards transport, accommodation and meals for participants

> team has also been working on similar costing concepts for other recreational period.





Marketing & Fundraising Report

Finance and Administration Report



Nadelle Manners Finance and Administration Manager

They say change is the only constant and for Muscular Dystrophy SA this has certainly been true for 2015/16. It has been a challenging year with a myriad of changes from systems and processes to strategic positioning for future growth. These adjustments a financial perspective, this can only be have not been without difficulty. However we can now see the budding potential of the work undertaken over the last 12 months.

and Admin team to automate and systemize our data processing, we have overhauled the way in which in which our expenditure can be that will continue into part of 2016/17 minimised. This body of work has will ensure better positioning within

led to increased transparency and improved reporting.

The Finance and Admin team have also been working closely with our Call Centre and Fundraising departments in order to provide management tools that assist with the review of Key Performance Indicators. Looking at the science behind the numbers does mean that we are looking back at the past quite frequently. However knowing where we have come from gives us a great foundation on which to build the journey forward.

Muscular Dystrophy SA's greatest aim in positioning for the journey forward is to provide the best services and outcomes for those who live daily with a neuromuscular condition and to support world leading research. From done by increasing revenue from our fundraising business units all the while decreasing expenditure in these same business units to maximize net return, which provides greater funding for With a commitment by the Finance our Client Services Department. This has been challenging for 2015/16 with the initial budget set being a deficit budget. However we do believe that we record all our revenue as well as the work carried out over the course the continued work to review ways of the 2015/16 year, as well as the work

In order to place Muscular Dystrophy SA as being NDIS ready, work has continued in ensuring that we know and understand the true cost of each Client Service we provide. This not only gives us the ability to review true costs against the NDIS estimate but also to provide greater insight into which areas need our fundraising

focus.

the Not for Profit space.

In 2015/16 Muscular Dystrophy SA was blessed with the provision of funding by Variety - the Children's Charity, for 10 Cough Assist machines. This had a significant positive impact on our organisation's finances decreasing the overall deficit position from the original budgeted deficit.

The business services side of Muscular Dystrophy SA would not function without the support and diligence of the Finance and Admin team. Each team member fills a myriad of roles from volunteer coordination. data entry, customer service, donor management, office management, payroll to financial support. Thank you team for your support.

Our organisation and in turn our clients benefit greatly from the support of the volunteers who give up their time every year. In 2015/16 Muscular Dystrophy SA volunteers have provided around 8200 hrs of support for which money can't buy. But if we did try to monetize these hours, our volunteers have added more than \$200,000 in value to our organisation. The Volunteer Hours graph portrays the spread of the volunteers' hours across each of our business departments. We greatly appreciate this support, thank you.



Sally Curtis Fundraising and Sponsorship Manager

The 2015/2016 financial year has been a period of significant change for the Marketing and Fundraising Department, as we work to streamline our processes. increase revenue streams, foster relationships with strategic goals.

In recent years, Muscular Dystrophy SA Under the previous model, the 2015 has worked to continuously improve our fundraising activities in order to client outcomes.

Our direct mail appeals continue to



outcomes. Over the past twelve months we have worked continually to refresh our approach to grow our database. This has built up our commitment to careful cultivation and stewardship of our existing donor base and our dedication to growing our supporter numbers.

Throughout 2015/2016 we continued to grow our donation boxes initiative in which boxes are placed in businesses throughout the community. Thank you to the many businesses who support us and to the members of the public who put money in the boxes.

The Adventure Challenge continues to be a successful initiative, serving to raise significant funds for the organisation and to elevate our profile in the wider community by supporting partners and deliver the creating committed and passionate

Adventure Challenge fundraisers created revenue for our organisation provide additional revenue streams for by reaching a \$10,000 target (some individuals exceeding that figure by more than \$7,000!). Volcanic action delayed the departure of their provide much needed funds for client December trip to February 2016, but once they were able to take off the team enjoyed an incredible week exploring the surprise destination of Bali. Many thanks to the CMV Foundation for supporting the 2015 Adventure Challenge.

> a new partnership with Andrew 'Cosi' Costello in conjunction with his charity Cows for Cambodia; a new fundraising target of \$6,000 and twice the fun as It was with great disappointment that a second Adventure Challenge was we learnt that we would not serve

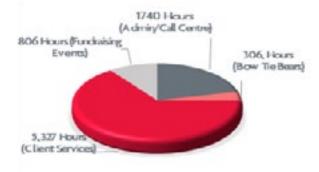


Adventure Challenge Bali

scheduled to run back-to-back in the 2016/2017 financial year. This remodel of the Adventure Challenge has already proven to be a great success, as our affiliation with Cosi has helped to raise our profile and social media reach.

Another major event that dominates the Marketing and Fundraising Department each year is the Big Red Ride and Run. On 16 January this year, over 400 runners, riders, volunteers fundraising results to achieve our ambassadors of Muscular Dystrophy and staff converged on Wigley Reserve, Glenelg to participate in this year's event. The Big Red Ride and Run is a huge undertaking that would not be possible without the support of a dedicated troop of volunteers who man water stations, registration and marshal positions.

> There is also a small group of volunteers who make up our event committee and do a wonderful job overseeing the planning of the event – thank you Rod Williams, Kevin Gruhl, Steven Sabine and Ron Lafferty. Our event sponsors also make a world of difference to the success of the event and we would like to extend our appreciation to the In 2016, the Adventure Challenge saw City of Holdfast Bay, FiveAA, Sammells Financial Services, Duncan Basheer Hannon and letts Fitness.



2015-16 VOLUNTEER HOURS

Marketing & Fundraising Report



as charity partner to the Adelaide Marathon Festival, having been involved with the event for over twenty years. Our long term relationship with the SA Road Runners is currently under review due to a significant restructure of their organisation. We were pleased to participate as charity partner of their 2016 Barossa Marathon, where we recruited over 100 runners to fundraise on behalf of our organisation. We are truly grateful for the support that SA Road Runners has extended to us over those previous years.

In 2016, our annual Golf Day Challenge made the move up the hill and was held at Mt Osmond Golf Club for the first time. Over sixty players joined us for an Ambrose competition, followed by a luncheon held at the club's impressive clubhouse. Many thanks to regular supporters of this event Vinocor, Beyond Bank, SAGE



Multicultural Feast

Automation and Karl Francis who help make this event happen.

In June, our Multicultural Feast attracted a record 170 guests to the Thebarton Community Centre. Guests enjoyed an array of multicultural food and entertainment. Thank you to the City of West Torrens for their support of this event, and to the generous restaurants who donated Consumer and Business Services. huge volumes of food, in particular Casablabla, Nu Thai and My Tho City.

Through the 2015/2016 financial year our lotteries continued to provide the majority of our revenues to support client outcomes. Through an organisational restructure we have established lotteries, a standalone department with its own Sales Manager. This will allow us to move towards a completely sales-focused department.

We have systematically introduced new systems and strategies to increase revenue from our call centre since December 2015. We introduced new scripting and a better system for monitoring Key Performance Indicators (KPIs) in the call centre. By driving requests for donations, we have increased donations in the lotteries from \$3,000 per guarter to \$15,000 per quarter by the last quarter of 2015/2016 financial year.

We have improved reporting which allows us to more accurately forecast lottery sales. This has also meant that we can now better look at revenue versus cost and strategically plan future lotteries.

Our current challenge in lotteries is meeting the requirements of



Adventure Challenge Bali

We are required to produce 35% net profit from each lottery. There are now more ticket sales required from our call centre as other sales avenues such as mail decrease. We also have increased costs such as wages and postage without increased revenue.

We are addressing this by aligning KPIs to match business requirements and finding efficiencies where we can. This is a 'work in progress' but we believe with these changes we have already seen great improvements and the team are confident about meeting our budgeted targets moving forward. We are committed to growing the lotteries and increasing revenue for Muscular Dystrophy SA.

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Bow Tie Bears Volunteer Events Committee 2015/2016



Janice Phillips Chairperson of the Bow Tie Bears Volunteer Events Committee

I am pleased to present the Bow Tie Bears Volunteer Events Committee report for 2015/2016.

The "Bow Tie Bears" as we are affectionately known is a dedicated group of ladies who work together happily to raise funds. The funds raised go directly to provide support, equipment, education and fun to people of all ages who live with a neuromuscular condition.

This year we held several of our very popular craft stalls selling a range of beautiful hand made products. All of our handmade stock is made and donated by our Committee and family and friends. Many quilting, sewing and knitting groups donate their exquisite work and we receive many compliments on the quality of our stock.

In conjunction with Rotary Club of Henley Beach we held a successful High Tea at the Semaphore Carousel. This event raised over \$2,000 and was a great afternoon's entertainment enjoyed by all who attended. We

auctioned a collectible and desirable Pro Hart print, kindly donated to help our cause.

We held our very first Badge Day and with a very small group of volunteer collectors we raised over \$1,700. Hard work but we were very pleased with the result and look forward to bigger and better next year.

The Bow Tie Bears very proudly financed and ran the Camp Capacity 2016 art and craft workshop.

We would like to thank the recently retired Phyl Turner for her many years of hard work, dedication and commitment volunteering as a member of the Bow Tie Bears Volunteer Events Committee.

The Bow Tie Bears would like to sincerely thank Storage King, Windsor Gardens for their continued support with clean and accessible storage of our stock.

We raised \$14,700 during the 2015/2016 financial year.

Throughout the year we have allocated these funds to:

- •Camp Capacity 2016 (\$7,000)
- •Client Xmas Party (\$2,000)
- •3 Oximeters (\$3,030)
- •Back up Bi-PAP battery (\$150)
- •New flooring for a client (\$500)

The passionate and dedicated volunteers who make up the Bow Tie Bears Volunteer Events Committee are very proud of their achievements and determined to continue supporting children and adults who live with a neuromuscular condition.









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Research Report 2015/2016

Research Report 2015/2016



Allan Bretag Director of Research

MDSA Research Report again, it is my great pleasure to be able to write this year's Research Report for you. This in Neuromuscular Disorder (NMD) research which is continuing at an ever increasing pace around the world. As a result, we can derive hope from developments in the understanding of disease processes and from promising and Facioscapulohumeral Muscular clinical trials for many different NMDs. Dystrophy with hopes for therapeutic

Annual Scientific Meeting of the Asian Neuromuscular Network and Building and Oceanian Myology Center (AOMC) held, on this occasion, in Hsinchu City. Taiwan, in May. These meetings are



Multicultural Feast

designed to provide the latest updates in research and to give overviews of clinical aspects of diagnosis and treatment (where possible) of NMDs for the benefit of young neurologists, scientists and allied health workers from developing countries. There were 338 registered delegates with 119 international participants. Highlights of the meeting included a Symposium on Spinal Muscular Atrophy with special reference to therapies being developed and updates on very promising preclinical and clinical trials (more below). A second Symposium covered Distal Myopathies in which newly-recognised phenotypes of Titinopathy and Laing Myopathy were discussed along with potential therapies for GNE Myopathy.

results of clinical trials of three promising therapies for Duchenne Muscular Dystrophy (more below) was offset somewhat by better understanding of Ullrich Congenital Muscular Dystrophy advances to come. A few weeks later. This year I have attended the 15th in June, I attended the Australian for the Future - Neuromuscular Conferences in Sydney. These meetings provided updates of NMD research and management of NMD conditions

> Following rapidly on from dramatically Unfortunately there have been guite successful preclinical trials of drug treatment of spinal muscular atrophy (SMA) in animals, many clinical trials are Duchenne MD. The United States Food under way in humans. Although the first and Drug Administration (FDA) has (in of these placebo-controlled doubleblind trials are only due for completion of the drug eteplirsen (Exondys 51).

parents and carers.



Grown Ups Getaway

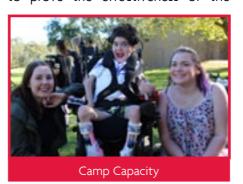
in 2017, rumour has it that certain infants and children participating in these trials are showing improvements that could not be expected if these infants and children were not in fact receiving the active drug. However, in order for drug regulation authorities to be satisfied that the trials are being undertaken according to the rules and to be certain that the active drugs will become available to all at the end of has been a year of dramatic advances Disappointing news regarding the the trials, they must first be completed without breaking the double-blind code.

> Among promising drugs being trialled are Nusinersen (IONIS-SMN Rx), CK-2127107, LMI070, RO6885247 and RO7034067. The Nusinersen trials are named as follows for, presymptomatic newborns with an SMA genetic diagnosis (Nurture), infants with SMA (Endear), children with SMA (Cherish), patients not eligible for the other trials (Embrace) and those who have participated in previous Nusinersen from an Australian perspective, the trials (Shine). Trials of the Hoffmann-La second of the conferences being Roche drugs (RO...) are also given the mainly for the benefit of clients, striking names, Moonfish, Firefish and Sunfish.

> > disappointing developments regarding clinical trials of treatments for May) severely criticised the clinical trial

This setback came very soon after the FDA's rejection (in January) of the drug drisapersen due to severe adverse side effects and notification (in February) that TranslarnaTM (ataluren, PTC124) did not meet the FDA's standards on effectiveness even though it had gained provisional approval from the equivalent European agency. Then, in an astonishing reversal, the FDA later overruled its own staff and advisers (in September) and granted Exondys 51, "fast track designation", "priority review" and "orphan drug designation". This development was triggered by the sudden resignation of the FDA's own supervisor of the clinical review of eteplirsen who had argued strenuously against approval because of unacceptable scientific results from the clinical trial.

It appears that the FDA, nevertheless, decided to approve the drug for two reasons. Firstly, there was extraordinary lobbying from parents of Duchenne boys for a more flexible and lenient view of the results of clinical trials in the case of serious diseases for which no effective treatment existed. Secondly, by granting these approvals, the drug company could sell the drug to help fund new developments. There was, however, a proviso that within two years, the company must have conducted a further, properly controlled and larger clinical trial to prove the effectiveness of the



drug. Some of you may have heard the media announcements about this treatment for Duchenne MD from Professors Steve Wilton and Sue Fletcher of Murdoch University who were involved in the design and development of eteplirsen. What must be taken into consideration, however, is the probable prohibitive cost of this drug at \$300,000 per patient per year, even if it is ever approved in Australia by our TGA. Finally, eteplirsen (Exondys 51) is only likely to benefit Duchenne boys who have a confirmed mutation in exon 51 of their dystrophin gene.

Despite these disappointments, more efficient and less toxic drugs are in development while there are entirely new methods of gene therapy, for example, genetic engineering using the recently developed gene editing procedure called "CRISPR".

In January this year, the journal, Science, published reports from three independent research laboratories each of which showed that mice with Muscular Dystrophy could be treated successfully by using CRISPR. This procedure actually corrects the mutations in the dystrophin gene by a process a bit like editing a text using a word processor – simply deleting the error in the DNA code and inserting the correction. Theoretically a genetic correction of this kind could be passed on to offspring of the affected animal or person. Ethical and legal implications of CRISPR gene editing (creating super-humans would be possible) will need to be considered before the technique is applied in humans.

Mitochondrial myopathies are also about to succumb to effective preventative therapy via



fertilisation (IVF). I have written about this possible scientific advance in one of my research reports from several years ago. It has now come to fruition. You may have heard recently about a baby born in Mexico with three parents. The mother and father were from Jordan and the IVF team were from New York where the procedure is not yet allowed. Because the cytoplasm of the mother's egg cells contains defective mitochondria, a donor egg cell is needed. The nucleus from the donor egg cell is removed and the nucleus from an egg cell of the mother is inserted into it. thus incorporating all of the DNA (and hereditary characteristics) of the mother but eliminating the mother's defective cytoplasmic mitochondria. The donor egg cell containing the mother's nuclear DNA is then fertilised by the father's spermatozoa as usual in IVF.

Our own MDSA has recently recommenced its involvement in research after many years in which all of its disposable income was directed towards providing as much as possible for the needs of clients. For almost two years the MDSA Board has been seeking a partnership with a research group in South Australia that would be able to contribute to the world-wide

Financial Report 2015/2016

Research Report 2015/2016



Big Red Ride & Run

search for ways to prevent, treat or cure Neuromuscular Disorders such as Muscular Dystrophy, Spinal Muscular Atrophy and more than 50 other similar diseases. This has been in line with the vision of MDSA to see a world free of Muscular Dystrophy and other Neuromuscular Diseases by 2050.

It was the view of the MDSA Board that it would wish to enter into a contract with an appropriate research group where MDSA could expect a financial return on its investment if the research discovered any method, treatment or other intellectual property that might bring in some profit from royalties or sales. I am pleased to let you know that MDSA has arranged just this kind of contract with the University of South Australia in which any profit that arises from research funded by MDSA is to be shared 50:50 between MDSA and the University of South Australia.

The particular research is to be conducted by Associate Professor Leanne Dibbens and her colleagues in the School of Pharmacy and Medical Sciences at the University of South Australia, City East Campus on Frome Road. Professor Dibbens is nationally and internationally recognised for her research into genetic conditions.

Her research project is entitled "Identifying New Genetic Causes of Neuromuscular Disorders". There are several reasons why this research project was chosen for funding by MDSA.

Firstly, there remain many people who have neuromuscular disorder but who have not had a genetic diagnosis. It is important to know the genetic diagnosis of any person with a Neuromuscular Disorder because some Neuromuscular Disorders are able to be treated to the point of being cured. For example, there are some people who have been labelled simply as having Muscular Dystrophy but who in fact have a disease such as Myasthenia Gravis that is readily treatable. An example of this was reported in The Advertiser just a few days ago where a man who had been in a wheelchair for most of his life was treated and within a year was able to walk again.

Secondly, research on Neuromuscular Disorders is proceeding at such a fast pace that within a few years, provided people have their particular genetic condition known and registered, and agree to participate, they will be able to take part in relevant clinical trials In this way more and more of these conditions will become treatable





Camp Capacity

Thirdly, Professor Dibbens's project will lead into a search for treatments of any new genetic causes of Neuromuscular Disorders that she and her team happen to discover. Once a genetic cause is known, it can now be induced in cells in tissue culture in the laboratory and vast banks of different existing and new drugs can be tested on them for effectiveness. Or, CRISPR could be used to edit the genetic error. Either of these methods, and possibly others, could then quickly lead to treatments and cures.

MDSA Board is pleased to announce this exciting research partnership.

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Summarised Statement of Surplus or Deficit and Other Comprehensive Income For the Year Ended 30 June 2016

Tof the Teal Effect 50 Julie 2010				
INCOME How we are Supported	2016	2015		
	\$	\$		
Donations & Bequests	367,525	492,495		
Government Grants	134,473	123,598		
Special Events	169,487	155,505		
Lotteries	1,275,980	1,324,282		
Interest & Dividends	17,977	21,611		
Miscellaneous	100,271	15,633		
TOTAL INCOME	2,065,713	2,133,124		
Less EXPENDITURE				
Depreciation & Amortisation	72,937	52,715		
Bank Charges	18,305	20,826		
Special Events	70,669	91,225		
Prizes	313,428	314,444		
Wages & Oncosts	1,240,510	1,250,000		
Consultants	12,739	68,458		
Finance Costs	1,773	4,026		
Other	390,287	332,045		
TOTAL EXPENDITURE	2,120,649	2,133,739		
NET CLIPPLUS (IDEELCIT)	(54.027)	(215)		
NET SURPLUS/(DEFICIT)	(54,.936)	(615)		
add OTHER COMPREHENSIVE INCOME				
Net fair value gain/(loss) on available-for-sale financial assets	(9,998)	7,874		
Fair Value revaluation of land & buildings	(.,)	(60,805)		
Tan value revaluation of land & buildings		(00,003)		
TOTAL COMPREHENSIVE SURPLUS/(DEFICIT)	(64,934)	(53,546)		
	(31,731)	(55,510		

The above statement of comprehensive income should be read in conjunction with the full financial report of Muscular Dystrophy SA. A copy of the full financial report is available upon request.

Financial Report 2015/2016

Financial Report 2015/2016

Summarised Financial Position - As at 30 June 2016

Summarised Fina	incial Position - As	•	
ASSETS	NOTES	2016	2015
		\$	\$
Current Assets	2		
Cash & Cash Equivalents	3	536,836	556,614
Trade & Other Receivables	5	75,816	61,232
Inventories		2,472	12,316
Total Current Assets		615,124	630,162
Non-Current Assets			
Available-for-sale Financial Assets	6	189,962	119,960
Trade & Other Receivables	4	2,757	3,864
Property, Plant & Equipment	7	1,169,856	1,142,146
Intangibles – Software		24,118	31,198
Total Current Assets		1,386,693	1,377,168
TOTAL ASSETS		2,001,817	2,007,330
LIABILITIES			
Current Liabilities			
Trade & Other Payables	8	207,605	162,854
Employee Provisions	9	119,178	113,915
Interest Bearing Liabilities	11	9,119	8,891
Total Current Liabilities		335,902	285,660
Non Current Liabilities			
Employee Provisions	10	59,773	42,198
Interest Bearing Liabilities	12	2,441	10,838
Total Current Assets	•	62,214	53,036
TOTAL LIABILITIES		398,116	338,696
NET ASSETS		1,603,701	1,668,634
ASSOCIATION FUNDS			
Retained Earnings		830,499	824,176
Reserve Funds		158,002	219,260
Net Unrealised Gains Reserve		23,291	33,289
Asset Revaluation Reserve		591,909	591,909
TOTAL FUNDS		1,603,701	1,668,634

The above statement of financial position should be read in conjunction with the full financial report of Muscular Dystrophy SA. A copy of the full financial report is available upon request.

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STATEMENT OF CHANGES IN EQUITY FOR THE YEAR ENDING 30 JUNE 2016

	RETAINED EARNINGS	RESERVES	ASSET EVALUATION RESERVE	NET UNREALISED GAINS RESERVE	TOTAL
Balance as at 1 July 2015	824,176	219,260	591,909	33,289	1,668,634
Total Comprehensive deficit for the year	(54,936)				(54,936)
Transfers To & From Reserves	61,258	(61,258)			-
Other Comprehensive Income				(9,998)	(9,998)
BALANCE AS AT 30 JUNE 2016	830,449	158,002	591,909	23,291	1,603,701

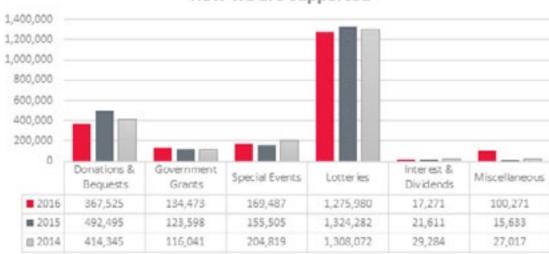
TABLE OF CASH MOVEMENTS FOR THE YEAR ENDED 30 JUNE 2016

	CASH AVAILABLE AT BEGINNING OF YEAR	CASH RAISED DURING YEAR	CASH DISBURSED DURING YEAR	CASH AVAILABLE AT THE END OF YEAR
Muscular Dystrophy SA Operating	556,614	2,052,237	2,072,014	536,836

Statement by Board Members 2015/2016

Financial Report

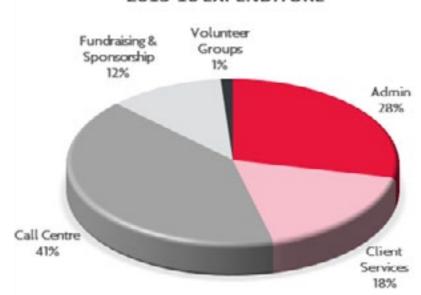




What we financed



2015-16 EXPENDITURE



We, Tim Anderson and Sandra Di Blasio, as members of the Muscular Dystrophy Association Inc. Board advise that in our opinion:

The Statement of Comprehensive Income of the Association presents a true and correct record of the financial results for the year ended 30 June 2016.

The Statement of Financial Position of the Association is a true and fair record of the state of affairs of the Associatron as at the 30 June 2016.

At the date of this statement there are reasonable grounds to believe that the Association can meet its debts as and when they fall due.

In accordance with Section 35 (5) of the Association Incorporation Act 1985, the Board of Muscular Dystrophy Association Inc. hereby states that during the financial year ended 30 June 2016

- a) (1) no officer of the association;
 - (2) no from of which an officer is a member; and
 - (3) no body of the corporate in which an officer has a substantial financial interest, has received or become entitled to receive a benefit as a result of a contract between the Officer, form, or corporate body and the Association.

This report is made in accordance with a resolution of the Board and is signed by 2 members of the Board.

Dated at Adelaide, 30 November 2016

Tim Anderson

Sandra DI Blasio

City of Unley

DI's R Us

Eastern Silk

Equip4Living

Festival Hire

Flight Centre

Furniture Access

Kennards Hire

Kevin Groh

Geoff Merrill Wines

City of West Torrens

CMV Foundation

Coopers Ale House

Coopers Brewery Foundation

Dave Freeman & the Reason

Flight Centre Active Travel

Harley Owners Group SA

Dallas McIntyre - Massage Therapy

Photo Page 2015/2016

Sponsors and Supporters

Patron

The Honourable Hieu Van Le AO

<u>Sponsors</u>

Core Physiotherapy & Pilates Duncan Basheer Hannon

Drakes Foodland Ernst & Young

Five AA Fox Creek Wines

Sammells Financial Services Group -

AMP

SA Road Runners Club

Supporters

Amart All Sports

Adelaide Football Club

Animal Capers Henschke Wines Aria Acoustic Instabooths Baiada Poultry Jetts Fitness

Barossa Fine Foods Beacon Lighting

Bells Fruit Bars Les Brazier Special Vehicles

Beyond Bank Link SA

Beyond India Maggie Beer Products Big Ang Deliveries Mark Lobert Gallery

Bracegirdles Mosaic AV

The Good Guys - Mile End Mt Osmond Golf Club

Budget Truck Hire - Richmond Myer

Bunnings Warehouse - Mile End My Tho City Casablabla Nova Systems Chapel Hill Nu Thai

Charlesworth Nuts

Patti Airbrush Tattooing Choice Pharmacy - Brickworks Philips Respironics

Cibo Cucina Port Adelaide Football Club

City of Charles Sturt Prices Fresh Bakery

City of Holdfast Bay Rockit Out - Dance Group

> Rod Williams Ron Lafferty

> > SA Country Fire Service

SAGE Automation

SANFL

Sarah Cotis Face Painting

Serafino Wines

Snapple Photobooths St Johns Ambulance

Storage King - Windsor Gardens

The Standish Wine Company

Verifire Vinocor

Warren Edwards









MD Ninjas



Client Christmas Party





Golf Day

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Camp Capacity



Camp Capacity

Adventure Challenge Bali



Big Red Ride & Run



Muscular Dystrophy SA 2015/2016 Annual Report

2015/2016 How you can help

The Team

People of Muscular Dystrophy SA

Board

David Anthony - President (resigned AGM 2015) David Noble - President (from November 2015) Tim Anderson

Allan Bretag -Vice President

Sandra Di Blasio - Director of Research

Ianakan Ravindran

Melissa Yule (resigned October 2015)

Simone Douglas (resigned March 2015)

Grant Heading (resigned October 2015)

John Caruso (from September 2015)

Lisa Field (from October 2015)

Sandy Murgatroyd (from October 2015 Resigned April 2016)

Research Committee

Allan Bretag - Chair Tim Anderson Janakan Ravindran Phil Martin Sandra Di Blasio

Finance and Governance Committee

David Anthony - Chair (until October 2015) Sandra Di Blasio - Chair (from October 2015) Rebecca Baines Sandy Murgatroyd (Resigned April 2016) Phil Martin Nadelle Manners

NDIS Readiness

Phil Martin Amber Pyle Phil Kiosses Sarah Pontifex Carol Koehler Esther Cremona

Management Team

Phil Martin
-Chief Executive Officer
Amber Pyle
-Client Services Manager
Sally Curtis
-Fundraising and Sponsorship Manager

Nadelle Manners
-Finance and Administration Manager
Doreen Hooper

-Sales Manager

Bow Tie Bears Volunteer Events

Committee
Janice Phillips (Chairperson)
Maria Catanzariti
Fay Jones
Andrea Redmon
Lorraine Blades
Melva White
Margaret Boylon
Marjory Livingstone
Janet Wedderburn
Jan Haughney
April Francesca
Leanne West

Life Members

Lew Angel [dec]
Thelma Angel [dec]

Del Barber [dec] Helen Blair [dec]

Allan Bretag

Maria Catanzariti Richard Cohn

Beryl Crouch [dec]

Lois Curnow [dec]
Annette Dew [dec]

Andrew Esworthy

Josephine Fuller [dec]

Fay Jones Phill Kiosses

Peter Landers [dec]

Lorraine Leske

Jenny Luscombe Peter Lyons

Janice Phillips

Hilary Rowe

Max Ryan Eric Shearer [dec]

Terrina Simcock
Ann Stanton [dec]

Margaret Tippett

Neil Tippett Merv Turner

NEWS Team

Sam Aforozis
Chantel Bongiovanni
Santo Bongiovanni
Garry Grigg
Jonathan Grigg
Scott Farell
Adam Hart
Jonathon Nguyen

You can help to improve the quality of life for those living with muscular dystrophy in a way to suit you:

- Making a tax-deductible donation either as a once off, or on a monthly basis
- Helping as a volunteer
- Fundraising and raising awareness in your local community
- Making a bequest

Name[,]

Email

• Buying our lottery tickets

If you would like more information on supporting us, our lottery tickets, or about our Association please contact us on (08) 8234 5266.

To buy lottery tickets on line visit http://mdasa.org.au/lottery

For online donations visit www.mdasa.org.au and click on the following icon:



Yes, I would like to make a tax-deductible donation

I enclose my Cheque Money Order Other..... for the amount of \$_____

OR please debit my Visa Master card Amex Diners

Card No: _ _ _ / _ _ _ / _ _ _ / _ _ _ / _ _ _ / _ _ _ / _ _ _ / _ _ _ / _ _ _ _ / _ _ _ / _ _ _ / _ _ _ / _ _ _ / _ _ _ / _ _ _ / _ _ / _ _ / _ _ _ / _ _ _ / _ / _ _ / _ _ / _ _ / _ _ / _ _ / _ _ / _ _ / _ _ / _ _ / _ _ / _ / _ / _ _ / _ / _ _ / _ / _ _ / _

Phone: Mobile:

Expiry: _ _ / _ _

Address:

Cardholder's Name:.....

Please accept my one off tax deductible gift for: \$30.00 \$50.00 \$100.00 My Choice of: \$

OR I'd like to make a regular tax deductible donation

Quarterly Monthly Fortnightly Other

Of the following amount:

\$30.00 \$50.00 \$100.00 My Choice of: \$_____



The Muscular Dystrophy Association Inc is a tax deductible gift recipient. Cheques should be made payable to Muscular Dystrophy Association Inc—a receipt will be sent to you. Please return to: Muscular Dystrophy Association Inc, Reply Paid 24, TORRENSVILLE PLAZA SA 5031

Thank you, your donation no matter how large or small will help make a difference.



36-38 Henley Beach Road MILE END SA 5032

PO Box 24 TORRENSVILLE PLAZA SA 5031

Tel: (08) 8234 5266 Fax: (08) 8234 5866 Email: info@mdasa.org.au Web: www.mdasa.org.au