



MUSCULAR DYSTROPHY
SOUTH AUSTRALIA



EMBRACING



PASSIONATE



INNOVATIVE



DETERMINED

2014/2015 Annual Report

MISSION:
Promise for Today



MUSCULAR DYSTROPHY
SOUTH AUSTRALIA

VISION:
Help for Today and Tomorrow

VALUES:
Determined - Passionate - Embracing - Innovative

Muscular Dystrophy SA is the premier organisation supporting children and adults with neuromuscular conditions.

We provide essential services such as therapies, respiratory aids and advocacy.

Muscular dystrophy is a progressive wasting of the muscles. It affects 1 in 1,000 people.

There is no cure.



President's Report

2014/2015



David Anthony - President

Seems that, when reflecting on the year, I have to say, yet again, it has been a challenging time for our organisation.

Certainly, from a financial perspective, it has been a tough year. I do believe, however, that as an organisation, we are continuing to see real improvements in what we are really here for, and that is providing the necessary services to our community.

I believe we also now have a better understanding of the NDIS, how it works and, more importantly, how we can help our clients and their families and support networks negotiate their way through the formalities so that they gain the maximum benefit from this system. I am also certain that we all have a long way to go in this area.

This year's financial result is, to say the least, disappointing. It is a culmination of a large section of the general community finding life difficult and uncertain and, often for similar reasons some of our fundraising events have struggled to meet their targets.

Having said that, Muscular Dystrophy SA is still in a financially strong position with cash reserves remaining at about 1/2 million dollars.

The Management and the Board have taken significant steps to address the issues of revenue and costs. They have also begun moves to raise the profile of Muscular Dystrophy SA as part of a revised strategy to attract more corporate support and so spread the financial risk across a broader base.

In addition after many years of little activity in the area of research, a blueprint for raising funds and encouraging research, hopefully in Adelaide is underway.

Once again I have to say that the level and pace of change at Muscular Dystrophy SA is, in my experience, almost unprecedented for an organisation of its size.

Credit must go, therefore, to the Management and staff of Muscular Dystrophy SA who have embraced each challenge over the past few years and tackled these issues with application and passion. Of course there has been some vigorous discussion on many aspects of this work, but the ability of all involved to work at improving outcomes, both from a financial and client service delivery point of view has been significant.

The Client Services team, lead by Amber Pyle, has worked hard all year to improve their knowledge of client needs so that they can, more efficiently and effectively, meet those needs. In this area in particular,

client and family feedback is always welcomed.

In a tightening and crowded market Stephanie Columbus and Christine Mikalainis and their teams have been refining their current fundraising approaches and exploring new ways of raising funds. A re-formed Marketing sub-committee has already provided valuable feedback on several projects that should provide insight and added value in this and coming years.

Janet Lee and more recently Nadelle Manners and their team have continued to improve our financial systems and controls. I think it is fair to say that Nadelle in particular has provided help and guidance to the Management team to enhance activity analysis and reporting.

This helps answer one of the most important questions for any business - what makes you the money? We should remember that it is the business aspect of Muscular Dystrophy SA that enables us to deliver services to our clients.



MD Ninja

President's Report

2014/2015

Our CEO Phil Martin has again been at the forefront of meeting the challenges facing the organisation. He has successfully facilitated better ways to deliver services, streamline internal processes and networked diligently at industry and government levels.

In addition, he and fellow Board member Sandra DiBlasio, have continued their valuable work at a national level in an effort to make the Muscular Dystrophy Foundation a strong and unified voice. That work continues and the progress in the past 12 months has been significant.

Our volunteers are a group without whom we would not function as we do. Long hours doing often tedious tasks of enveloping, folding letters and running BBQs assist us greatly each year.

Lastly I would like to thank the Board, all of whom have other pressing matters in their lives, but who, on a regular basis, put in valuable hours each month and often during the intervening time as well. They have the ability to look beyond the day to day issues and assist the Management to develop strategic plans to ensure the future success of Muscular Dystrophy SA. It makes them yet another vital group in the team at Muscular Dystrophy SA.



Grown Ups Getaway 2014



Barossa Marathon



Camp Capacity 2015

CEO's Report 2014/2015



Phil Martin - CEO

Throughout the 2014/15 financial year we continued to work within the unprecedented changes occurring in the Australian Disability Sector. We continue to work closely with the National Disability Insurance Agency and Department for Community and Social Inclusion as the 'trial' site in South Australia progressively grows and increases in relevance and opportunity for our client group. While considering the implications and forward planning necessary to thrive in this changing environment we have maintained our commitment to improving the quality of life of all people living with a neuromuscular condition.

During the year we consulted extensively with clients and families through questionnaires and workshops. The outcomes of these sessions now form a solid basis as key pillars of our strategic objectives in services and research. This Annual Report highlights the many areas of community support that Muscular Dystrophy SA provides the South Australian muscular dystrophy community. Through the generous contributions of our supporters we have been able to expand the scope of services.

The introduction of the Duke of Edinburgh award program, in conjunction with Muscular Dystrophy NSW, as part of a world leading national initiative has generated much excitement and fantastic opportunities for many of our young clients.

The continued popularity of 'Camp Capacity' and the positive outcomes for the camp are fantastic to see. The growth of our Support Groups is a welcome addition to our client initiatives. These Support Groups also provide a great opportunity for all employees to meet clients and families. It is both humbling and inspiring to see the courage and passion our clients bring with them.

We are indebted to over 100 volunteers who make such a big impact on our organisation through events, lottery support and administration assistance.

Our Marketing and Fundraising team continues to ensure that our lotteries and events generate revenues to support the work of the Association. In the current economic climate this has required considerable flexibility and resourcefulness to ensure our services can continue to grow and meet client needs. Fundraising and events require major sponsors and we are thankful to the committed organisations that help ensure the success of our Fundraising and Client Services activities.

The high level of service and support we provide to people with a neuromuscular condition is only possible because of the passion and dedication of our highly professional

and skilled staff and volunteers as well as their commitment to ensuring we make a real difference to the lives of our clients and families. In addition to the changes within the NDIS we are experiencing greater regulatory requirements through state and federal agencies such as DCSI. Our Finance and Administration team continue to ensure we meet these standards and streamline our processes.

We remain committed to a research strategy which is planned to include local, national and international commitments. Our preliminary work with UniSA, SAHMRI and local businesses is planned to build on and compliment work with the Australian Neurological Network and NHMRC to conduct collaboration research initiations across the country.

Through our partnership in Muscular Dystrophy Foundation we have been pleased to develop and implement a single client database for a majority of states and territories. This builds on our need to have empirical quantifiable and accurate data to support advocacy, research and lobbying at a state and national level. The Muscular Dystrophy Foundation provided funding for the development and implementation of the system.

I would also like to thank our Board and Sub-Committee members who continually give their time, resources and expertise to ensure Muscular Dystrophy SA is well prepared to meet our goals of greater services and supports to more people and a more significant involvement in world leading research to improve clinical practice and strive to find a cure.

Client Services Report

2014/2015



Amber Pyle - Client Services Manager

The 2014/15 period has been one of development and expansion for the Client Services team. A significant focus has been on improving client interface and social supports available to our clients. This was in response to results obtained from the client needs survey sent out to over 300 clients in 2014. Whilst this focus continues into 2015/16 there has been some marked achievements with meeting these outcomes during 2014/15.

The Client Services team continues to remain abreast of developments and rollout of the National Disability Insurance Scheme, attending workshops, NGO forums and seminars to obtain up to date information and provide feedback on the scheme development.



MD Ninjas 2015

Whilst significant concerns surround the future success of the NDIS, Muscular Dystrophy SA's families and clients have been satisfied with the supports provided to them through established individualised plans for support.

Full rollout of the scheme will have significant impact on Muscular Dystrophy SA clients. Hence as an organisation, developing a supportive, trusting relationship with clients is imperative to providing clients with an avenue to have their voices heard and needs addressed when developing their plan of support through the scheme. Increasing client interface through a variety of means is a way of working towards achieving this outcome.

Embracing

Client interface is conducted through, but not limited to, face to face case management contact, Support Groups, recreational activities, remote communication (usually via email or phone), social media and therapy intervention.

In July 2014 monthly client contact was recorded at 70 clients and in June 2015 client contact had increased to 143. This was a combination of increased client access to services and also improved data recording.

The Family Christmas Party held on Saturday 29 November 2014 at the Goodwood Community Centre had over 140 clients, families, carers, volunteers and supporters attend the event. One of the highest recorded attendance numbers for this event.

Passionate

Support Groups have seen a significant increase over this financial year with an additional three Support Groups commencing. These include the MD Ninja's a group for children aged 7-14 diagnosed with a neuromuscular condition, the Myotonic support group and the Myasthenia Gravis support group. This brings a total of eight Support Groups running at various frequencies throughout the year, with over 75 different clients accessing these groups.

These Support Groups are developed in line with identified needs of the participants and frequency and facilitation of each group can vary significantly.



Support Group

Grown Ups Getaway (GUG) was held at Victor Harbor Beach-front Holiday Park; 14 clients attended with 5 carers. This was the first time this venue had been used as a GUG location. Each year Client Services endeavours to find alternative accessible accommodation that meets the criteria for GUG attendees.

Camp Capacity recorded a total of 48 campers and siblings attending the event with a further 34 full time carers for support. The event was again held at the Mylor Baptist

Client Services Report

2014/2015



Camp Capacity 2015

campsite, due to its high number of wheelchair accessible rooms and on site program support and facilities.

2015 Camp Capacity theme was 'Superheroes & Secret Surprises', with campers enjoying a week of superhero challenges and activities.

Innovative

A milestone development has been preparation for implementation of a new client database which is being developed by Community Database Solutions a database developer with a focus on the needs of not for profit charities like Muscular Dystrophy SA. Historically the previous database has provided limited access to accurate client data making grant applications and advocating client needs difficult and time consuming.

The new database will allow for national statistical data to be securely stored and utilised for advocating on behalf of all individuals living in Australia with a neuromuscular condition. This will vastly improve the Client Services team's ability to support individuals living with a neuromuscular condition as the capability of the database will allow for better recording and a higher level of information available for improved service provision.

Full implementation of the database will take place over a three month roll out period and will involve extensive updating and uploading of client information and additional service related data.

Determined

The Client Services team continues to develop and expand services and supports to clients, their families and carers. Introduction of the Duke of Edinburgh Scheme has seen young clients, including those with high care needs, register to complete this life changing award scheme.

Continuation of supports such as the buddy up program, therapies and recreational activities help to improve the relationship between the organisation and the clients who access it.

Increased use of social media has also enabled new avenues of communication between the Client Services team and clients. Social media has also assisted greatly in the promotion of client specific services and events.

Community awareness of the organisation and the services it provides to clients continues to develop through social media, partaking in community events, working in collaboration with other not for profit organisations and increasing client presence at internal fundraising events.



MD Mafia



N.E.W.S. at the Big Red Ride & Run



Camp Capacity 2015



Grown Ups Getaway 2014

Finance and Administration Report 2014/2015



Nadelle Manners - Finance and Administration Manager

This financial year has been one of change for the Finance and Administration team with the addition of new staff and the inception of new processes to streamline our department. Change is always challenging and I would like to thank the Finance and Administration team for their time and great effort during the course of the year.

The Financial Year ended June 30, 2015 saw Muscular Dystrophy SA dealing with many of the same financial challenges that other sectors of the SA economy have had to face. Our lead challenge has been dealing with a down turn in expected revenue across our varied fundraising activities while balancing this with the rising cost of raising funds.

Our attention as such has been dedicated on shoring our financial stability in an uncertain economic climate, timely reporting, as well as greater reviews of each of our fundraising strategies, all the while ensuring that our focus remains on the provision of quality services for our clients.

As in previous years, our revenue is predominantly (94%) obtained by the fundraising activities conducted by Muscular Dystrophy SA and our supporters. Our organisation wishes to thank our diligent supporters who have invested their time, energy and finances in supporting Muscular Dystrophy SA. With your help, Muscular Dystrophy SA has been able to raise total revenue exceeding \$2.13 million. This was assisted by volunteers contributing in excess of 1434 hours, an estimated \$29,000 of in-kind support. Thank you.

In 2014/15 Muscular Dystrophy SA was blessed by the provision of over \$90,000 in Bequest Funds. These funds have been specifically earmarked for use in providing services to our clients over the next couple of years. Thank you to the families who have provided this support.

The financial changes our organisation faces with the introduction of the National Disability Insurance Scheme has led us to a review of where we sit financially in light of the proposed changes. Currently 6% of Muscular Dystrophy SA's revenue is provided by bulk funding from the Department of Community and Social Inclusion and this continues to benefit our Client Services department with being able to provide much needed therapies, counselling and social support.

The proposed Federal changes will impact our organisation and over the coming years we will see a decline in this bulk funding. However, with this change comes opportunity. Our Client Services and Finance teams are in the process of researching ways in

which we can assist clients in securing funding for the areas in which our organisation has maximum impact on their wellbeing.

I for one am looking forward to the opportunities that the next financial year will bring and am grateful for the team that I get to share the work with.



Camp Capacity 2015



Adventure Challenge 2014



Grown Ups Getaway

Fundraising & Marketing Report 2014/2015



Stephanie Columbus - Marketing & Fundraising Manager

The past twelve months have been a roller-coaster ride for the Marketing and Fundraising team. 2014/2015 saw many highs, but we also faced many challenges as we worked to raise funds to support client outcomes.

Corporate support is always welcome and we were pleased to have the continued support of Baiada Poultry, Core Physiotherapy and Pilates Studio and Jetts Fitness.

We continue to develop beneficial relationships with councils, community and sporting groups, including SA Road Runners club, City of Holdfast Bay and Adelaide City Rotoract – who have all contributed to the success of our events in different, worthwhile ways. Whether these organisations join us as an event partner, supply us with volunteers or provide incentive prizes – we are incredibly grateful for their support of our organisation.

Despite a difficult economic climate, the Marketing and Fundraising team works tirelessly to try to reach projected budgets to continue to

provide essential services to children and adults living with a neuromuscular condition.

Passionate

In our mission to promote our organisation and educate the public about neuromuscular conditions, we encouraged our supporters to 'put their muscles behind muscular dystrophy'.

Throughout the year, we recruit supporters to participate in our 'Muscle Team' – a dedicated group of active, passionate fundraisers for Muscular Dystrophy SA. In 2015, we introduced an additional website – www.mdmuscleteam.org.au – to work as a platform for this fundraising. The Muscle Team website is now a hub for all of our community and peer-to-peer fundraising.

Barossa / Adelaide Marathons

With the support of SA Road Runners Club, Muscular Dystrophy SA serves as the charity partner of both the Athlete's Foot Adelaide Marathon and Jacob's Creek Barossa Marathon Festival.

Throughout the year, over both events, we were able to encourage over 450 participants to register to fundraise with the Muscle Team. When combined, these events raised over \$50,000 through participants' fundraising!

Our friends from Core Physiotherapy and Pilates Studio joined us at both events, to provide well-deserved massages to our fundraisers.

Many thanks must go to our volunteers, including representatives

from Jetts Fitness, who came along to marshal for the Adelaide Running Festival. Jetts also provided us with a double-branded marquee with both Jetts and Muscular Dystrophy SA logos which has proved very useful for a number of events.

Big Red Ride and Run

Proudly sponsored by the City of Holdfast Bay, the fourth annual Big Red Ride and Run was held on Saturday 17 January 2015. This year, we were joined by over 500 riders and runners, who took on either the ride course from Glenelg to Outer Harbor or a 5km/10km run.

A big thank you to Brad McGee who returned as our ambassador, and brought along members of the UniSA team who lead the pack of riders. In 2015, we also saw a big growth in the number of runners who joined us for the event.

We were pleased some of our clients were involved at this event, with members of our NEWS team putting on a demonstration of wheelchair sports for the participants.

Our vibrant event village hosted entertainment from Aria Acoustic, a bouncy castle, coffee from Cibo



Big Red Ride & Run

Fundraising & Marketing Report

2014/2015

Espresso Glenelg, sweet treats from the Honey-puff Ladies and a barbecue from Glenelg Rotary. Thanks must go to event sponsor 5AA for providing emcee Leith Forrest and radio advertising leading up to the event.

We are also grateful for the support of event sponsors Fox Creek Wines, Amart Sports, Sammells Financial Services, Duncan Basheer Hannon, Drakes Supermarkets and Steggles. As this event is first and foremost a fundraiser, we were encouraged to see an increase in the total amount raised by our Muscle Team participants.

This event would not be possible without the support of all of our hard-working volunteers, in particular event committee members Kevin Gruhl, Rod Williams, Ron Lafferty and Stephen Sabine.

Embracing Multicultural Feast

This year's event attracted a record number of guests, who enjoyed cuisine from Beyond India, Nu Thai, From Orient, Hello Dolly, Casablaba and delicious yiros prepared by 2014 Adventure Challenge Participant Sam Koulianos, with chicken donated by Baiada Poultry.

Our guests were treated to a live bagpipes performance from Ollie Von



Multicultural Feast 2015

Doussa from the Scotch College Pipe Band and entertainment from Aria Acoustic. Organisation ambassador Mark Aiston was an engaging host and Stephen Venn conducted a successful live auction.

This event would not have been possible without the help of a troupe of hard-working volunteers who worked tirelessly to prepare and serve food.

Determined Golf Day Challenge

Fortuitously, the 2015 Golf Day Challenge was blessed with magnificent autumn weather, as over fifty players joined us for an Ambrose competition at Glenelg Golf Club on 1 May. Our Golf Day Challenge continues to strengthen our relationships with the corporate sector with many teams and businesses embracing our organisation's cause and returning year after year.

Fox Creek Wines generously provided all of the wine for the day, on course and at luncheon, for which our weary guests were very grateful.

We would like to also recognise Karl Francis for his ongoing support of this event.

Innovative Muscle Team Adventure Challenge

In 2014, nine dedicated and passionate individuals took on the challenge to each raise \$10,000 for Muscular Dystrophy SA – and succeeded wonderfully! Together, with sponsorship from Baiada Poultry and Sammells Financial Services, our Adventurers raised \$150,000.



Adventure Challenge 2014

As their reward, the Team were treated to a five day trip full of surprises to the Sunshine Coast. Their journey was documented in collaboration with Troy Gray from Vox Ventures, and a documentary was aired on Channel 7 in February.

Thanks to our other sponsors Fox Creek Wines, Drakes Supermarkets, Main Freight Distribution and our many suppliers.

Sugar Free January

In the spirit of promoting health and wellness to our clients and the broader community, in 2015 we introduced the inaugural Sugar Free January.

Using social media, we encouraged clients and the public to make healthier food choices and give up sugar for the month of January. Participants paid a sign-up fee and then fundraised on behalf of Muscular Dystrophy SA.

We received wonderful feedback from participants, in particular from a number of clients who experienced the health benefits as a result of going sugar free!

Lotteries

Muscular Dystrophy SA would not

Fundraising & Marketing Report 2014/2015

be able to provide the level of services that it does without the significant revenue raised from our major lotteries throughout the year. Thank you to those supporters who have continued to purchase tickets in our lotteries, in particular our VIP members who commit to supporting our organisation on a regular basis.

The Lotteries team continues to strive to meet targets. I would like to express my gratitude to the hard-working Lotteries team, led by Chris Mikalainis, who work tirelessly to raise this revenue for our organisation.

Donations

We conduct four letter appeals each year and in 2014/2015, these campaigns raised over \$60,000 for our organisation.

We also distribute over 100 collection boxes throughout the community, which continue to raise significant revenue. Thanks to Janice Phillips for her co-ordination of this campaign, and her team of volunteers, especially Maryann McPhee.

Finally, I would like to extend my appreciation to Lucy Russell Byrne and Nicole Anderson for their tireless commitment and dedication to the organisation.

Though we continue to face a number of challenges in the Marketing and Fundraising department, we are committed to meeting these challenges with a positive and can-do attitude.

We look forward to exploring new opportunities and expanding existing projects in 2015-2016.



Golf Day 2015



Adventure Challenge 2014



Big Red Ride & Run 2015

Bow Tie Bears Volunteer Events Committee

2014/2015



Janice Phillips - Chairperson of the Bow Tie Bears Volunteer Events Committee

I am pleased to present to the Bow Tie Bears Volunteers Events Committee Report for 2014/2015.

The 'Bow Tie Bears', as we are affectionately known, are a dedicated group of 13 women who work together tirelessly to raise funds that directly support Clients of Muscular Dystrophy SA. With the guidance of the Client Services team we have allocated the funds raised to various items and services that otherwise would be unavailable to clients of Muscular Dystrophy SA.

Again this year our most successful fundraising initiative has been the making and selling of our beautiful range of hand knitted baby items. We also specialise in sewing and quilted items, all hand made by the committed and talented Committee members and friends of the Bow Tie Bears.

Throughout 2014/2015 we held stalls at the April Gift and Craft Fair (3 days), ABC Gardeners Market (2), Salisbury Craft Fair and the very popular Xmas Craft Fair. Our many stalls are attended by thousands of

people and this increases awareness of neuromuscular conditions and Muscular Dystrophy SA.

We held a 'Diamond Raffle' to celebrate 60 years of Muscular Dystrophy SA. First prize was a diamond ring that was kindly donated. We were the lucky recipients of the funds raised from an afternoon tea held at an Open Garden in Nairne. This day was organised by one of our loved Committee members, Joy McLean, who sadly passed away not long after.

Throughout the year The Bow Tie Bears have allocated the following funds:

- \$5000 to Camp Capacity 2015 and the running of the craft workshop
- \$2000 to Clients Xmas Party 2014
- \$600 for the purchase of a long life battery that enabled a client to leave home
- \$375 to relocate audio/visual equipment, which is regularly used, by the MD Mafia and the MD Ninjas
- \$600 for prescription glasses for a client
- \$600 for wheelchair/lifter friendly marine carpet for a young client

The Bow Tie Bears Volunteer Events Committee have worked diligently throughout the year to raise funds that will enrich the lives of children and adults who live everyday with a neuromuscular condition, and have thoroughly enjoyed every moment of their fundraising.

The Bow Tie Bears would like to thank our friends who have strongly supported us with their donations of craft, produce, time and energy throughout the year.

A big thank you must go to Rikki and Storage King, Windsor Gardens for their ongoing support with their offer of an accessible solution to our storage problem.

We would also like to thank Phyl Turner who recently retired from the Committee after many years of dedicated voluntary hours.



Bow Tie Bears



Bow Tie Bears



Bow Tie Bears

Research Report

2014/2015



Alan Bretag - First Vice President
Director of Research

It is always a pleasure to report that neuromuscular disease (NMD) research is continuing at an ever increasing pace around the world and that we can derive hope from developments in understanding the disease processes and from promising clinical trials for many different NMDs. This year I have attended the 14th Annual Scientific Meeting of the Asian and Oceanian Myology Centre held in Bangkok, in March. As usual, it was 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 in developing countries. Briefly, there was an emphasis on genetically determined myasthenic NMDs where communication from nerves to muscles is disrupted causing muscle weakness.

Importantly, treatments are now available for many of these particular diseases. Some of you may have seen a TV report on "New Generation Sequencing" recently, in which a boy with an NMD, but no genetic diagnosis, was at last, using this new method, discovered to have a treatable myasthenic NMD. A number of NMDs caused by auto-immunity were also

presented with many of them also now being treatable. As well, there were updates on disease registries and on some clinical trials. In Japan, the REMUDY (Registry for Muscular Dystrophy) database contained, already in March, 1,454 names of boys and men with Duchenne and Becker muscular dystrophy (DMD and BMD) who would be available for clinical trials.

Unfortunately, I was unable to attend the 20th International Congress of the World Muscle Society held in Brighton, UK, a couple of weeks ago. Just a few highlights from this meeting can be reported because of the time it takes to read and digest the huge amount of written information provided to those unable to attend in person. Of particular interest, are completely new approaches to therapies for limb girdle muscular dystrophies (LGMDs) and for facio-scapulo-humeral muscular dystrophy (FSHD), these involve recently-discovered modulators of the immune system.

Updates on a number of early stage clinical trials in other NMDs were presented, generally showing that newly-developed drugs have a low incidence of side effects, or none at all, but that biomarker levels are increased. Biomarkers are proteins or other substances that are typically associated with function so that, when they are sufficiently increased, a decrease in disability (increase in performance) can be expected. For example, the usual biomarker for muscle function in DMD is the dystrophin level in muscle. New or extended clinical trials of drugs for DMD, Spinal Muscular Atrophy (SMA) and other diseases were also presented. I hope to be able to report more on these at a later date.

I must again, however, raise some notes of caution. Media accounts always refer

to "breakthroughs" and often medical and scientific journals also resort to using statements like "complete amelioration" with respect to serious diseases like NMDs. Careful reading of these accounts usually discovers that the advance referred to has been made only in an animal model of a human disease or even only in cells in tissue culture and then that only some small aspect of the dysfunction has been rectified.

Another caution relates to press releases that claim "statistically significant improvements" compared to untreated subjects. Often these "improvements" still amount to substantial deterioration, hardly less than would occur without treatment. Finally, a further caution regarding "stem cells": a major Australian NMD organisation has recently provided a large grant to an Australian stem cell company with considerable associated publicity. The particular company claims to have diseased embryonic stem cells in tissue culture available for the testing of different therapeutic agents. Independent assessment of these diseased stem cells is necessary and is said to be under way.

Meanwhile, reputable research updates on most individual NMDs are available on websites maintained by official NMD organisations including MDA USA and TREAT-NMD, I can be contacted through Muscular Dystrophy



Grown Ups Getaway 2014

Research Report 2014/2015

SA's Client Services for specific information.

For many years, Muscular Dystrophy SA has not funded NMD research for a variety of reasons, including, (1) difficulty in justifying the directing of funds to research compared to the necessity for maintaining and improving client services, and, (2) failure to attract research proposals of sufficient merit given the low level of funds available in Muscular Dystrophy SA's Research Foundation. A visionary plan to initiate appropriate research and to encourage significant donations towards research had also been lacking. As mentioned in the reports from both our CEO and our President, elsewhere in this Annual Report, Muscular Dystrophy SA's Board has put in a considerable effort in the last year to address these issues. Personally, I have placed two proposals before the Muscular Dystrophy SA Board.

Firstly, I suggested that any researchers presently working in an appropriate research field in South Australia be approached to see if they might wish to undertake relevant Muscular Dystrophy SA-funded research. One group at the University of South Australia that has expertise in the diagnosis of extremely rare and previously undiagnosed genetic diseases expressed interest. As a result, a Memorandum of Understanding between Muscular Dystrophy SA and the University of South Australia has been signed in



Big Red Ride & Run 2015

anticipation of receiving an application to fund relevant research. In this regard, a recent Adelaide newspaper article highlighted the anxieties faced by the parent of a four year old child with an as yet undiagnosed neuromuscular disease. Our Board has felt that, although it would consider interstate or international research, if possible, Muscular Dystrophy SA's funded research should take place in South Australia. This would be more likely to attract ongoing and future support from local donors and corporate sponsors, a view reinforced by advice we have received from the South Australian Health and Medical Research Institute (SAHMRI).

Secondly, I outlined a vision for an integrated NMD clinic/research facility to be located within Adelaide's new western North Terrace health and medical precinct (expected to include SAMHRI, the new Royal Adelaide Hospital, the University of Adelaide's new Medical, Dental and Nursing School, the University of South Australia's new Health Innovation Building, the proposed new Women's and Children's Hospital, and perhaps others). Integrated facilities of this kind already exist in some interstate and many overseas centres. This is, however, a complex issue for us that will require careful consideration and planning by Muscular Dystrophy SA Board.

Very likely, lengthy negotiations, considerable lobbying and massive fundraising will be needed, if it is ever to be achieved. Currently, Muscular Dystrophy SA's fundraising and lobbying is based on the plight of children with NMDs, but far more adults than children in the population live with an NMD. Our Board's view is that if Muscular Dystrophy SA was fully able to utilise the relevant skills, initiatives



Camp Capacity 2015

and drive of its clients who are adults with NMDs, as well as, parents of children with an NMD, and their families and carers, it could benefit enormously, as does the French MDA.

It has recently been suggested by a client that "Capital Raising" for research would be more likely to be acceptable to high-end donors than "General Fundraising". Our Board is seriously considering this proposal as part of its vision for the future. The Capital Fund would have to be promoted as existing purely, solely and for no other purpose than to support an integrated NMD clinic/research facility, or to fund NMD research, through income derived from its investments. It would need to be demonstrated that 100% of tax deductible donations received would go either to the capital fund or directly to NMD clinic/research activities and that any funds required for administration would be both minimal and raised by other means and through the efficient use of volunteers. Other Australian and international NMD organisations manage to do this.

As always, your comments and questions are welcome.

Summarised Statement of Surplus or Deficit and Other Comprehensive Income For the Year Ended 30 June 2015

INCOME How we are Supported	2015	2014
	\$	\$
Bequests	90,610	26,318
Donations/Appeals	401,885	388,027
Government Grants	123,598	116,041
Interest & Dividends	21,611	29,284
Miscellaneous	15,633	27,017
Lotteries/Raffles	1,324,282	1,308,072
Special Events	155,505	204,819
TOTAL INCOME	2,133,124	2,099,577
Less EXPENDITURE		
Depreciation & Amortisation	52,715	39,260
Bank Charges	20,826	17,215
Special Events	91,225	89,504
Lotteries	314,444	322,617
Wages & Oncosts	1,250,000	1,151,165
Consultants	68,458	81,820
Finance Costs	4,026	0
Other	332,045	374,191
TOTAL EXPENDITURE	2,133,739	2,075,773
NET SURPLUS/(DEFICIT)	(615)	23,805
add OTHER COMPREHENSIVE INCOME		
Net fair value gain/(loss) on available-for-sale financial assets	7,874	32,681
Fair Value revaluation of land & buildings	(60,805)	
TOTAL COMPREHENSIVE SURPLUS/(DEFICIT)	(53,546)	56,486

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

2014/2015

Summarised Financial Position - As at 30 June 2015

ASSETS	NOTES	2015 \$	2014 \$
Current Assets			
Cash & Cash Equivalents	2	556,614	545,550
Trade & Other receivables	3	61,232	42,657
Inventories	5	12,316	14,036
Total Current Assets		630,162	602,243
Non- Current Assets			
Available-for-sale Financial Assets	6	199,960	192,085
Trade & Other Receivables	4	3,864	19,326
Property, Plant & Equipment	7	1,142,146	1,155,230
Intangibles – Software		31,197	27,508
Total Current Assets		1,377,166	1,394,149
TOTAL ASSETS		2,007,330	1,996,392
LIABILITIES			
Current Liabilities			
Trade & Other Payables	8	162,854	156,127
Employee Provisions	9	113,915	81,792
Interest Bearing Liabilities	11	8,891	0
Total Current Liabilities		285,660	237,919
Non Current Liabilities			
Employee Provisions	10	42,198	36,293
Interest Bearing Liabilities	12	10,838	0
Total Current Assets		53,036	36,293
TOTAL LIABILITIES		338,696	274,212
NET ASSETS		1,668,634	1,722,180
ASSOCIATION FUNDS			
Retained Earnings		824,174	1,044,051
Reserve Funds		219,260	0
Net Unrealised Gains Reserve		33,289	25,415
Asset Revaluation Reserve		591,909	652,714
TOTAL FUNDS		1,668,632	1,722,180

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.

STATEMENT OF CHANGES IN EQUITY FOR THE YEAR ENDING 30 JUNE 2015

	RETAINED EARNINGS	RESERVES	ASSET EVALUATION RESERVE	NET UNREALISED GAINS RESERVE	TOTAL
Balance as at 1 July 2014	1,044,051	0	652,714	25,415	1,722,180
Total Comprehensive deficit for the year	(615)				(615)
Transfers To & From Reserves	(219,260)	219,260	(60,805)	7,874	(52,931)
BALANCE AS AT 30 JUNE 2015	824,176	219,260	591,909	33,289	1,668,634

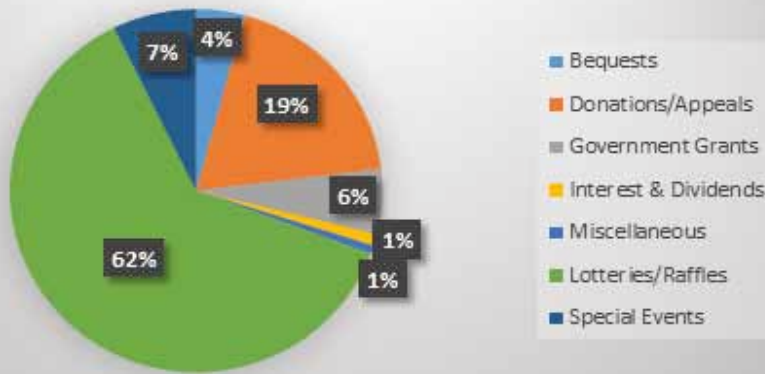
TABLE OF CASH MOVEMENTS FOR THE YEAR ENDED 30 JUNE 2015

	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	545,550	2,130,011	2,118,947	556,614

Financial Report

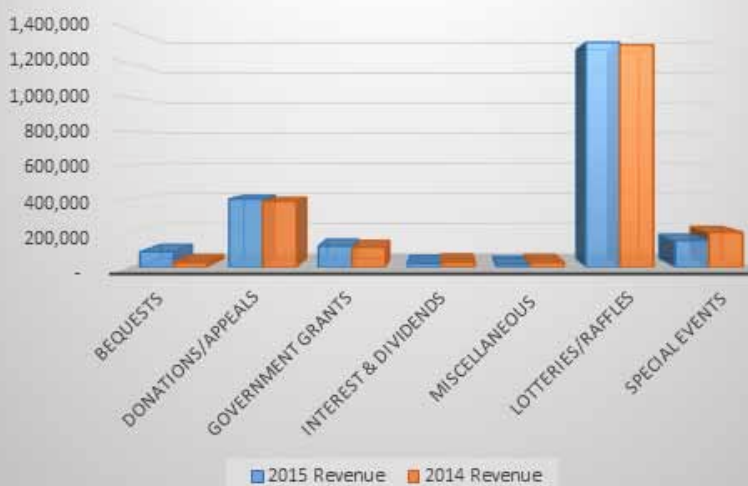
2014/2015

2015 Total Revenue *How we are Supported*



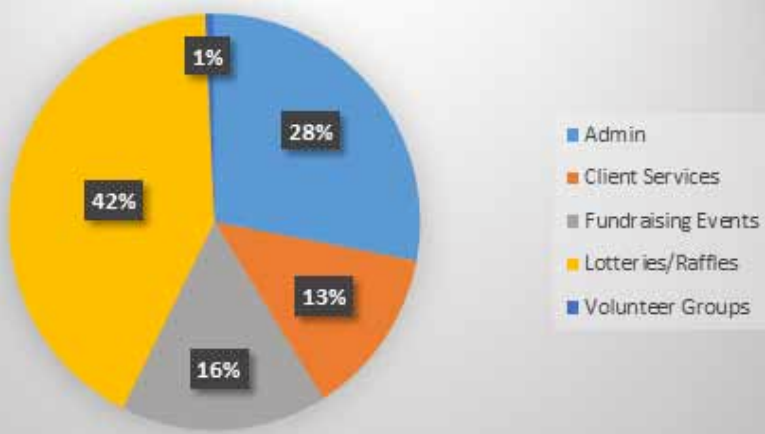
The pie chart illustrates the various sources of income received by Muscular Dystrophy SA over the course of the 2015 financial year. 88% of income is generated from the generous giving of our fundraising supporters, be it by the purchase of a lottery ticket, fundraising for an event, responding to an appeal or regular/one off donations. Thank you for your generosity.

MDSA COMPARATIVE REVENUE



Our total 2015 revenue increased slightly from 2014. Adjacent is a graphical representation of the revenue change on each of our different revenue sources.

2015 EXPENDITURE



Our aim in future years is to ensure that we maximise our frontline by providing additional resources to clients, all the while looking at ways where we can minimise the cost of raising funding.

Statement by Board Members
2014/2015

Statement by Board Members

We, Sandra Di Blasio and David Anthony, as members of the MDA Inc Finance Committee advise that in our opinion:

The Income and Expenditure Statement of the Association presents a true and correct record of the financial results for the year ended 30 June 2015.

The Balance Sheet of the Association is a true and fair record of the state of affairs of the Association as at the 30 June 2015.

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 2015

- a) (1) no officer of the association;
- (2) no firm 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, firm, 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, 27 October 2015

  , 27 October 2015

Sandra Di Blasio

David Anthony

Sponsors and Supporters

2014/2015

Patron

The Honourable Hieu Van Le AO

Major Sponsor

Sammells Financial Services Group - AMP

Sponsors

Cibo Espresso

Core Physiotherapy & Pilates

Duncan Basheer Hannon

Drakes Foodland

Ernst & Young

Five AA

Fox Creek Wines

Myer

SA Road Runners Club

Supporters

Adelaide Football Club

Amart All Sports

Anthony's Confectionery

Barossa Fine Foods

Bells Fruit Bars

Beyond Bank

Beyond India

Big Ang Deliveries

Brooksy's Good Guys

Budget Truck Hire - Richmond

Bunnings Warehouse - Mile End

Cannon

Caruso's Fresh Foods Glenelg

Casablaba

Chapel Hill

Charlesworth Nuts

Chemplus

Cibo Cucina

City of Charles Sturt

City of Holdfast Bay

City of Unley

City of West Torrens

Coca Cola

Craig Anthony Entertainment

Dallas McIntyre - Massage Therapy

Dave Freeman & the Reason

Duncan Basheer Hannon

Eastern Silk

Edible Blooms

Enable College

Equip4Living

Festival Hire

Flight Centre

Flight Centre Active Travel

From Orient

Furniture Access

Geoff Merrill Wines

Glenelg Golf Club

Harley Owners Group SA

Henschke Wines

International Linen Service

Instaboosts

Kennards Hire

Kiwanis Clubs of Adelaide

Les Brazier Special Vehicles

Link SA

Maggie Beer Products

Mark Lobert Gallery

Mosaic AV

Mt Barker Hahndorf Golf Club

North Adelaide Football Club

Nu Thai

Pauls Cartoons & Caricatures

Pirramimma Wines

Plympton Steel

Port Adelaide Football Club

Prices Fresh Bakery

Pulteney Grammar School

Rebel Sport

Rockford Wines

Romeo's Foodland Magill

Rotoract Adelaide City

Sarah Cotis Face Painting

Serafino Wines

Steve Presto - Magician

St Johns Ambulance

Supreme Sausages

Technical Aid for Disabled (TADSA)

The Standish Wine Company

Verifire

Vinocor

Wallaroo North Beach Tourist Park

Warren Edwards

Photo Page

2014/2015



Art Therapy



Grown Ups Getaway 2014



Big Red Ride & Run 2015



Big Red Ride & Run Volunteers



Barossa Marathon 2015



Big Red Ride & Run



Camp Capacity 2015



Multicultural Feast 2015



Camp Capacity 2015



Camp Capacity 2015

The Team

People of Muscular Dystrophy SA

Board

David Anthony-President
Allan Bretag-Vice President
Sandra Di Blasio-Vice President
Tara Nicholson
Janakan Ravindran
Tim Anderson
Melissa Yule
Glen Winkler
(resigned January 2015)
Grant Heading
Simone Douglas (from June 2015)
David Noble (from May 2015)
John Caruso (from September 2015)
Lisa Field (from October 2015)

Research Comittee

Melissa Yule
Tara Nicholson
Sandra Di Blasio
Allan Bretag
Janakan Ravindran
Phil Martin

Finance and Goverance Committee

David Anthony
Sandra Di Blasio
Phil Martin
Rebecca Baines

Marketing Committee

Simone Douglas (from June 2015)
Grant Heading
John McLaren (from June 2015)
Phil Martin
Stephanie Columbus

Ambassadors

Mark Aiston
Bradley McGee

Management Team

Phil Martin
-Chief Executive Officer
Amber Pyle
-Client Services Manager
Stephanie Columbus
-Marketing and Fundraising Manager
Nadelle Manners
-Finance and Administration Manager

Bow Tie Bears Volunteer Events Commitee

Janice Phillips (Chairperson)
Maria Catanzariti
Fay Jones
Andrea Redmon
Melva White
Phyl Turner
Margaret Boylon
Marjory Livingstone
Janet Wedderburn
Jan Haughney
April Francesca
Leanne West
Joy McLean [dec]

NDIS Readiness

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

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
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

Matthew Clarke - Captain
Santo Bongiovanni - Vice Captain
Scott Farell - Coach
Sam Aforozis
Jonathan Grigg
Chantel Bongiovanni
Adam Hart
Jonathon Nguyen
Garry Grigg
Rob Clarke - Coach

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
- 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.

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

Name:.....

Address:.....

.....

Phone: Mobile:

Email

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

OR please debit my Visa Master card Amex Diners

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

Expiry: _ _ / _ _

Cardholder's Name:.....

Signature

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: \$_____



<p>For online donations visit www.mdasa.org.au and click on the following icon:</p> 	<p>Scan this QR code on your smart phone</p> 
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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.



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SOUTH AUSTRALIA

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