



MUSCULAR DYSTROPHY  
SOUTH AUSTRALIA



# 2012/2013 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

2012/2013



In a difficult environment a surplus has been achieved for the first time in many years. This was achieved by a combination of good management, adherence to a well planned budget and diligent and continuous application to the many tasks at hand by Phil Martin, his staff, our team of volunteers and the Board.

National Disability Insurance Scheme (NDIS) continues to be rolled out by the Government. It has some distance to go but we have no reason to assume that the new Government will not support the scheme in the same manner as the previous administration. The initial trial in South Australia involves children under 2 years of age. Children up to 5 years of age will be included before July 2014, after which children up to 13 years of age will be eligible to join the scheme. In the third year of the launch it is planned that all children up to 14 years of age will be able to enter the scheme.

Muscular Dystrophy SA will be working hard to ensure that all eligible children with a neuromuscular condition are

included in the scheme. We will continue to offer and facilitate services and assistance to these children in tandem with their families and carers.

In this regard Debbie Smith and her team in Client Services have been working hard to identify ways to extend the range and effectiveness of services that we provide to clients and their families. Indeed they have been successful in a number of situations where other forms of assistance have not fully met clients' needs. Their efforts to assist each client achieve the best possible outcome in often difficult situations is to be commended.

I would also particularly like to thank Phil Martin who has been the prime mover in effecting a cultural change within Muscular Dystrophy SA over the past 2 ½ years. His encouragement has helped Stephanie Columbus transform her Fundraising team in a crowded and tight market. Stephanie and her team continue to meet and exceed targets even in new and ambitious events. Christine Mikalainis has similarly improved the operation and outcomes from her Telemarketing team in an equally tough market.

The Finance and Administration area often gets overlooked. This year they have been involved in some significant changes in their area, some of the benefits of which are only now starting to be seen. Thank you to Debbie Nicholson and her Administration team for their continuing efforts in

improving operating efficiencies and providing Phil and the Board with more relevant and precise financial information.

We also gratefully acknowledge the invaluable and selfless work of our volunteers who help us out in many ways from Fundraising, running BBQs, to enveloping letters and newsletters. Without them Muscular Dystrophy SA would not be able to function as it does.

I would also like to thank the Board and the management team at Muscular Dystrophy SA for their combined, continuous and invaluable input throughout the year. The challenges have been considerable and will, in all likelihood, continue to be so. But I feel we have the people and systems in place to enable Muscular Dystrophy SA to succeed in improving the range and level of services to our clients and their families in the year and years to come.

David Anthony  
President

## CEO's Report 2012/2013



In 1954 a group of concerned parents got together and formed the organisation that is today known as Muscular Dystrophy South Australia. Throughout those 59 years the organisation has worked to improve support for people living with neuromuscular conditions and their families and to foster research.

The original goals remain as important today as they were when the organisation was established. Muscular Dystrophy SA's values are: Determined; Innovative; Embracing; and Passionate. These values and strategic goals drive all of our activities and have resulted in fantastic outcomes for our clients, families and supporters.

Throughout the year we have actively supported the development and implementation of the National Disability Insurance Scheme. We believe this scheme will eventually result in considerable improvements to the quality of life for our clients and families. The launch of NDIS in South Australia was on 1 July 2013 and is initially focused on children under 5 years of age (currently with under 2 years).

We are looking forward to the progressive growth of the scheme to eventually support all of our clients.

Our funding support from SA Government has remained consistent and has contributed to the overall service outcomes. We are pleased to be implementing the 'Service Excellence Program' as part of our determination and passion to maintain a strong client focus and to continuously improve our service offerings.

We also thank the Premiers Department for the provision of computers which are greatly assisting the young adults in our support groups.

Support from Little Heroes Foundation has resulted in 227 outcomes this financial year and 750 overall outcomes for families and children, as well as facilitating the development of a USB memory card which is available to all families. This card will enable families to store vital information and assessments for ready use in key aspects of their lives. Our strategy to broaden the fundraising base through a range of innovative ideas has continued to be successful with fantastic support from organisations and participants who each year contribute to the range of supports we provide to clients.

- The thousands of South Australians who regularly support our lotteries
- Sponsors and participants of the

Multicultural Feast, Marathons, Big Red Ride and Adventure Challenge

- The tireless work of the Bow Tie Bears Volunteer Events Committee and NEWS Team who volunteer to raise funds for individual client support
- The Adelaide Harley Owners Group who frequently volunteer their time and bikes to support us at camps and key events

Our Client Services team has significantly expanded the supports to families through:

- Support to an increased number of groups with specific muscular dystrophy types
- Services to regional and remote locations
- Direct support to individuals
- The introduction of transition support to assist young adults as they embrace the challenges of moving from school to work, change of hospital systems and interface directly with Commonwealth departments for support
- Participation in the paediatric Neuromuscular Clinic in collaboration with Womens and Childrens Hospital. This work also helps our longer term strategies for consistent data collection to better inform National research initiatives

## CEO's Report 2012/2013

Throughout the year we have maintained our commitment to training our staff. Three of our permanent employees graduated from independently run diploma courses and all employees received in house accredited training on child protection.

The combined efforts of our teams and Board have resulted in more revenue from fundraising activities and more services to more clients. The work to ensure this occurs through effective and efficient processes has also contributed to an operating surplus for the financial year. Our dedicated staff and their passion for their work and our cause remains a fundamental building block for our success.

Throughout the year we maintained our commitment to working with like-minded Muscular Dystrophy Associations to increase community awareness about muscular dystrophy, advocating on a national level for enhanced services and creating opportunities for research. Muscular Dystrophy SA continues to provide leadership and support at an operational and governance level for Muscular Dystrophy Foundation.

The tireless efforts of our volunteer Board continues to be a vital support as they guide the development and implementation of our strategic initiatives.

Phil Martin  
CEO



Clients and Carers at Transition Camp



Clients at Grown up Getaway



Board members at Melbourne Cup 2012



His Excellency, Liz, Phil at Government House



Client and carer at Camp Capacity 2013



Volunteers at Adelaide Marathon

## Client Services Report

2012/2013



Client Services continues to work to enable individuals, and families living with neuromuscular conditions to have as full and active life as possible, by providing services and support that are responsive to individual needs. During 2012-13 funding for service delivery was received from several sources:

1) Government: The Department for Communities and Social Inclusion provided funding towards the costs of provision of therapies (hydrotherapy, physiotherapy and speech therapy), counselling and recreational activities (such as camps, support group activities and the Christmas Party).

2) Little Heroes Foundation: Funding for the LittleHeroesCare program made it possible to provide additional support and services for clients aged under 25

years and their families.

3) External grants: Muscular Dystrophy SA has been successful in obtaining additional funding through community grants programs. This funding has supported the development of a regional visiting program and a social support program for clients.

4) Muscular Dystrophy SA's fundraising activities continue to assist all services, activities and support provided by Client Services.

The Client Services team work closely with clients and their families to identify needs and to provide services and support to assist in meeting those specific needs. The tables below summarise client outcomes achieved for the 2012-13 year:

<b>Service Type</b>	<b>ODACS Funding: Service output requirements</b>	<b>Actual client outcomes achieved</b>
<i>Counselling</i>	300	2302
<i>Therapies</i>	1095	2128
<i>Recreation</i>	350	2210
<b>TOTAL</b>	<b>1745</b>	<b>6640</b>

Table A: Outcomes against ODACS funding targets

<b>Service Type</b>	<b>Client Outcomes achieved</b>
<i>Information</i>	7609
<i>Equipment</i>	610
<i>Advocacy</i>	830
<i>Accommodation</i>	156
<i>Practical Support</i>	313
<i>Education</i>	306
<i>Other Contacts</i>	609
<b>TOTAL</b>	<b>10,433</b>

Table B: A summary of the balance of services provided over the last twelve months

## Client Services Report

2012/2013

The following are some examples of events and services that were provided during 2012-13, under our guiding organisational values.

### PASSIONATE

#### *Grown-ups Getaway*

A very successful Grown Ups' Getaway was held at Wallaroo, from Feb 8-11. In total, 18 clients, 12 carers, 3 staff and 1 volunteer, went away for a wonderful weekend. The Copper Coast District Council asked for feedback from our group on making the council owned park more accessible and this was presented to the next council meeting. Council has informed us that they have acted on most of those recommendations, and have asked that we return there next year to see the developments.

#### *Camp Capacity*

A really successful Camp Capacity was held at Mylor Baptist Centre Campsite from Mon 15th to Fri 19th April 2013. 37 campers, 27 carers, 4 staff, volunteers from Bow Tie Bears and other day visitors enjoyed a week of fun, social interaction and opportunities to explore issues surrounding living with a neuromuscular condition.

#### *MD Mafia*

'MD Mafia', a program originally set up by Novita, was taken over by Muscular Dystrophy SA. The terms of reference of the group have been broadened to have a transitional focus for all young men with neuromuscular conditions aged between 15 and 23 years.



MD Mafia group 'hanging out'

The group meets once per month on a Saturday, and keeps in touch via a private Facebook group in between meetings. Meetings have a different focus each month, and have included playstation games, movies and heading off together to the Royal Adelaide Show. Some of the comments made by the young men about the group include:

*"I think this is fantastic – a great chance to catch up with other people who get what it is like to have a disability"*

*"I didn't have to worry about what people thought about me having a disability – nobody cared about that"*

### EMBRACING

#### *Christmas Party*

130 clients and family members attended the Christmas Party at Cheltenham Community Centre. The day included a fabulous band, face painter and a visit by Santa. Lots of positive feedback was received with some clients stating it has been the best Christmas Party they have attended.

#### *LittleHeroesCare Program*

Generous funding from the Little Heroes Foundation has enabled Client Services to support young people with neuromuscular conditions, their immediate and wider families in a variety of

positive ways that would not have been otherwise possible. This has enabled the provision of a range of services and supports including practical supports to families, therapies, equipment, counselling and transport assistance.

#### *Neuromuscular Clinic, Women's and Children's Hospital*

Clients Services staff continue to be an ongoing part of the neuromuscular clinic team. The clinic runs once per month at the Women's and Children's Hospital and a pre-clinic meeting is also held each time to discuss issues relating to neuromuscular conditions. Attendance each month has strengthened networking and collaboration between Muscular Dystrophy SA and staff from both the hospital and Novita.

#### *School Involvement*

School visits have been undertaken at many schools attended by our clients, to provide information about specific conditions for staff and students, and to assist in educational planning for students living with neuromuscular conditions. A regular visiting program has been established with the LINK program at Roma Mitchell Secondary College where many of our clients attend.



Grown-ups Getaway trip to the beach

## Client Services Report

2012/2013



Clients enjoying Art Therapy session

### INNOVATIVE

#### *Art Therapy Sessions*

Small group Art Therapy sessions were offered for young clients during the summer school holidays. The sessions were very successful, and they have continued on as group or individual sessions during the year on a regular basis. One of the parents wrote to say "Just wanted to say thanks to everyone again. The kids had such a great time and really loved the masks that they made. I enjoyed having a bit of a break too!"

#### *Transition Camp*

In September 2012, a very successful three day transition camp, billed as a 'three day residential workshop' was held at Mylor Baptist Adventure Campsite for young male clients aged between 16 and 20 years. Staff and voluntary carers ensured that the boys were well supported in the activities and discussions that took place. Sessions explored post school educational, vocational, financial and social, leisure and recreation options.

#### *Student Placements*

As well as the students who are recruited to assist as carers at camp or hydrotherapy aides, this year Client Services began a program to encourage students

to undertake their practicum placements within the Client Services team. The placement program gives students first hand experience in working with individuals living with neuromuscular conditions and provides Client Services with opportunities to undertake additional activities or projects. We have welcomed students from a range of courses during the year including: disability (students from TAFE and the Disability degree programs at Flinders University), counselling, art therapy and health sciences.

### DETERMINED

In the coming year Client Services is committed to strengthening and further developing strategies and programs to enable support and facilitation of service provision for all clients, including those living in regional and remote areas. Funding from Muscular Dystrophy SA fundraising activities will continue to be supplemented from additional sources such as Government funding (through grants and DisabilityCare Australia (NDIS) ), contributions from Little Heroes Foundation and other grant opportunities.

Muscular Dystrophy SA will continue to closely monitor developments relating to DisabilityCare Australia, identifying how the organisation can ensure maximum benefit for clients and their families. In addition we will continue to work closely with the State Government as they move towards individualised funding for people who have a disability

and who are not yet covered under the DisabilityCare Australia program.

The Client Services team is committed to providing optimal services and support for clients and their families living with neuromuscular conditions, and to working in close collaboration with other service providers and professionals working in the disability sector.

Debbie Smith  
Client Services Manager



Transition Camp 2012



Client Services  
Christmas Party 2012



Grown-up's Getaway 2012

## Finance and Administration Report 2012/2013



### *Results for the year*

Overall, the final result for the organisation for the year ended 30 June 2013 demonstrated the organisation's place in the community as a well-respected and long established charity with a proven track record in supporting the community by consistently delivering on its objectives. As the economic environment in which it fundraises struggles, Muscular Dystrophy SA has recorded a small increase over last year.

Below is a chart which shows the sources of funds for the organisation. As can be seen, by far the majority of funds arise from the fundraising activities conducted by Muscular Dystrophy SA: specifically its programme of regular raffles. We would like to take this opportunity to thank our supporters. The community continues to be incredibly generous, with some of our supporters participating in every single raffle, sometimes buying more than one ticket each time.

Enhanced reporting, coupled with proactive strategies around financial management, form the backbone of preserving future viability.

### *Accounting and Budgeting*

Critical to the monitoring of the organisation's performance and effective decision-making is the need for an accounting system which captures and reports information accurately and efficiently. During the year, we embarked on a process of reviewing the accounts structure. This was done in collaboration with the departmental managers, to ensure that their information needs and expectations were met, and to provide them with a framework within which they will be able to monitor and analyse their own department's results.

The other exciting development in this area was the implementation of a budgeting system, fully integrated with our current accounting software. Not only did it make the budgeting process for the coming year much easier, but it facilitates the reporting of results in varying, user-defined degrees of complexity (or simplicity).

## Finance and Administration Report 2012/2013

Broadly speaking, it can provide results from a multi-dimensional viewpoint: by account code, by activity, or by month, or by a combination of two or more of these parameters. The system also facilitates comparisons of actual results compared to budget, and compared to prior year's results.

### *Costs review*

As part of an ongoing programme of review, this year saw the introduction of some further cost-savings. Examples include the renegotiation of the contracts with regular service providers, as well as the investigation of using existing bartercard 'dollars' to purchase goods and services.

In addition, recently, the organisation has entered into a contract for the installation of solar equipment which, after the initial pay-back period of approximately four years, will result in significant and ongoing savings in our electricity spend.

Finally, the introduction of the new budgeting and reporting system mentioned above, has already had the effect of highlighting other spends, which, when looked at from an organisation-wide perspective, will justify a detailed analysis potentially resulting in further cost-savings.

### *Major projects*

At the time of writing this report, there are two major projects underway:

- The 'Donman Project'. Donman is the system which

is used to manage our lottery fundraising activities. It has functional capabilities which can be used in other areas of the organisation: for example, in recording and reporting on client services outcomes. The objective of this project is to review the way in which the system is currently being used, to identify improvements, and to incorporate its use across other areas in Muscular Dystrophy SA as appropriate. Underpinning these objectives, naturally, is the desire to have a tangible and recognisable positive effect on our financial results.

- The 'CompliSpace Project'. From 1 July 2013 The Australian Charities and Not-for-Profits Commission (ACNC) has introduced mandatory governance standards for all charities. Generally speaking, governance can be defined as encompassing those systems, processes and activities that together provide the framework within which an organisation can achieve its objectives. Importantly, effective governance is achieved by ensuring that these systems are not only designed, but that they are properly implemented. In collaboration with the Muscular Dystrophy Foundation and with Muscular Dystrophy associations around Australia, MDASA is in the process of implementing the CompliSpace Fundamentals system, which provides a customised intranet through which content can be made available to all employees and board members. We have initially subscribed to content in

the areas of Human Resources and Workplace Health and Safety, as well as an online Boardroom module. CompliSpace provides content which meets the regulatory requirements of current legislation, both state and federal. It also provides regular updates for changes in legislation. The system represents an important step for the organisation in the change management process anticipated by the governance requirements.

Finally, I would like to thank the Finance and Administration Team for their great work, and for their unflinching good nature and unflappable countenances in the face of such change (both during the year just passed, and in the year ahead). I would also like to thank our previous Finance Manager, Kate McLean, for the exemplary work which she carried out in implementing and improving the accounting system over the last few years, providing a solid basis from which this year's changes could be confidently introduced.

Debbie Nicholson  
Finance and Administration  
Manager



Bouncy Castle Attendants at  
the Big Red Ride 2013

## Fundraising & Marketing Report 2012/2013



As we look back over the past year we had some wonderful highs. We have welcomed new supporters and sponsors, new volunteers from all demographics including schools, businesses and social clubs. We have continued working with local councils and building new relationships with corporate bodies.

This year, we have embraced our organisational values in everything we do to enhance our fundraising and marketing programs. By embracing the community, we have been able to inspire members of the community to become passionate about making a difference in the lives of people living with neuromuscular conditions.



Determined little rider at Big Red Ride 2013

Despite the tough economic climate, we were determined to ensure our organisation continues to thrive through strong relationships, innovative new events and lotteries and strategies for continuous improvement within existing initiatives.

### PASSIONATE

#### *Big Red Ride*

The second Big Red Ride saw almost 400 participants put their muscles behind muscular dystrophy and ride the scenic seaside route from Glenelg to Outer Harbour and back to raise funds for Muscular Dystrophy SA.

The ride was once again led by pro cyclists, including members of the GreenEdge team. Following the event riders and their families enjoyed entertainment, coffee from major sponsor Cibo and a BBQ cooked by hard working passionate Muscular Dystrophy SA volunteers. We are looking forward to a bigger and better Big Red Ride in 2014!

#### *Badge Day*

Badge Day, held in March, saw over 50 passionate volunteers take to the streets to collect donations and sell merchandise for Muscular Dystrophy SA. Volunteers were situated around the city, as well as at Westfield West Lakes and Westfield Marion. Councils and schools also got involved, holding casual days or collecting donations and selling merchandise.



Guests at Multicultural Feast 2012

As part of our Badge Day initiative, we were named a charity partner for the Garden of Unearthly Delights and collected change from Adelaide Fringe attendees at the gates. The people of Adelaide turned out their pockets and embraced the initiative, and we were very successful in raising both funds and awareness.

### EMBRACING

#### *Multicultural Feast*

The Multicultural Feast was once again a sell out event, with over 130 supporters enjoying an eight course meal accompanied by entertainment from around the globe including Bollywood Dancing and Italian Opera.

Once again, Adelaide restaurants embraced the event, supplying cuisines from around the globe for our feast. A special thankyou to My Tho City, Beyond India, Tongue Thai'd, Cibo Cucina, From Orient and Barossa Fine Foods for their support of this event.

#### *World of Trivia*

After some fierce intra school competition, SA's best and brightest students gathered to find out which team of 4 would win the trophy and be named the World of Trivia champions in each year level. Over 1,000 students

## Fundraising & Marketing Report 2012/2013

from 15 schools participated, embracing our organisation and fundraising for Muscular Dystrophy SA in the lead up to the event.

As well as trivia and fundraising, this event also ensured each student left the competition with a better awareness of neuromuscular conditions and the day to day issues faced by our clients as well as how our organisation helps. A huge thank you has to go to Sammells, the major sponsor for this event.

### *Golf Day Challenge*

With 18 teams and over 70 participants, Muscular Dystrophy SA's Golf Day held at the beautiful Glenelg Golf Course was once again a success. Sponsorship was overwhelming for this event and sponsors included Vinocor, Scouts SA, All Transport Industries, Verifire and Ernst & Young.

This event continues to strengthen our relationships within the corporate sector, with many businesses and teams embracing our organisation's mission and returning year after year.



Muscle Team Adventurers

### **INNOVATIVE**

#### *Muscle Team Adventure Challenge*

This year, we have launched an innovative new fundraising initiative, the Muscle Team Adventure Challenge. 12 dedicated participants have volunteered their time to fundraise \$10,000 each for our organisation. In early December 2013, the participants will embark on the adventure of a lifetime. Led by Troy Gray, participants won't know where they're going or what they're doing, and the entire journey will be filmed by the award winning crew from Charity Adventure TV. The documentary will be aired locally on Channel 7, as well as nationally and internationally.

#### *'Voices for Muscular Dystrophy' Karaoke Competition*

Another innovative new event, our inaugural 'Voices for Muscular Dystrophy' Karaoke Competition was a huge success. Hosted by MC Jenny Winter, the event invited community members with a passion for singing to compete against each other and be named the Voice for Muscular Dystrophy. Celebrity judges Matt Gilbertson (Hans), Sarah Lloyd and Matt Carey critiqued performances and named their favourite singer, while the audience made donations to award people's choice.

### **DETERMINED**

#### *Adelaide and Barossa Marathon Running Festivals*

The Muscle Team 'put their muscles behind muscular dystrophy' once again fundraising for Muscular Dystrophy SA in the



Winner of the Autumn Lottery

Athlete's Foot Adelaide Marathon Running Festival and the Jacobs Creek Barossa Marathon Running Festival. For the Adelaide Marathon Running Festival we had many volunteers on the day, who marshalled the race, as well as assisting in catering to around 1,800 participants with toasties, espresso coffee and more!

For both events, volunteers also assisted in the Muscle Team VIP tent, which featured giveaways and massages from supporter Core Physiotherapy & Pilates exclusively available to Muscle Team members.

Thank you to all the Muscle Team runners for their determination and amazing fundraising efforts.

### *Lotteries*

Thank you to all of our supporters who purchased lottery tickets in the past year. Lotteries continue to be our biggest source of income and through your continued support we are able to raise much needed funds for our clients.

Our relationship with suppliers continues to be an integral part of our lotteries. These relationships

## Fundraising & Marketing Report 2012/2013

continue to grow and in many cases these suppliers have also supported other Muscular Dystrophy SA initiatives.

A special thanks goes to Drake Foodland, Brooksy's Good Guys, Flight Centre Melbourne Street, Myer and Wirra Wirra Wines.

### *Donations*

Muscular Dystrophy SA conducted four letter appeals over the past 12 months and raised over \$99,000. We continued to place donation boxes around the state, and we now have a total of 129 boxes in cafes, pubs, pharmacies and other retail outlets.

The overall results in marketing and fundraising were only able to be achieved through generous support from the Muscular Dystrophy SA community. We'd like to thank all volunteers, staff, clients, donors, sponsors and guests who embraced our events, lotteries and projects throughout the year. It is through your determination, passion and support that we have achieved and will continue to achieve such fantastic fundraising results to support our clients. We would also like to thank the Bow Tie Bears Volunteer Events Committee who volunteer their time and creativity to raise funds for Muscular Dystrophy SA.

In the coming 12 months we will continue to face challenges, but with some determination, innovative solutions and the continued support of the Muscular

Dystrophy SA community, we believe we will continue to achieve positive outcomes.

Stephanie Columbus  
Marketing & Fundraising Manager



Volunteers at the Big Red Ride



Muscle Team members at Barossa Marathon



Adventurer Jaimie's Win a Date with Josh from Big Brother event



Badge Day at the Garden of Unearthly Delights



Adventurer Michael's Peter Coombe Night



Team Francis at Golf Day 2013

## Bow Tie Bears Volunteer Events Comittee Report 2012/2013



I am pleased to present the Bow Tie Bears Volunteer Events Comittee Report for 2012/2013.

The 'Bow Tie Bears' as we are affectionately known is a dedicated group of 14 women who work together tirelessly 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.

One of our most successful fundraising concepts is selling our beautiful range of hand made products such as knitted baby/toddler items and toys, sewing and quilting all made by the committed and talented committee members and many friends of the Bow Tie Bears. Throughout 2012/2013 we held stalls at Salisbury Craft Fair (3), ABC Gardeners Market (2), Magill Foodland (2), the Lollipop Market and the October Gift & Craft Fair.

We held a Quiz Night at The Woodville Town Hall and although there were some technical hitches on the night, everyone enjoyed themselves. The Bow Tie Bears were fortunate enough to be the recipient of the gold coin donation at the very popular Lollipop

Market. Many volunteers collected on a very hot day. A fantastic result. We also had a stall selling our wares at this market. We held 2 raffles during the year and we received a donation from a Community Club of \$1,000.

We raised just over \$16,000 during the 2012/2013 financial year.

Throughout the year we have allocated these funds to:

- Camp Capacity
- Client Xmas Party
- Towards audio/visual entertainment system for the 'Drop-In Centre'
- Purchased technical aids for a client
- Assisted 3 Clients with house cleaning
- Funded the craft workshop at Camp Capacity

The innovative, passionate and dedicated volunteers who make up the Bow Tie Bears Volunteer Events Committee are determined to embrace and support people of all ages who live everyday with a neuromuscular condition.

And proudly so.....

Janice Phillips  
Chairperson



BTBVEC at the ABC Gardeners Markert



Long time Bow Tie Bears - Phyl and Melva



BTBVEC at the October Gift and Craft Fair



BTBVEC at the Gardeners Market

## Research Report

2012/2013



Once again, it is my great pleasure to be able to write this Annual Research Report for you.

In this instance it will mainly be taken up with a short summary of news from clinical/scientific research conferences that I have attended since writing my previous annual report, backed up in part by information from medical/scientific journal articles that I have read in the meantime.

A more complete account of research developments in the last year will be mounted on the Muscular Dystrophy SA website:

[www.mdasa.org.au](http://www.mdasa.org.au)

In the 'Neuromuscular Condition' tab under 'Conferences'

**AOMC 2013** – This year's Annual Scientific Conference of the Asian and Oceanian Myology Center (AOMC) held in early June in Xi'an, China. It was attended by 280 participants from 11 countries, mainly China, of course, but also from Japan, Korea, Singapore, Thailand, Australia, India, Malaysia, The Philippines, Iran and the United States.

Particular highlights from the Conference were:

AOMC President, Dr. Ikuya Nonaka from the National Centre for Neurology and Psychiatry, Tokyo, then opened the scientific program with a presentation on 'Inclusion Body Myositis (IBM): Clinical and Pathological Aspects' in a symposium entitled, Inflammatory Myopathies. Because it is possible to treat many inflammatory myopathies successfully and inexpensively with anti-inflammatory drugs, this symposium was of considerable interest to the Asian region. Other speakers in the session covered the diseases, Polymyositis and Dermatomyositis.

A symposium on Metabolic Myopathies followed and among other presentations, Dr. Yuh-Jyh Jong from Taiwan described his successful experience of neonatal screening and enzyme replacement therapy for Pompé Disease.

The next conference symposium provided extremely encouraging updates on therapeutic trials. Dr. Shin'ichi Takeda gave an update on Exon Skipping therapy for Duchenne Muscular Dystrophy with the good news that a Japanese pharmaceutical company, Nippon Shinyaku, is about to trial a new drug to skip exon 53 in DMD. Another company, Daiichi-Sankyo, is preparing a drug to skip exon 45. He also announced that by April 2013, the Japanese DMD Registry in Japan had included more than 1,050 patients.

Advances in viral and cell-based therapies for DMD were presented by Dr Dongsheng Duan from the University of Missouri, USA, who described very promising results in muscular dystrophy dogs.

On the morning of the second day, the conference was again devoted to symposia, the first being on diagnostic techniques for NMDs. In this session, I spoke on NMDs involving ion channels and how to diagnose them. Presentations on the NMD now known as GNE Myopathy, formerly Hereditary Inclusion Body Myopathy (hIBM) occupied another symposium with Dr. Ichizo Nishino describing promising preclinical trial results using the novel sugar, sialic acid, essential for normal muscle structure but missing in the disease. Accounts of GNE Myopathy in China, Thailand, Malaysia and Korea followed.

As in previous AOMC Meetings, there was a Muscle Pathology Case Conference in which the characteristics of unusual or undiagnosed cases are presented for all in attendance to consider. As well as the lecture presentations, there were also 188 clinical and scientific



## Research Report 2012/2013

research posters describing new studies in most areas of NMD.

WMS 2013 – The 18th International Congress of the World Muscle Society (WMS) was held in the second week of October, in Asilomar, California at the splendid Asilomar Conference Grounds on Monterey Peninsula. There were some 550 registered delegates in attendance despite the US Government closing down and preventing lectures or other presentations (under threat of two years goal) by those scientists and clinicians who worked for the National Institutes of Health or the Centres for Disease Control.

Particular Highlights of the Conference were:

Myomatrix, the thin fibrous felt-work enveloping individual muscle fibres, attaches them to the connective tissue which acts as the overall support scaffolding between muscle fibres. If it is defective, muscle cells can be damaged resulting in rare kinds of Muscular Dystrophy. These diseases and potential approaches to their respective therapies were discussed by researchers from several different US universities.



Each year, new rare NMDs are characterised and this year has been no exception. Drs Debbie Hicks and Volker Straub from the Newcastle Institute of Genetic Medicine and their colleagues have described new disorders with similarities to Bethlem Myopathy and Ulrich MD that are

associated with mutations in the collagen 12 gene, collagen 12 being an essential protein in the connective tissue surrounding muscle and skin cells.

There was a lot of good news regarding Spinal Muscular Atrophy (SMA). Much of this was delivered in a lecture by Dr Arthur Burghes of Ohio State University, USA. He outlined a new understanding of why some people with the SMN (Survival Motor Neurone) mutations that normally cause severe disease can be only mildly affected or unaffected. This depends on what is called the 'Copy Number' of a related gene, SMN2. The more copies of this SMN2 gene in a person's genome the more resistant they are to the bad effects of an SMN mutation.

Dr Burghes and a colleague, Dr Sandra Duque, provided extraordinary evidence of therapy in SMA mice (one procedure increasing lifespan from 14 to 365 days) and in SMA piglets where the symptoms of the disease seem to be totally corrected. Dr Kathy Swoboda from the University of Utah, Salt Lake City, USA presented the results of a Phase 1 clinical trial of the AON drug ISIS-SMNRx from ISIS



Pharmaceuticals in which most children in the trial had improved motor function and none had declined 14 months after a treatment involving a single injection of the drug. There were no safety issues.

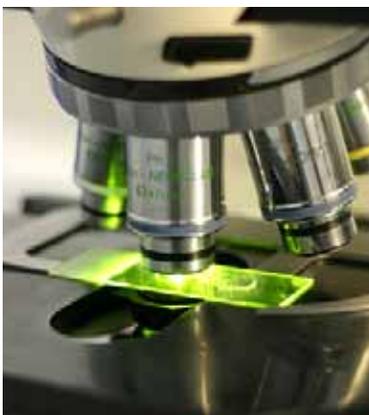
On another front, Dr Kathy Matthews from Iowa, USA, spoke about 'MD starNET' an initiative funded by the US Centres for Disease Control and Prevention. MD starNET aims to find everyone with DMD or BMD, born after 1981, living in those US states that have joined the organisation. To this statistical data will be added information about the health and services needs of these people. This knowledge, which should be widely applicable, is expected to inform all stakeholders from those with these diseases and their parents/carers through doctors, allied health workers, public health officials and educators to not-for-profit support organisations. It is hoped that this data gathering will be extended to all NMDs.

An update on clinical trials of treatments for DMD was presented by Dr Francesco Muntoni from University College London. Invasion of muscle by inflammatory cells is a feature of MDs. Powerful new anti-

## Research Report 2012/2013

inflammatory drugs are also being tested in boys with DMD. Halo Therapeutics HT-100 is in Phase 1b clinical trial. For many years it has been known that the protein, utrophin, can replace dystrophin and allow almost normal muscle function in dystrophic mice. Now a drug that increases utrophin production, Summit C1100, is in Phase 1b trial in DMD boys and is expected to enter Phase 2 clinical trial next year.

The results in clinical trials using AONs for DMD have been mixed recently. As of the end of September, PRO051 (Drisapersen) from Prosensa/ GlaxoSmithKline has been found to be no better than placebo in a lengthy trial – a great disappointment. Final results from the Sarepta/AVI Biopharma trial of AVI-4658 (wEteplirsen) are still being awaited, although after 96 weeks of trial the condition of the boys seems to be stable rather than worsening. This is encouraging but questions remain as to why only stabilisation has been seen and there is no



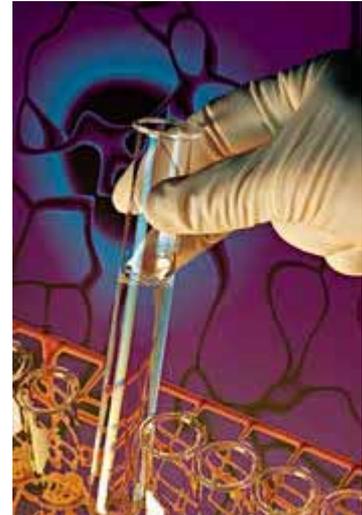
Advances in gene therapy using viral vector delivery were presented by Dr George Dickson from the University of London who encouraged us all with the news that the first ever therapy of this kind had been licensed for use in Europe. While this viral 'drug', 'Glybera' (from UniQure, formerly Amsterdam Molecular

Therapeutics), is not a treatment for an NMD, other European organisations including Généthon in Évry, the Paris-based Institute

of Myology and Atlantic Gene Therapies in Nantes are hard at work developing similar strategic approaches to NMD therapies. Many other exciting therapeutic approaches were presented in lectures and poster sessions, too numerous to describe in detail here.

Finally, I shall only briefly comment on Australian NMD research. Since its recent establishment, the members of the Australian Neuromuscular Network (ANN) have made considerable progress towards coordinating clinical research and clinical trials in Australia. Much of this is outlined in the ANN Annual Scientific Report for 2012 which is available to be downloaded from their website (below) and on the Muscular Dystrophy SA website.

<http://www.ann.org.au/annual-scientific-report-2012/>



Muscular Dystrophy SA, has this year started to revitalise its funding of NMD research. A Subcommittee of the Muscular Dystrophy SA Board was established to promote NMD research in hospitals, universities and other research institutions. It is anticipated that this will lead to more interest and larger research projects able to be funded by Muscular Dystrophy SA in future.

Professor Allan Bretag  
Director of Research



Muscular Dystrophy Association finished the 2012/2013 financial year with an operating surplus of \$11,561 before allocation of unrealised gains on Investments of \$34,289, an overall surplus of \$45,850. This was largely due to the continued success of fundraising initiatives and the full implementation and management of budgeting and operational controls for major activities.

Overall income for the year was \$2,035,560 which represents an increase of \$107,989. A significant proportion of this was due to the introduction of a pilot program 'Little Heroes Care' throughout the year. Government Grants for the year were marginally less than the previous year. This was because we attracted some once off grants in 2011/12 which were not available in 2012/2013.

A summary of gross Income and expenditure is as follows:

<b>Income</b>		
Donations and Bequests	276,246	208,980
Government grants	112,097	128,759
Special events	260,039	238,477
Lotteries	1,333,526	1,308,310
Interest and dividends	25,960	34,407
Other	27,692	8,638
	<b>2,035,560</b>	<b>1,927,571</b>
<b>Expenditure</b>		
Depreciation	46,340	43,312
Bank Charges	15,691	14,526
Special Events	92,108	94,096
Lotteries	352,646	329,668
Wages and on costs	1,103,130	1,125,260
Consultants	77,970	55,417
Other	336,114	312,764
	<b>2,023,999</b>	<b>1,975,043</b>

Expenses - The Board continues to support initiatives to meet identified client needs through the budget process and approved enhancements to rostering processes which enabled the generation of efficiencies in salaries and wages.

Balance Sheet - The balance Sheet shows total assets of \$1,944,312 and total liabilities of \$348,621 with a net position of \$1,595,691.

Cash Flow - Cash flow remains strong with a total Cash and Term Deposits of \$539,425, an overall increase of \$123,605 for the year.

Investments - The Association continues to hold investments in a number of Listed Investment Companies (e.g. Argo, Australian Investment Company etc.). The long term objective of this approach is to provide a secondary income stream and buffer against any future falls in income from other activities.

*A copy of the full financial statements is available for members on request.*

# MAIN TITLE

Description of title

## Patron

His Excellency Rear Admiral  
Kevin Scarce AC CSC RANR

## Major Sponsor

Sammells Financial Services  
Group - AMP

## Sponsors

Cibo Espresso

Core Physiotherapy & Pilates

Duncan Basheer Hannon

Drakes Foodland

Ernst & Young

Flight Centre (Melbourne Street)

Five AA

Myer Stores

SA Road Runners Club

## Supporters

Adelaide Football Club

All Transport Industries

Aluco

Amart All Sports

Anthony's Confectionery

Barossa Fine Foods

Beyond India

Brooksy's Good Guys

Caruso's Fresh Foods Glenelg

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

David Lampard

Edible Blooms

Flight Centre Active Travel

Fox Creek Wines

From Orient

Furniture Access

Garden of Unearthly Delights

Glenelg Golf Club

Gluttony

Grand Chifley Hotel

Harley Owners Group SA

Haselgrove

Henschke Wine

Hoyts Norwood

Hypnothaized

International Linen Service

Kennards Hire

Kiwanis Clubs of Adelaide,

Athelstone

Mark Lobert Gallery

Matthew Carey

Matthew Gilbertson (Hans)

Mosaic AV

Mt Barker Hahndorf Golf Club

My Tho City

North Adelaide Football Club

Officeworks

Peter Lehmann Wines

Plympton Steel

Port Adelaide Football Club

Pulteney Grammar School

Rebel Sport

Rockford Wines

Romeo's Foodland Magill

SA lotteries

Sarah Lloyd

Scouts SA

St Johns Ambulance

Stamford Grand Adelaide

Supreme Sausages

Swing Corner

The Factory

'The Gov' – The Governor

Hindmarsh Hotel

The Standish Wine Company

Tim Allan Photography

Verifire

Vinocor

Wallis Cinemas

Westminster School

Wirra Wirra Wines

Yalumba

# Photo Page

2012/2013



Guests enjoying Melbourne Cup Lunch 2012



'Thank You' from Camp Capacity 2013



Waiting for a turn on the Flying Fox at Camp Capacity 2013



Volunteers at Big Red Ride 2013



Crossing the finish line for the Muscle Team at Adelaide Marathon



Guests enjoying Multicultural Feast 2012



Volunteers at Government House



Client enjoying Art Therapy



Riders at Big Red Ride 2013

## Statement by Board Members 2012/2013

We, David Anthony and Sandra Di Blasio, as members of the Muscular Dystrophy SA 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<sup>th</sup> June, 2013.

The Balance Sheet of the Association is a true and fair record of the state of affairs of the Association as at the 30<sup>th</sup> June 2013.

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 Associations Incorporation Act, 1985, the Board of Muscular Dystrophy Association Inc hereby states that during the financial year ended 30<sup>th</sup> June 2013.

- (1) no officer of the association;
- (2) no firm of which an officer is a member; and
- (3) no body corporate of 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, from, 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 2013



David Anthony



Sandra Di Blasio

## 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  
Grant Heading

### Research

#### Comittee

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

### Finance and Governance

#### Committee

David Anthony  
Sandra Di Blasio  
Phil Martin

### Marketing Committee

David Anthony  
Grant Heading  
Keen Meek  
Phil Martin  
Stephanie Columbus  
Jessica Klar

### Leadership Team

Phil Martin  
-Chief Executive Officer  
Debbie Smith  
-Client Services Manager  
Stephanie Columbus  
-Marketing and Fundraising Manager  
Debbie Nicholson  
-Finance and Administration Manager  
Jaimie Riggs  
-Finance Administrator  
Christine Mikalainis  
-Lotteries Coordinator  
Jessica Klar  
-Event Coordinator  
Amber Pyle  
-Client Services Coordinator

### Bow Tie Bears Volunteer

#### Events Committee

Janice Phillips - Chairperson  
Andrea Redmon  
April Francesca  
Fay Jones  
Janet Wedderburn  
Joy McLean  
Leanne West  
Margaret Boylon  
Maria Catanzariti  
Marjorie Livingstone  
Melva White  
Phyl Turner  
Shirley Rees  
Yvonne Saleeba

### 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 Tippet  
Neil Tippet  
Merv Turner

### NEWS Team

Matthew Clarke - Captain  
Santo Bongiovanni - Vice Captain  
Scott Farell - Coach  
Tim Holman  
Sam Afrozis  
Clinton Woodman  
Chris Spencer  
Jonathan Grigg  
Chantel Bongiovanni  
Dale Holman - Coach  
Rob Clarke - Coach  
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 by:
- 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: \$\_\_\_\_\_



For online donations visit [www.mdasa.org.au](http://www.mdasa.org.au) and click on the following icon:



'Make a Donation or Payment' and follow the prompts

Scan this QR code on your smart phone



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.*



MUSCULAR DYSTROPHY  
SOUTH AUSTRALIA

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](mailto:info@mdasa.org.au)  
Web: [www.mdasa.org.au](http://www.mdasa.org.au)