



MUSCULAR DYSTROPHY
SOUTH AUSTRALIA

Muscle TALK

SUMMER
2016



MESSAGE FROM MUSCULAR DYSTROPHY SA'S CEO

Welcome to the summer edition of the Muscular Dystrophy SA newsletter. There has been a lot happening throughout the year as we continue to implement strategies to meet our vision: 'a world without neuromuscular conditions by 2050'.

Our activities are focused on ensuring we provide supports and services to people living with a neuromuscular condition and their families and to support research to find a cure and improved clinical practice. We continue to be committed to delivering high quality client services and fundraising activities with a dedication to invest in future neuromuscular research.

Thank you to all of the people who attended the Annual General Meeting (AGM) and the research presentations which followed. Some key information from the CEO presentation to the AGM was:

- Client Services have increased supports to a wider client base and are now supporting 640 people with neuromuscular conditions.
- Client Services continue to support families transition to the National Disability Insurance Scheme (NDIS) and are seeing increases in supports from the developing NDIS plans
- All client related performance targets were met or exceeded
- The Board recently approved \$75,000 as the first stage collaborative project with University of South Australia as part of our investment into research initiatives to seek a cure and advanced clinical practice
- We are part way through repositioning our fundraising and events initiatives to achieve greater net returns and will be reporting in March on progress
- Lotteries continue to grow and we greatly appreciate the ongoing support of the many people who purchase lottery tickets and support our client outcomes
- Independent benchmarks for key performance areas have been introduced and are being met

Members present at the AGM approved the finance statement and annual report. These are now available on our web site. Janakan Ravindran, David Woodcock and Michelle Pfitzner were reelected to the Board. Tim Anderson and Sandra Di Blasio resigned from the Board and we thank them for their considerable efforts in assisting the organisation over many years.

Merry Christmas and a happy new year to all of our clients, families, members, staff and supporters.

Phil Martin



OFFICE CLOSURE 2016/17

Please note that our office will be closed for the Christmas period.

CLOSING

Thursday 22 December 2016
at 12:00pm

OPENING

Tuesday 3 January 2017 at
9:00am

If you should have an emergency that cannot wait to be followed up please contact Amber Pyle in Client Services on
0438 830 111

We wish you and your family a happy and safe Christmas and a wonderful New Year.

CONNECT WITH US www.mdasa.org.au info@mdasa.org.au



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SUPPORT GROUPS

Read below to see what support groups we have and some activities they have done. If you would like to become a part of one of the support groups or have an idea for an activity or guest speaker, please contact Client Services!

MD MAFIA

Chilled out group for male clients aged 15-30 diagnosed with a neuromuscular condition! This year the group went to an AFL game, cricket, fringe event, Royal Show, dinners out and much more.

MD NINJAS

Clients aged 7-14 had some exciting adventures this year including the movies, cooking classes, Lego workshops and a wheelchair games day!

OUT AND ABOUT

A new social group for adults 30+ diagnosed with a neuromuscular condition. So far the group have been to the movies, visited the central markets and have plenty planned for next year

SCA GROUP

For individuals diagnosed with SCA and their family members/carers. The group continues to meet monthly in a relaxed environment to hear guest speakers, go out for a coffee or attend local community activities

CHARCOT-MARIE-TOOTH

The CMT Support group meets quarterly to hear guest speakers and share information

MYTONIC SUPPORT GROUP

The Myotonic Support Group for individuals and carers meets quarterly to gain information and build networks.



FAMILY CHRISTMAS PARTY

The annual family Christmas party was held on the 3rd of December 2016 at the well equipped Thebarton Community Centre. The weather was absolutely perfect and the 140 attendees enjoyed cooler temperatures on the day this year! Fabulous food was in abundance and 'Dave Freeman and the Reason' played fantastic tunes getting lots of people into the groove. Sarah Cotis delighted children (and some grown-ups!!) with her face painting skills, making sure everyone was in the Christmas spirit. Santa took time out of his schedule to come along and visit everyone, with some extra gifts for children under 12 (no thanks to the elves who had hidden the gifts!).

The day was a huge success and enjoyed by all. Once again 15 volunteers worked tirelessly across the day to make sure everything went smoothly and we would like to give a huge thank you as the day could not have happened without you! Thank you also goes out to the Bow Tie Bears Volunteer Events Committee for contributing funds towards the event, Dave Freeman and the Reason for donating their musical talents, Prices Fresh Bakery for donations of desserts and bakery items, Sarah Cotis for face painting and of course Santa for his special visit!

DONATION AND BEQUEST NEWS

Muscular Dystrophy SA has been truly blessed! Donations large or small, one off as well as regular giving provides Muscular Dystrophy SA with much needed monetary resources by which we are able to provide continued supports to our clients and their families. To all our donors, thank you for the contributions over the course of 2016. We value you and truly appreciate your gift.

In recent weeks Muscular Dystrophy SA has been the recipient of a number of significant bequests. Deep gratitude is felt by our organisation for these bequests and thank you to the individuals and families concerned.

A donation of \$25,000 was received with much elation and will help fund our newly contracted research efforts with the University of South Australia. This donation launches our quest in raising \$250,000 for stage two of this research. The current research undertaken contributes to the world-wide search for ways to prevent, treat and cure neuromuscular conditions. We look forward to sharing the progress of this research with you.

Receiving bequests at Muscular Dystrophy SA is a bitter sweet occasion. Deep sadness is felt for the families who have lost a loved one and our hearts break for them. On the other hand, our hearts are warmed by the generous bequests we receive in memory of these loved ones and the ability to have their legacy live on through Muscular Dystrophy SA. Recently Muscular Dystrophy SA has been the recipient of over \$30,000 of bequests. These bequests assist in making a significant investment into the future of Muscular Dystrophy SA by providing resources by which we can sustain the vision and purpose of Muscular Dystrophy SA. Again, thanks to each and every donor who has so generously supported Muscular Dystrophy SA.

RESEARCH ANNOUNCEMENT

Muscular Dystrophy SA recently gifted \$75,000 to fund a collaborative research project with Associate Professor Leanna Dibbens from the School of Pharmacy and Medical Sciences at the University of South Australia. This exciting initiative marks the beginning of a new enhanced form of supporting our vision to have 'a world without neuromuscular conditions by 2050'.

Associate Professor Dibbens and her team have been responsible for some of the most significant new research into the genetic cause of epilepsy and related neurological disorders. The research project has the potential to discover more about the genetic causes and new treatment for muscular dystrophy, a disorder that has more than one form and affects people of all ages.

WHAT WE DID IN THE NORTHERN TERRITORY

Some of you might be aware that Muscular Dystrophy SA also provides support to individuals in the NT. Whilst this area is still very much in the developmental stages and we have much work to do we thought the Summer edition of Muscle Talk would be a great one to sum up some of the work we have done!

Muscular Dystrophy SA has provided a vital Coughassist machine and oximeter to support a client in the remote town of Katherine, NT. Provision of this machine will reduce hospital admissions, severity and duration of respiratory infections and hence greatly improve quality of life for this individual. To purchase these machines it cost approximately \$9,500 each plus an additional \$1,000 for the oximeter.

Earlier in the year Muscular Dystrophy SA funded a specialised car seat for young client Felicity Brown. This enabled Felicity to travel with her family and makes transfers in and out of the car so much easier, Felicity's mother Claire states having the car seat 'has been a real game changer'. A big thank you to the Katherine community who helped raised funds to contribute to equipment such as this in the NT. Lastly in conjunction with the Katherine South Primary School (KSPS) and Variety NT, Muscular Dystrophy SA has committed \$6,000 towards purchasing an 'All Abilities Swing Set' to be constructed with soft fall surfacing at the school. The specialised play equipment would also be available to non-KSPS students if necessary.



GROWN UPS GETAWAY

The 2016 Grown Ups Getaway (GUG) was held on 23-26 September at the beachside town of Victor Harbour. This year as a result of client feedback the Client Services team decided to try a slightly different approach with accommodation, as each year there is always a challenge to find an adequate amount suitable for clients with high mobility needs. So as the group ventured off on the much anticipated getaway this year there were two accommodation sites. The first, and previously utilised accommodation was the Victor Harbour Beach Front Caravan Park and the second site was the fully accessible Bundalee cabins located in Pt Elliot (yes, minutes away from the famous Pt Elliot Bakery!). This enabled additional clients with mobility needs to attend the event.

In total 15 clients attended the event with an additional six carers to provide support. This year GUG had an additional four client's visit for the day or a meal, which was a real treat! GUG experienced the highs and lows of Victor Harbour weather and despite the wet Saturday weather it did not dampen our spirits! One of the highlights of the weekend was boccia and Family Feud played on the sunny Sunday afternoon. A bit of healthy competition was enjoyed by all (once we all knew how to play Family Feud!).

Muscular Dystrophy SA was lucky enough to receive a grant from the Coopers Brewery Foundation for \$9,150 which contributed towards accommodation costs, vehicle hire and catering. The Bow Tie Bears Volunteer Events Committee also contributed \$2,000 towards the always wonderful massages by Dallas McIntyre and a dinner out at the Crown Hotel. Also a special thank you to photographer Brad Lamont for capturing some great moments throughout the weekend.





MUSCULAR DYSTROPHY SA's LOTTERIES

Would you like to win big? You could be as lucky as Cheryl and Richard (pictured right) the winner of our Fabulous Fifty Lottery.



Did you know that we run two different lotteries here at Muscular Dystrophy SA? Our \$50 Lottery has a first prize of \$10,000 and our \$35 Lottery has a first prize of whopping \$50,000!! To purchase your ticket or to find out more, call our office on 8234 5266 or buy online at mdasa.org.au/lottery

You've got to be in it to win it so buy your ticket today!!

BIG RED RIDE & RUN



Registrations for the Big Red Ride and Run are now open! We're hoping with your support, next year's Big Red Ride & Run will be more fun than ever before! Join us for the ride from Glenelg to Outer Harbour and back, or try a 10km or 5km run or walk. We'd love to see even more clients involved, so make sure you take advantage of our client discount by contacting Client Services for the code on 8234 5266.

If running or riding isn't for you, the event village will keep you entertained with food, drink, a bouncy castle and face painter. Join us for a great day out with the family and enjoy Muscular Dystrophy SA's biggest event!

Register at www.bigredrideandrun.gofundraise.com.au

ADVENTURE CHALLENGE CAMBODIA 2017

Are you interested in Adventure Challenge Cambodia 2017? We still have three spots to fill but they are filling fast to contact us on 8234 5266 or visit muscleteamadventurechallenge.gofundraise.com.au to find out more!

The Muscle Team Adventure Challenge is an initiative of Muscular Dystrophy South Australia which raises essential funds to support children and adults living with a neuromuscular condition.

In 2016-17, Muscular Dystrophy South Australia has joined forces with Andrew 'Cosi' Costello (South Aussie with Cosi) to offer you a cultural and charitable experience of a lifetime.

Our tour, hosted by Cosi, will see participants journey deep into Cambodia, exploring the country's rich, turbulent history and immersing themselves in Cambodian village life. In addition to bringing rice and supplies to a local village, you will positively impact the communities and yourself with this life changing experience.



I'd like to help improve the lives of children and adults living with neuromuscular conditions

Name:.....

Address:.....

Email:.....

Phone:.....

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 _____

For the following amount:

\$30.00 \$50.00 \$100.00 My choice of \$ _____

OR please debit my:

Visa Master card Amex Diners

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

Expiry: _ _ / _ _

Cardholder's Name:.....

Signature

CHRISTMAS APPEAL

This Christmas, please consider making a gift to Muscular Dystrophy South Australia. Your support creates the happy smiles on the faces of Harrison and his friends.

