



MUSCULAR DYSTROPHY
SOUTH AUSTRALIA

Muscle TALK

SPRING
2016



MESSAGE FROM MUSCULAR DYSTROPHY SA'S CEO

As our long term supporters will be well aware, Muscular Dystrophy South Australia exists to provide supports and services to people living with a neuromuscular condition (and their families) and to support research to find a cure and improved clinical practice. We are committed to delivering high quality client services and fundraising activities and are dedicated to investing in neuromuscular research.

The client services team works diligently to support our 750 registered clients and also to work through the Women's and Children's Hospital Neuromuscular Clinic to support newly diagnosed clients. In the past few months we have continued to increase supports to clients with the most recent addition being the 'Out and About' social support group.

We were deeply saddened to learn of the passing of George Vrastaminos. Over an extended period of time George provided our Association with valuable and unique paintings as well as permission to make prints. The Association created Christmas cards and greeting cards for sale through our support networks.

We are in the advanced stages of completing a memorandum of understanding with the University of South Australia to commence stage one of a three stage research initiative and look forward to the progress of this key strategy within our 2020 goals. In the past month we have realigned the organisation's structure to increase our focus on sponsors, fundraising and partnerships as well as strengthening our focus on lotteries. Revenues from these activities support our client activities.

One of our great fundraising activities, the Adventure Challenge, is in its fourth year and this group of 13 fundraisers have met their goals and have travelled to Cambodia for a great adventure this month mixing a great holiday experience with opportunities to provide practical support to disadvantaged families in Cambodia. This fundraiser provides outcomes for clients here in SA as well as a family with a disabled child in Cambodia. Well done to our fantastic Adventurers.

At the August Board meeting our President (David Noble) was approved three months leave of absence and has stood down as President. Tim Anderson has accepted the Board's nomination to be Muscular Dystrophy SA's President until at least the AGM. Congratulations Tim.

Phil Martin

MUSCULAR DYSTROPHY SA'S ANNUAL GENERAL MEETING (AGM)

The AGM will be held on Wednesday, 30 November 2016 at 5:00pm at the Thebarton Community Centre Meeting Room 4, Corner of South Road and Ashwin Parade, Torrensville.

The AGM can be attended by anyone who has Membership for the 2016-2017 Financial Year. If you are unsure if you have renewed your Membership please contact us on 8234 5266 or info@mdasa.org.au. Members will receive an invitation in the mail soon.

At the AGM we will approve the 2015-2016 audited financial statements and the Annual Report, receive an update on Muscular Dystrophy SA's Board Members and hear from our President and CEO on progress towards our 2020 vision.

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



[/MuscularDystrophySouthAustralia](https://www.facebook.com/MuscularDystrophySouthAustralia)



[@MusDystrophy](https://twitter.com/MusDystrophy)

Ph: (08) 8234 5266 | Fax: (08) 8234 5866

36-38 Henley Beach Road MILE END SA 5031

PO Box 24 TORRENSVILLE PLAZA SA 5031



MESSAGE FROM MUSCULAR DYSTROPHY SA'S PRESIDENT

On behalf of the Muscular Dystrophy SA Board, I would firstly like to acknowledge David Noble's valued contribution to Muscular Dystrophy SA and wish him well during his leave of absence.

The Muscular Dystrophy SA Board acts on behalf of the Muscular Dystrophy SA members to oversee and govern the organisation. We are responsible for driving the strategic direction of Muscular Dystrophy SA, which is to continue to provide our clients and their families with required services and support as we strive to reach our vision - a world without neuromuscular conditions.

Our vision is our 'light on the hill' and the purpose of Muscular Dystrophy SA supporting research is for us to help the world to get there, as we also contribute to improving clinical practice and practical supports to clients and families. In this regard it is noteworthy for us to recognise the commitment and contribution of long-standing Muscular Dystrophy SA Board Director and former President Professor Allan Bretag to research in neuromuscular conditions. It is through Allan's efforts that we are now in negotiation with The University of South Australia for the Research Agreement for Stage One of a proposed three stage research initiative. We will be in a position to provide you with details of the research initiative once we have the Research Agreement in place.

Finally, on behalf of the Muscular Dystrophy SA Board, I would like to make special mention of the great fundraising work of our 13 highly successful Adventure Challenge fundraisers and hope they experienced a wonderful productive and richly rewarding experience in Cambodia.

Tim Anderson

BUDDY UP PROGRAM

The Buddy Up program has been created to establish a social support avenue for individuals living with a neuromuscular condition who have difficulty accessing the community or have limited social networks. Buddy Up involves linking a person with a neuromuscular condition with a volunteer. Volunteers are generally recruited through South Australian Universities.

Since the commencement of Buddy Up, over 25 individuals have been involved in the program. Volunteers meet up with their buddies independently to attend certain social and community events. The program is extremely flexible and we attempt to match people with similar interests, who live in similar locations. Buddies spend time attending sporting games, the cinemas, concerts, exhibitions or even just hanging out at home.

The program provides volunteers with an opportunity for personal and professional growth through the development of social skills by interacting with their buddies and family supports. Through this interaction, the program also increases community awareness of neuromuscular conditions. Buddy Up has been a fantastic way for individuals living with a neuromuscular condition to increase their confidence and self-esteem, in turn improving quality of life.



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

Male clients aged 15-30 diagnosed with a neuromuscular condition! The group has enjoyed dinner out at the newly renovated Gepps Cross Hotel now named the Coopers Ale House and also spent an afternoon at the Royal Adelaide Show. The group also teamed up with the MD Ninjas to spend an afternoon playing wheelchair sports. Next on the list is Test Cricket at the Adelaide Oval.

MD NINJAS

Clients aged 7-14 have been meeting up to enjoy activities which have included a cooking class at Norwood and a morning at Plaster Fun House at Brighton. A visit from Lego at our office is coming up as all of the Ninjas love Lego.

OUT AND ABOUT

This is a new group for adults 30+ diagnosed with a neuromuscular condition. The group had their first gathering at the Adelaide Central Market where they enjoyed a coffee, chat and looked around the stalls. The next time they meet up they will be going to the movies to see the movie Sully.

SCA GROUP

For individuals diagnosed with SCA and their family members/carers. The group enjoyed a getaway to Victor Harbour (GUG) and have planned a visit to the Botanic Gardens for a coffee and a lovely afternoon.

CHARCOT-MARIE-TOOTH

The CMT Support group continues to meet quarterly and members of the group recently attended the annual CMT Forum on September the 3rd. The forum was facilitated by the CMT Association of SA and proved to be a very interesting and informative session.



ADVENTURE CHALLENGE 2016

What an incredible journey the 2016 Adventure Challenge has been! This year's remodelled Adventure Challenge saw thirteen fundraisers each challenged to raise a minimum of \$6,000: \$3,000 which would cover the costs of their travel, and another \$3,000 that would go directly to Muscular Dystrophy SA. From February our fundraisers have channelled their energies into a range of different fundraising activities. From coffee runs, to barbecues, to hoe-downs, to simulated horseracing events, these thirteen fundraising superstars earned their place on our September trip to Cambodia.

In 2016, we partnered with Andrew 'Cosi' Costello's charity, Cows for Cambodia, to participate in one of their unique Cambodian tours. Cosi's cow breeding program has seen dozens of families 'loaned' a cow, providing them with a sustainable source of food and alleviating poverty one household at a time. The team arrived in Phnom Penh on 17 September and spent two days exploring the country's capital, including a confronting and emotional visit to the Killing Fields. In Siam Reap, the team visited the Angkor Wat complex – the oldest religious monument in the world – and several other temples, before moving onto a village near Bakong Temple.

There the team assisted Cosi with some of the activities he undertakes as part of Cows for Cambodia: immunising cows, harvesting king grass, visiting the school and delivering gifts they had brought from home. Our team also helped Cosi assemble a huge trampoline he had shipped from Adelaide for the village kids. These kids had never even seen a trampoline before - you can imagine the looks on their faces! With the support of Cosi's crew of local labourers, our team also helped to build a home for a family living with disability – a single mother and her two children who until last week did not have a home to call their own.

The Fundraising Team would like to thank Cosi, his wonderful team and our travel agent Julie Davies from Travel Superstore for sharing this journey with us. But most of all, we would like to extend our utmost gratitude to our fundraisers – thank you for giving us your time and energy. You have been wonderful ambassadors for our organisation and we are so grateful to have your support.

DUKE OF ED

Muscular Dystrophy SA is a facilitator of the Duke of Edinburgh's International Award for young people between 14 to 25 years of age looking to challenge themselves physically and mentally while also helping their community.

MEET ONE OF OUR PARTICIPANTS TRAVIS ASHWORTH

Travis is currently studying IT at UNISA and in 2015 received his diploma at TAFE in Software Development. He enjoys playing online video games, programming and creating computer software. Travis is a very social young man who enjoys spending time with friends and especially attending outings with the MD Mafia group. Travis and 7 of his friends have recently started their own software development company called Unified Technology Solutions. Their company has just released their own mobile phone app called Love Shake. Travis actively plays wheelchair sports which includes balloon soccer, touch rugby and hockey. He also loves Judo and would love to join a club again one day.



Travis is currently undertaking his Gold award as he obtained his Bronze and Silver awards while at school. He is completing his Gold award through Muscular Dystrophy SA alongside other Duke of Edinburgh participants. The aim for Travis is to gain new skills and develop the confidence to get out of his comfort zone. Travis is in the process of planning his adventurous journey which he is enjoying doing with the help of Muscular Dystrophy SA. He is also looking into courses on leadership and public speaking.

Travis regularly volunteers at Muscular Dystrophy SA, helping with the design of new client information booklets and data base updating. With the help of Muscular Dystrophy SA and other participants Travis is hoping to complete his Gold award which he will be very proud to achieve.




MUSCULAR DYSTROPHY SA SOUTH AUSTRALIA

Muscle Team ADVENTURE CHALLENGE CAMBODIA 2017

A once-in-a-lifetime cultural and charitable experience!

INFORMATION NIGHT
6pm Monday 17 October 2016
Coopers Ale House
Pulteney Street, Adelaide

www.mdasa.org.au

ADVENTURE CHALLENGE INFO NIGHT

Interested in participating in our next Adventure Challenge? Come along to our Information Night and learn more! Cosi, our travel agent Julie and the Fundraising Team will be there to answer all of your questions. Be sure to RSVP for the Information Night at mtacinformationnight.eventbrite.com.

AISLING'S TESTIMONIAL

Aisling is one of Muscular Dystrophy SA's dedicated Client Services Coordinators and a participant of the 2016 Adventure Challenge.

"I cannot even begin to encapsulate all that the Adventure Challenge achieves both in SA and Cambodia.

Working for Muscular Dystrophy SA, I see first-hand where the money goes. To be able to give guidance, options and hope to people when they or their loved ones are diagnosed with a neuromuscular condition is the most incredible thing.

To give to people who can offer you nothing but pure gratitude in return, is the most rewarding experience imaginable. To be able to do that in two separate parts of the world has been absolutely remarkable.

After doing the maths, we worked out that we helped over 1,000 people in the week that we were in Cambodia. We made the most of every minute; volunteering at the local school, delivering rice to the poorest families we had ever seen, helping to build a house for a family who did not have a house before we arrived, and getting stuck into whatever else we could. To anyone considering taking part, I cannot recommend the Challenge enough."

CHRISTMAS TREES 2016

Don't forget to order your fresh Christmas tree from Muscular Dystrophy SA! Once again all funds raised will be going to help the Muscular Dystrophy SA State Electric Wheelchair Sports team to compete in the national competition.

If you have purchased a tree in the past you will receive an order form via email or post shortly. Please contact us on 8234 5266 or info@mdasa.org.au for more information or to order.

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



**DONATE TO OUR
SPRING APPEAL**

Social isolation for many of our clients is a chronic unmet need.

We need your help to make a difference in the lives of children and adults living with a neuromuscular condition.