



MUSCULAR DYSTROPHY
SOUTH AUSTRALIA

Client Services Newsletter

APR-MAY
2016



Camp Capacity 2016

While you are reading this article, the Client Services Team has set off with 42 campers and siblings, and 36 volunteer-carers on our annual Camp Capacity. This year's Camp theme is OMG Oceans and LOL Adventures. Our program is packed full of exciting activities to keep us all entertained for the week. We promise to upload plenty of photos while we are away. So, if you haven't already, follow us on Facebook to see what we are getting up to



www.facebook.com/MuscularDystrophySouthAustralia

MDSA's Hydrotherapy Program



Hydrotherapy is a very beneficial form of exercise for people with a neuromuscular condition as it can assist with maintaining flexibility, mobility and strength. Muscular Dystrophy SA provides a group hydrotherapy program tailored to suit individual needs, free of charge to clients over eighteen. The sessions are run by a qualified neuro-physiotherapist and have hydrotherapy attendants to assist in the water and provide some dry land assistance. Sessions are held every Thursday at the Women's and Children's Hospital. For more information contact Aisling on 8234 5266 or email aotoole@mdasa.org.au

Myotonic Dystrophy (DM)

Myotonic Dystrophy (DM) is a form of muscular dystrophy that results in weakness of the voluntary muscles in the face, neck and lower arms and legs. DM can affect other areas of the body system including the heart, breathing and swallowing muscles and cognitive function. Client Services can provide clients diagnosed with DM and family members with information and support about the condition. Client Services can also source DM research and findings. If you would like information regarding DM contact us on 8234 5266 or email aotoole@mdasa.org.au

Common symptoms of DM2 and their Impact on Daily Living

A study recently published in the Journal of Neurology on Patient-Reported Impact of Symptoms in Myotonic Dystrophy Type 2 found that while symptom themes such as inability to do activities, mobility limitations and weakness were the most common, fatigue was the symptom that had the greatest impact on people's lives. This research will help develop treatment strategies on the most important issues reported by people living with DM2. For more information, please visit www.neurology.org

MD Support Groups

Muscular Dystrophy SA proudly holds two separate social group outings per month for the MD Ninjas (clients age 7-14) and the MD Mafia (clients aged 15-25). From arts/craft for the Ninjas to dinner/shows for the Mafia, these outings provide a wonderful social opportunity for clients in similar age demographic. If you would like more information about the groups, or to get involved, contact Client Services on 8234 5266 or email Hoda at hoda@mdasa.org.au



Building for the Future Neuromuscular Conference

The Neuromuscular Conference will be taking place on Fri 17th and Sat 18th June, 2016. It will be hosted at Novotel, Sydney Olympic Park. The conference will cover topics ranging from Research updates, clinical care updates, school and beyond, assistive technology, registries, the NDIS, exercise and neuromuscular conditions and sexuality. The conference will incorporate presentations from a wide variety of medical and scientific professionals. Muscular Dystrophy SA has \$10,000 to contribute to the cost of flights and accommodation for clients and carers to attend both days. The Muscular Dystrophy Foundation also has \$10,000 federally, to contribute to the cost of registration fees. Please see the flyer enclosed or go to <http://nmconference.org.au/> to find out more. To apply for financial assistance, please contact conference@mdnsw.org.au. Please provide your details with an outline of the support you require.

What you need to know NDIS

Get together to hear from Sam Paior, parent and advocate from The Growing Space to learn what the NDIS is all about and how to make the most of it. You will come away from the session understanding what the NDIS is, who is eligible, how to plan for your planning meeting, what supports the NDIS can fund, how the money stuff works and how to choose providers and support workers. There will also be time for a Q&A session. This event is for families of children living with disability up to the age of 17 who are not yet, but will likely be part of the Scheme over the coming year in SA. It is not suitable for young children to attend. The session will be held on Thursday 5th May 2016 from 6:45pm (for 7:00pm start) – 9:00pm at JFA Purple Orange, 104 Greenhill Road Unley SA. Some accessible parking is available. To register, follow this link eventbrite.com.au/e/ndis-101-with-sam-paior-tickets-24421240588. The cost will be \$20 per person. Light snacks and drinks will be provided.

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



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NDIS Confidence and Capability Training

Julia Farr Association Purple Orange is currently hosting a series of workshops dedicated to helping participants learn about the NDIS as well as learn about other important facets to disability life. The main aim of these workshops is to give people confidence and a sense of capability towards dealing with the NDIS. Up to 8 workshops are available and each workshop runs from 10:00am to 2:00pm at JFA on 104 Greenhill Road UNLEY. **For more information about the workshops and when they are held, contact JFA Purple Orange on 8373 8333 or email admin@purpleorange.org.au**

Gene Therapy in FSHD

Researchers at the University of Massachusetts Medical School (UMMS) have successfully used a type of gene therapy which is a derivation of the CRISPR-based gene-editing method known as dCas9 to target and silence the DNA sequence implicated in Facioscapulohumeral Muscular Dystrophy. The methods demonstrated by this study should hopefully pave the way for effective and stable correction of FSHD and other epigenetic diseases. **For more information go to www.fshsociety.org**

Siblings Australia

Siblings of children or adults with illness or disability can reach out for support through Siblings Australia.

Since 1999, the organisation has helped a multitude of families by providing direct support and other resources to aid the solidification of relationships between siblings as well as parents and siblings. **For more information contact Siblings Australia via siblingsaustralia.org.au/contactus.php or via email kate@siblingsaustralia.org.au**



Chronic Medical Condition Assistance

The Australian Government provides financial support to help people who are living with a chronic medical condition. You can claim benefits and payments for certain health care services and equipment. **Please visit humanservices.gov.au/customer/subjects/chronic-medical-condition-assistance to find out what you may be eligible to claim for.**

Freedom Motors Australia

Freedom Motors Australia is the nationwide leading converter of vehicles into wheelchair accessible automobiles. With nearly 20 years in the business, Freedom Motors can assist you in buying and converting a vehicle or just simply convert an existing one. **For more information call Garry Dale on 9673 4033 or email at garry1@vanmullekom.com**



The University of Queensland - Project DMD

Project DMD is a research project focused on exploring the journey to adulthood for young people living with Duchenne Muscular Dystrophy. The project aims to learn what living as an adult with DMD is like and how young people and their families can best be supported to plan and prepare for adulthood. Interviews have taken place with people living with DMD, parents/cargivers and health professionals about the transition to adulthood. The next stage of the project is to develop resources and tools to assist with planning for life as an adult. The University of Queensland needs young people with DMD who have left school, living in Australia to participate in their video resource. **Head to www.projectdmd.com if you are interested in being involved.**

How to Communicate Effectively

Written by MD New Zealand Client Ben Robertson

Communication and everyday interactions can be difficult for all people. Interactions for people living with disability are often made harder as a result of a lack of understanding. There are several things that people with a disability can do to get the right result when explaining what you can do yourself and what you need help with. One of the most important things to remember is to have a clear idea of what you hope to achieve and therefore keep the communication lines open. If you try to remain polite, it is more likely that the result will be along the lines of what you hoped to achieve. **If you would like to have a chat about some of the best ways to communicate with your carers and other people who are unaware of your support needs, contact Client Services on 8234 5266 or email apyle@mdasa.org.au**

Carer Gateway

The new National Carer Gateway provides a website and phone service to help carers access practical information and resources to help them in their caring role. Carer Gateway provides information about the services and support available for people who care for someone with a disability, chronic illness, mental illness or who are frail aged. **The new service is available via www.carergateway.gov.au or by phone on 1800 422 737 Monday to Friday from 8:00am-6:00pm, local time in all states and territories.**

Walkers for Loan

Muscular Dystrophy SA has four-wheel walkers for loan at no cost to clients. The walkers are in good condition and feature hand grip brakes, a carry basket and seating in the centre of the walker.

If you are interested in loaning a walker, contact Client Services on 8234 5266 or email aotoole@mdasa.org.au

