~Upcoming Muscular Dystrophy SA Events & Notices~

You’re Invited!
Muscular Dystrophy SA currently facilitates a support group for individuals diagnosed with Spino-cerebellar Ataxia. The group meets on a monthly basis as an opportunity to share information, experiences and learn new and interesting things from invited guest speakers. The next meeting will have the Disability Advocacy & Complaints Service of South Australia (DACSSA). DACSSA provides support, information and advocacy for all people with disability, their family, friends and carers. They will be talking about the services they can offer Muscular Dystrophy SA clients and family members. The group would like to invite other Muscular Dystrophy SA clients to attend this meeting and learn general information regarding falls prevention. The support group will meet on Wednesday the 10th September at 1:30pm at the Muscular Dystrophy SA office, 36-38 Henley Beach Road, Mile End. If you would like to attend this meeting please contact Amber or Hoda by 8th September 2014 on 8234 5266 or email apyle@mdasa.org.au

Charcot-Marie-Tooth Luncheon
Charcot-Marie-Tooth is one of the most commonly inherited peripheral neuropathies, and although it is not life threatening does result in muscle weakness and wasting. As part of CMT Awareness month Muscular Dystrophy SA will be holding a casual lunch for clients diagnosed with CMT. The lunch will provide a relaxed atmosphere and an opportunity to share information and experiences. The lunch will be held on Tuesday 16th Sept, 12:30pm at Muscular Dystrophy SA, 36-38 Henley Beach Road, Mile End. To RSVP please contact Client Services on 8234 5266 or email apyle@mdasa.org.au. RSVP NO LATER THAN 11th September, lunch will be held subject to sufficient numbers.

Art Therapy in the School Holidays
Client Services is taking expressions of interest in facilitating some art and craft activities for students during the school holidays (from Tuesday the 30th Sept to Saturday the 4th of October). The activities will be held at the Muscular Dystrophy SA office at 36-38 Henley Beach Road, Mile End. If you or someone you care for are interested in participating in these art and craft activities please contact Client Services on 8234 5266 or email apyle@mdasa.org.au

Australian Rare Diseases Survey
This study is being conducted by the Office for Population Health Genomics, Department of Health WA in partnership with Rare Voices Australia (RVA), The Genetic and Rare Disease Network (GARDN), Genetic Support Network Victoria (GSNV) and the Association of Genetic Support Australasia (AGSA). The purpose of this study is to explore the healthcare experiences of adults living with a rare disease/disability in Australia. This includes experiences of: diagnosis, access to information, support and treatment; use of health services; patient registries, clinical trials and research. Survey participants must be aged 18 years or older and living with a rare disease/disability in Australia, or a carer or paid support worker who is permitted to complete the survey if the person aged 18 years or older living with a rare disease/disability does not have the intellectual and/or physical capability to complete the survey. The responses provided will be beneficial in obtaining a comprehensive picture of the health care experiences of people living with rare diseases/disability in Australia. It will provide important information that can be used to advocate for rare diseases/disability, plan for rare diseases/disability at a state and national level and to develop evidence based government policy. To participate in the survey, please visit www.surveymonkey.com/s/AustralianRDsurvey. The survey is anonymous and takes 20-25 minutes to complete. Closing date is 5pm on 1st September 2014.

Royal Show Tickets!
The Royal Adelaide Show is here again and Muscular Dystrophy SA has been lucky enough to receive tickets to enter the show free of charge! Tickets are very limited but do include Adult tickets and Child tickets. Due to the high demand for such tickets we may not be able to provide them to everyone however if you would like to register your interest for tickets please RSVP by 5pm, 1st September 2014 to Kelly in Client Services on 8234 5266 or email kmclean@mdasa.org.au

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Christmas Party at Adelaide Zoo
The 2014 ‘Christmas Party for Special Children’ is here again! The ‘Christmas Party for Special Children’ is held in conjunction with The Salvation Army and supported by a number of media companies to provide a Christmas Party for children with a variety of special needs. The day is filled with entertainment, a ‘Zoo BBQ’, drinks, ice-cream and much more. Children invited to the Christmas Party must be between 3-16 years of age, have a disability or illness or be disadvantaged through circumstance. The Party will be held on Sunday 30th November, 8:30am-1pm. For more details on eligibility criteria and conditions or to lodge an expression of interest please contact Kelly on 8234 5266 by Wednesday 1st October.

JFA Noske Christmas Fund
The JFA Noske Christmas Fund distributes grants of up to $200 to assist eligible adults living with physical disability, acquired brain injury or degenerative neurological condition, to celebrate Christmas. The Fund was established in 2009 in honour of the late Mr Noske who set aside funds to spread the joy of Christmas. Eligible recipients have received grants for various personal items, including short holidays, electrical goods, presents for loved ones, personal gifts, clothing, food for Christmas day and more. To be eligible to apply you must be 18 years of age or over; live with physical disability or degenerative neurological condition; currently reside, or perceive you would have been eligible to reside, at Highgate Park were your circumstances different and receive, or be eligible for, a disability support pension or equivalent. Applications are due by 5:00pm on Wednesday 27 August 2014. To apply, please complete and send the attached application form to: JFA Noske Christmas Fund, PO Box 701 Unley Business Centre SA 5061 or email admin@juliafarr.org.au For any further queries phone (08) 8373 8333

What New Carers Need to Know!
Have you recently become a non-paid carer for a parent, child, partner or friend? ‘What New Carers Need to Know’ is a training program specifically designed for new carers. Topics include identifying the phases of caring, support services, balancing of work and caring and strategies to manage your own health and wellbeing and those of the person you care for. Sessions are as follows; Monday 1st September 10am-4pm OR evening sessions over a three week period between 7-9pm on Tuesday the 9th, 16th and 23rd of September 2014 at Royal Park. To register your interest phone Western Carers on 8240 2900

Energy & Water Expos
Uniting Communities will be holding two free energy and water expos over coming months. Expos are open to everyone in the community, and feature quality information about how to read bills and save on utilities, the concessions available, customer rights and obligations, assistance available from the Energy and Water Ombudsman, financial counsellors and more! Please encourage family and friends to attend the following sessions:
Findon Community Centre
Wed 27th August 11am – 1pm
222 Findon Road
Findon SA 5023
Overseas Chinese Association
Friday 19th September 12 noon – 2pm
110 Crittenden Road
Findon SA 5023
Expo attendees will be able to wander between stations, pick up information and talk to people who can give them information, advice and referrals where required. Some issues may be able to be resolved on the day, so attendees are encouraged to bring along any troublesome bills and questions.

Duchenne Smart Phone App
The TREAT- NMD family guide for DMD, ‘The Diagnosis and Management of Duchenne Muscular Dystrophy’ is now available as an app for Android smartphones. The app contains the same amount of information that can be found in the DMD family guide which is available on both the TREAT-NMD and CARE-NMD websites. The app can be downloaded for free by using the QR-Code provided or by visiting the Android app store and searching for ‘DMD guide’ https://play.google.com/store/apps/details?id=de.uni_freiburg.imbi.dmd_guide

FOR LOAN
Three Wheeled Scooter for Loan: Muscular Dystrophy has a Victory three-wheeled scooter for loan to clients. The scooter is maroon in colour and features arm rests, rotating seat and head rest. Three month loan of the scooter is at no cost to clients but longer loan periods may be negotiable, also at no cost. If you are interested in loaning this equipment please contact Client Services on 8234 5266 or email apyle@mdasa.org.au

MDSA: 8234 5266
info@mdasa.org.au
36-38 Henley Beach Rd Mile End