



### Friedreich's Ataxia

Friedreich's Ataxia (also called FA or FRDA) is a rare inherited condition that causes nervous system damage and movement problems. It usually begins in childhood and leads to impaired muscle coordination (ataxia) that typically worsens over time. The condition is recessive, meaning it occurs only in someone who inherits two defective copies of the gene, one from each parent. Although rare, Friedreich's ataxia is the most common form of hereditary ataxia. Client Services can provide clients diagnosed with Friedreich's Ataxia and family members with information and support about the condition.

**If you would like information regarding Friedreich's Ataxia contact Client Services on 8234 5266 or email [apyle@mdasa.org.au](mailto:apyle@mdasa.org.au)**



### Grown Up's Getaway (GUG)

The annual Grown Up's Getaway offers the opportunity for clients aged 25 and over to journey with the Client Services team to an accessible

Holiday location. This year, the getaway will see the group travel to Victor Harbor to take in the picturesque surroundings as well as relax and unwind. The getaway provides a great opportunity for clients to mingle, share stories and get to know one another. RSVPs for this trip closed on Friday 1st of July. Participant information sheets and consent forms have been sent to clients who expressed interest. **If you are no longer interested in participating in this year's GUG, please contact Hoda on 8234 5266 or via email at [hoda@mdasa.org.au](mailto:hoda@mdasa.org.au)**

### Push and Powered Sports Association (PAPSA)

PAPSA returns for 2016/17. Are you a wheelchair user? Do you yearn for high impact and adrenaline filled competition? Why not join up and play in the Push and Powered Sports Association! PAPSA has provided sports recreation in wheelchair soccer, hockey, rugby and power football, to **disabled people of all ages** for the past two decades! Both **powered electric wheelchair or manual wheelchair users** can join and play! The season kicks off on **Monday, 8<sup>th</sup> of August at 6:30pm at St. Paul's College on 792 Grand Junction Road, Gilles Plains** and will then be played weekly on Monday's. It is a great opportunity to meet new people and play competitive sports. **For more information contact Jacob Gracey from Disability Recreation and Sports SA on 0457 232 813 or email [jacob@drssa.org.au](mailto:jacob@drssa.org.au)**



### Get your Royal Adelaide Show Tickets

Muscular Dystrophy SA has been provided with some tickets to this year's Royal Adelaide Show, held from the 2nd to the 11th of September at the Wayville Showgrounds. This is a wonderful opportunity to experience all that this fun-filled event has to offer. If you would like to make an expression of interest to receive show tickets, please contact Client Services on 8234 5266 or email [kmclean@mdasa.org.au](mailto:kmclean@mdasa.org.au). Please indicate how many adult and child tickets you would like and we will do our best to accommodate. RSVP by 5:00pm 22nd of August 2016.



Save our Sons, the leading national organisation fighting for people with Duchenne Muscular Dystrophy to find a cure, has welcomed the Duchenne Foundation into their family. The merger occurred on the 1<sup>st</sup> of July and will see the two organisations operate under the new name **Save our Sons Duchenne Australia**. Moving forward, the organisation will continue to fight for the quality of life of each individual living with Duchenne Muscular Dystrophy. Save our Sons Duchenne Australia will also continue their tireless work of raising money to fund vital research that could one day lead to a cure for DMD.

### Promising Employment Pathways – JFA

The Promising Employment Pathways session, brought to you by JFA Purple Orange, will be held on Friday, the 2nd of September 2016 at 9:30am-4:30pm. It will take place at the JFA Office; 104 Greenhill Road, Unley. With special guests Bruce Uditsky and Anne Hughson, the workshop session will detail their experience of working in Canada helping people living with a disability to find their way into paid employment. Other topics covered in this workshop include the importance of having an active life, ways to find suitable jobs, how to think about the job you want and various other anecdotal stories and experiences about disabled people in the work force. **If you would like to register for this event, please contact JFA on 8373 3333 or register via [www.eventbrite.com.au/e/promising-employment-pathways-tickets-26675047786?ref=ebtnebtckt](http://www.eventbrite.com.au/e/promising-employment-pathways-tickets-26675047786?ref=ebtnebtckt)**

### NDIS External Merits Review

External Merits Review (EMR) is a system of independent review of decisions made by the National Disability Insurance Agency (NDIA). An EMR system is important in ensuring NDIA decisions are fair and robust. The EMR supports people and





families to assist with navigating the process of applying for an appeal to their NDIS Plan. The EMR provides assistance in understanding the Administrative Appeals Tribunal process, attending conferences and hearings with applicants and assisting applicants to put their own case before an AAT. **For more information about the EMR please go to [www.dss.gov.au](http://www.dss.gov.au) or contact Tegan Wittard – External Merits Review Support Officer at [tegan@braininjurysa.org.au](mailto:tegan@braininjurysa.org.au) or phone 8217 7603.**

## Parents as Case Managers

Parents as Case Managers is an interactive workshop that is designed to support parents to develop the skills to manage the service sector in order to meet the needs of their child. Some topics will be covered includes: Understanding a case management model, identifying existing support networks and developing specific, measurable, attainable, realistic and time based goals. It will be held on the 16<sup>th</sup> of September at the South Australian Council of Social Service, Marjorie Black House, 47 King William Road, Unley. It will be held between 10:00am and 1:00pm. There is a \$5 investment to be paid per person. **For more information please visit [www.owllearningaustralia.com.au](http://www.owllearningaustralia.com.au) or contact Rebecca Ascher on 0415 403 676 or at [rebecca@owllearningaustralia.com.au](mailto:rebecca@owllearningaustralia.com.au)**

## Christmas Party for Special Children

The annual Christmas Party for Special Children is back again for 2016! A day promised to be filled with lots of entertainment, fun, friends and food will be running for as many kids with special needs as possible. Once again, the Christmas Party will be held at the Adelaide Zoo, this year on the 13<sup>th</sup> of November. This is a free event for children aged 3-16 to attend, who meet the criteria. **If you would like to attend the party or would like further information please contact Client Services on 8234 5266 or email [kmclean@mdasa.org.au](mailto:kmclean@mdasa.org.au)**

## Self-Directed Funding - JFA

The Self-Directed Funding session, brought to you by JFA Purple Orange, will be held on Saturday, the 3<sup>rd</sup> of September 2016 at 1:00pm-5:00pm from 104 Greenhill Road, Unley. With special guests Bruce Uditsky and Anne Hughson, the workshop session will detail their experience with Inclusion Alberta, the first resource centre on self-directed funding for people living with a disability in Canada. The session would be particularly useful for family members who are self-managing or interested in self-managing under the NDIS as well as planners, professionals, managers, CEO'S, policy developers and other people in leadership positions. Afternoon tea will be provided and attendance cost varies from \$75 for professionals and \$25 for families. **If you would like to know more about this upcoming session, please contact JFA on**

8373 3333 or register via [www.purpleorange.org.au/news-links/purple-orange-news/self-directed-funding-event/](http://www.purpleorange.org.au/news-links/purple-orange-news/self-directed-funding-event/)

## Raising awareness for CMT

CMT (Charcot-Marie-Tooth) may be a strange name for a disease but it is the most commonly inherited peripheral neuropathy. CMT is also known as (HMSN) Hereditary Motor and Sensory Neuropathy. CMT can be a very debilitating disease and is estimated to impact 1:2500 Australians. Potentially more than 3 million people worldwide live with the condition, many without knowledge. Due to damaged nerves CMT symptoms can include loss of sensation, balance, and strength to the feet and hands predominantly. Moreover, persons with CMT can suffer excessive levels of fatigue, tremours and diminished fine motor skills. People with CMT generally exhibit slow and degenerative symptoms that can develop early or later on in life. Despite no known cure for CMT there are many treatments that can be used to effectively manage its symptoms. Knowing about the condition and identifying the type of CMT is the first step in the journey. Thankfully, there has been significant research to better understand CMT.

## September - Awareness Month for CMT

Since 1988, the CMTAA (Charcot-Marie-Tooth Association Australia Inc.) has built a strong CMT community in Australia. In line with its motto "Enhancing the quality of life for People living with CMT," the CMTAA and their many enthusiastic state volunteers work tirelessly to raise awareness. September is International CMT Awareness Month. The SA CMT Team will kick off the month with their 2nd Awareness Day, 3<sup>rd</sup> September at the Adelaide Pavilion from 10am - 3pm (see flyer enclosed). If you require assistance to attend this event, please contact us and we may be able to contribute. The SA CMT Team will also be entering a team in the City to Bay Fun Run and finalising stall arrangements in the Disability, Ageing and Lifestyle Expo. **Contact the SA CMT Team on 0459084437/0416051438, via email [cmtaa-sa@cmt.org.au](mailto:cmtaa-sa@cmt.org.au) or join**

<https://www.facebook.com/groups/charcotmarietoothsa/>

## 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](mailto:aotoole@mdasa.org.au)**

