

Client Update



- **Christmas 2016 Edition** -



MDQ Christmas Gathering

Come along and celebrate the Christmas Season!



Join us for
Muscular Dystrophy Queensland's

Christmas Party

Sunday 11th December
10am - 2pm
33 Teevan Street, Stafford

for some
fun, food & festivities

Please RSVP by Nov 28 to
hannahs@mdqld.org.au
Or call 3243 9700
let us know if you have any dietary
requirements.



Research News

Exciting developments in SMA research!

The last few months have seen some extraordinary developments in the search for a treatment for SMA. Biogen have had some amazing results in their trial of SPINRAZA (nusinersen) in SMA type 1 and now in SMA type 2. The analysis found that children receiving SPINRAZA experienced a statistically significant improvement in motor function compared to those who did not receive treatment. SPINRAZA demonstrated a favourable safety profile in the trial. The initial results in the trial group were so impressive that double blind study was stopped and all participants getting the placebo were able to transition into the open-label study, in which all patients receive SPINRAZA.

Read more information about the clinical trial at media.biogen.com under the 'press releases' tab.



Research News

Duchenne drug gets FDA approval

In September, the U.S. Food and Drug Administration approved Exondys 51 (eteplirsen) injection, the first drug approved by the FDA to treat patients with Duchenne muscular dystrophy (DMD). Exondys 51 is specifically indicated for patients who have a confirmed mutation of the dystrophin gene amenable to exon 51 skipping, which affects about 13 percent of the population with DMD.

It is an idea that started right here in Australia. Murdoch University medical scientists Steve Wilton and Sue Fletcher have spent decades developing the technique that has now been licensed to Sarepta Therapeutics.

The underlying cause of DMD is a mutation or error in the gene for dystrophin, an essential protein involved in muscle fiber function.

Investigational therapies for DMD are designed to skip an exon in the dystrophin pre-mRNA to enable the synthesis of a shortened, functional form of dystrophin protein.



Exondys 51 is designed to skip exon 51. A candidate for exon 53 skipping (SRP-4053) is in clinical development, and a candidate for exon 45 skipping (SRP-4045) has entered early clinical development. There are other drug candidates in discovery and preclinical development that are designed to skip exons 44, 52, 50, 43, 55, 8 and 35, and Sarepta is committed to exploring the potential of this technology to address all DMD patients who may be candidates for exon skipping.

At this stage we cannot say when this Exondys 51 will be available in Australia. Sarepta Therapeutics is required to continue trials from which the benefits of the drug will be assessed. It may be some time before the drug is approved for use in Australia by the Therapeutic Goods Administration but getting the green light from the FDA is an exciting step in the right direction.



Facebook

CMOs now have their own MDQ Facebook pages

Did you know that each of our Case Management Officers now have their own MDQ Facebook pages? Maryanne, Lindell and Hannah have started their own MDQ Facebook pages so that you can keep up to date with news specific to your region. You can also message them directly through Facebook if you find that an easier method of communication. Of course, we still have our main Muscular Dystrophy Queensland Facebook page, so don't forget to like us and keep up to date with all the latest MD news.



The heat is on!

Can you get the Medical Cooling & Heating Concession?

The Medical Cooling and Heating Electricity Concession Scheme helps with electricity costs for people who have a chronic medical condition which is aggravated by changes in temperature. It currently provides \$329.96 (incl GST) per year to eligible applicants who:

- are a Queensland resident and
- have a qualifying medical condition and need cooling or heating to stop their symptoms becoming significantly worse
- lives at their principal place of residence, which has an air-conditioning unit.

The applicant and/or legal guardian of a minor with a qualifying medical condition must:

- hold a current Pensioner Concession Card or a current Health Care Card and
- be financially responsible for paying the electricity bill.

If you are already receiving the Electricity Rebate or other energy concessions, you can apply for this new concession.

Full details of eligibility for the concession including qualifying medical conditions, are listed on the application form. Your medical specialist must fill out the medical certification section.

For more information go to www.qld.gov.au/community/cost-of-living-support/medical-cooling-heating-electricity-concession-scheme/



North Brisbane Adult Support Group

Restarting in the new year

The North Brisbane Adult Support Group is taking a break over Christmas. Thanks to everyone who has come along throughout the year. In the new year we are looking forward to linking up with Carers Queensland to put some focus on caring for the carers. Please let us know if you are interested in coming along and we'll make sure that we keep you up to date. You might also like to 'like' Maryanne's Facebook page which will have all the details of each meeting.



Tracey Jackson presenting her story on living with FSHD at the October meeting



Annual General Meeting

MDQ welcomes three new Board Members

MDQ's Annual General Meeting took place this month. This year we welcome three new members to our Board; Ken Robertson as Treasurer and Victor Attwood and Anthony Biggar as Directors. They join President Lorna Peters, Vice President Graeme Newton, Secretary Ian Godbold and Director Helen Posselt.

We also farewell outgoing Board Members Tom Dickson and Peter Kearney who both decided to retire this year after many years of service to Muscular Dystrophy Queensland. We wish them both the very best for the future!

The Annual Report for 2015-16 is now available on our website.



Undefeated Champions!

The Queensland team triumphant at the Australian Powerchair Football Association Nationals



MDQ would like to congratulate the Queensland Powerchair Football Team on its success at the Australian Powerchair Football Association Nationals in Sydney this October. The team were undefeated throughout the competition - way to go guys! If you are interested in what it's all about, there is some great footage of the matches on the QFPA Facebook page.

The sport of Powerchair Football is played on a basketball court by people that use an electric wheelchair. There is no restriction on age or disability, so anyone can have a go!

The QFPA welcomes anyone and everyone with a disability and an interest in sport. If that's you and you have yet to find an outlet, Powerchair Football is the sport for you. On offer is freedom and independence in a competitive environment, and a great way to meet people that share similar experiences. QFPA hold regular 'come and try' days at Bowen Hills YMCA so check out their Facebook page for more information about how to get involved.



Changes to Transport Subsidies

Mobility Allowance & Taxi Subsidy Scheme changes under the NDIS

Do you receive a Mobility Allowance from Centrelink or use the Taxi Subsidy Scheme? These concessions will cease when you begin an NDIS plan - so make sure that you consider your transport needs when developing your NDIS plan!

The NDIS has three levels of support for transport assistance:

Level 1 – Up to \$1,606 per year for participants who are not working, studying or attending day programs but are seeking to enhance their community access.

Level 2 – Up to \$2,472 per year for participants who are currently working or studying part-time (up to 15 hours a week), participating in day programs and for other social, recreational or leisure activities.

Level 3 – Up to \$3,456 per year for participants who are currently working, looking for work, or studying, at least 15 hours a week, and are unable to use public transport because of their disability.

Exceptional circumstances: participants can receive higher funding if they have supports (mainstream, informal or funded) in their plan that enables their participation in employment.

Public transport: You might like to access some capacity building funding under the NDIS, so that you can develop your skills to travel more independently.

You may also be eligible for a TransLink Access Pass if you are able to use public transport on your own but have difficulty swiping on and off with a go-card. This pass entitles you to unlimited travel on all South East Queensland TransLink bus, train, ferry and tram services (except Airtrain) for \$67.40 per year.

Private Vehicle: Vehicle modifications can be considered 'reasonable and necessary' under the NDIS, for example if you need special seating or equipment to get in and out of the vehicle.

Choose one of three major prize options valued at **\$20,000**

Holiday \$20,000 (incl. travel vouchers & spending money)

Harvey Norman \$20,000 shopping spree

Gold Bullion \$20,000

MDQ Art Unions
Take Your Pick
\$10

Don't miss your chance!
Call 1800 676 364, buy online www.mdqld.org.au or by mail.

MDQ's Art Union 83 is drawn on the 16th December - Do you or your family and friends want a chance to win a \$20,000 prize this Christmas? With only 10,000 tickets available make sure you don't miss out!



NDIS News

Are you ready for the NDIS?

The NDIS is well under way in North Queensland with Mackay and Whitsunday joining the planning process right now. Toowoomba and South West Queensland will be next - starting in January 2017.

From everything we've heard so far, if you are well prepared, you are much more likely to get what you need from your plan. There are a few things that you can do right now to get ready:

- Work through the NDIS 'Getting ready for your planning conversation' workbook
- Attend Readiness Workshops in your area - there are numerous events happening all over Queensland - find one that's right for you on the NDIS Events Calendar
- Make a list of your current equipment (including consumables), services, allowances and subsidies to ensure you discuss all of your needs with the planner. Some allowances like the Taxi Subsidy and the Continence Aids Payment Scheme will cease when you transition to the NDIS - make sure that you consider this in your plan.
- Talk to your MDQ Case Management Officer - Maryanne, Hannah and Lindell are only too happy to help you get started!

Don't forget that MDQ will also be offering the following services under the NDIS:

- **Plan Management Provider** - MDQ can help you manage your NDIS funding including processing invoices, claiming from the NDIA and developing service agreements with providers.
- **Coordination of Supports** - This service is very similar to the Case Management services that we have provided to our clients prior to the NDIS. Please note that if you wish to continue to receive this service from MDQ after you enter the NDIS, you will need to ask your planner to include funding for MDQ to provide Coordination of Supports.

If you are interested in including supports from MDQ in your NDIS plan, please contact your Case Management Officer for advice before you go into your planning meeting.



Blue Badge has you covered

Your disability parking permit could save you money

It comes as no surprise that people with disabilities often face discrimination when purchasing everyday goods and services, and the insurance industry is no different. Most insurers have not taken the time to understand the needs of people with disabilities. They are not familiar with disability conversions or how such vehicles are used. The result is that they struggle to provide comprehensive cover at a fair price. Unfortunately, this means most drivers with disabilities have been paying higher insurance premiums than they should. In many cases, they may also be underinsured.

Most insurers depreciate the value of conversions in the same way they depreciate the value of a car. The problem here is that most disability conversions don't depreciate over time. If anything, materials and labour get more expensive with each passing year and that creates a risk of underinsurance because if your car were to be written-off, you could face a big gap between your insurance payout and the cost of getting you back on the road.

Thankfully things are changing with the launch of Blue Badge Insurance, Australia's first independence and mobility insurance specialist. The company has been insuring wheelchairs and mobility scooters for almost two years and has recently developed a Comprehensive Car Insurance policy that positively discriminates for the hundreds of thousands of Australians who use a Disability Parking Permit. Blue Badge's refreshing approach is based around the knowledge that people who value their mobility are safer drivers who deserve lower prices. That's why their policy actually provides discounts for vehicles using a Disability Parking Permit, including those that have been converted for drivers or passengers with a disability.

Blue Badge Insurance are offering Muscular Dystrophy QLD members an additional \$25 off your first year's premium if you switch your insurance to them before 31 January 2017 (one discount per customer).

Call 1300 304 802 and quote offer code "MDQ001" to claim your discount.

Terms and Conditions can be found on our website.



MDQ Family Day

Family fun with the Fabulous Lemon Drops

This month, MDQ hosted a family day. We had the Fabulous Lemon Drops to keep the kids (and the kid's at heart) entertained. Although the unpredictable weather kept a few families away, those who did come along had a good time and were able to make some meaningful connections with other families who can understand the challenges of living with neuromuscular conditions.

