



MUSCULAR DYSTROPHY QUEENSLAND

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LOOKING FORWARD TO 2016 - by Helene Frayne

It is a smidge over a year since I commenced as CEO of Muscular Dystrophy Qld and what a year it has been. I feel privileged to be a leader of my team of superb and dedicated staff and to work closely alongside our clients and families.

MDQ continues to provide practical and often life changing services which include individual advocacy for more support hours, equipment, and access to government services. In my year here, I have observed that my staff will exhaust every last option to enable our clients and families to improve their lives, and being a part of that is stimulating and inspiring.

We have re-defined our core service - case management - and become more efficient with our time, so we have been able to support more clients and families. Our outreach program continues, with trips last year to Townsville, Cairns, and Hervey Bay. We have been on the road again already this year visiting Gympie and the Sunshine Coast. We have developed an NDIS readiness workshop for our families and will be taking this to as many areas as possible in 2016. If you are interested in a workshop in your local area, give us a call.

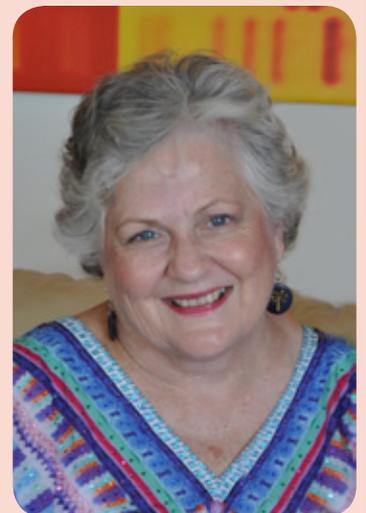
Our Hi-Lo bed loan program has been as popular as ever – these beds are in high demand and as our waiting list continues to grow we are constantly sourcing funding to continue this important program. We also continue to administer the No Interest Loan Scheme. Our Your Life Your Choice (YLYC) program is growing and as the NDIS approaches with its funding based on plan management, it is a good time for our clients with packages to enter the YLYC program and practise plan management. Interested? Call us.

In 2015, we introduced a new, free Helpline, where literally anyone can call and have questions answered about any aspect of living with a neuromuscular condition. Our Case Management Officers have also regularly attended the paediatric neuromuscular clinic to provide information and support to our children and to families whose child has just been diagnosed.

With our growing and trustworthy services there is a pressure to grow the organisation and it is my job as CEO to balance capacity with need. That has been 2015's challenge and I have had to make some difficult decisions and many changes to ensure a sustainable organisation. Our wonderful donors, event supporters, sponsors, and Art Union supporters invest extensively in our services, providing more than 80% of our income. I am grateful for their interest and investment and I am also mindful to spend their donations as they would want.

Muscular Dystrophy Qld also benefits from a close relationship with other state based organisations throughout Australia. Our mutual support is beneficial for our clients as it creates efficiencies and saves precious funds which can be directed to our services.

Last, I would like to acknowledge the Muscular Dystrophy Qld board who have led and encouraged a year of change and worked diligently to inform themselves of all the strategic issues related to this new world. I am already excited about 2016 and a continuation of the work we have done. And 2016 will be all about the NDIS, which gives hope for more choice and control and better lives for people with neuromuscular conditions throughout Queensland.



MORNING TEA FOR MD 2016

It's nearly Red Bow Appeal time and again we're asking our supporters and the community to host a Morning Tea for Muscular Dystrophy. The fundraising morning tea can be as small or as grand as you wish, a small gathering of friends in your home, a bake-off challenge at work, or a high-society high tea. Last year's morning tea events raised an incredible \$13,600 and we would love you too, to get involved by hosting a morning tea at any time during March.

Register now through our website to receive a fundraising pack or email Samantha at samanthab@mdqld.org.au or call 3243 9700.

host a
Morning Tea
for muscular dystrophy

Join us this March and host a Morning Tea for MD and show your support to Queensland families living with Muscular Dystrophy and other neuromuscular conditions.

RED BOW APPEAL
MARCH 2016

NEUROMUSCULAR HELPLINE

Late last year, we quietly introduced our new Neuromuscular Helpline service. We want everyone in Queensland to have access to information about the conditions and living positively with them. We also want to spread the word about neuromuscular conditions and get more support for people living with them.

The Helpline is open Monday to Friday (9.00 – 3.00) excluding public holidays. Anyone can call the Helpline and ask any questions – people with neuromuscular conditions, carers, family and friends, health professionals, teachers, students and even politicians! If we don't know the answers, we have a network of experts we can consult with and get back to you.



Help us spread the word about the Neuromuscular Helpline by telling your family, friends, health professionals and teachers! Invite them to call us with their questions. The number is 1800 676 364.

REGIONAL VISITS

This month, our little team visited Gympie and the Sunshine Coast to provide face to face case management sessions and an NDIS Readiness workshop. Nicolas went to Gympie and Killivan and Maryanne and Helene visited the Sunshine Coast. It was excellent to catch up with old families and to meet and support new families.



On 3-5 March, Maryanne and Helene are visiting Rockhampton to provide a similar program of services. We have sent invitations to the events we are holding. If you live in the Rocky/Gladstone area and would like to attend, it's not too late!!! Just call us to register your interest.

We have an ambitious outreach program this year to our regional centres. If you would like us to visit your region we'd love to hear from you. We will keep you updated about our outreach calendar through our website, Facebook page, or email.



MEET OUR NEW PATRON

Muscular Dystrophy Queensland is honoured to have a new patron. Emeritus Professor John Pearn may be a familiar face to some of our clients. He is a senior paediatrician at Lady Cilento Children's Hospital and for many years he served as Professor of Paediatrics and Child Health at the University of Queensland and the Royal Brisbane Women and Children's Hospital.

His research publications in international literature have contributed to child safety and welfare, clinical genetics, neuromuscular disease and medical ethics.

Professor Pearn has received numerous awards including the Order of Australia for service to medicine, particularly in the areas of paediatrics and medical ethics, to medical history, and to the community through injury prevention and first aid programs.

KEEP IN TOUCH!

We want to keep you up to date with all the latest information, particularly as we approach the NDIS. Please let us know if your contact details change and advise us of your preferred contact method.



Did you know that we post regular updates on the NDIS, community events and news stories that may be relevant to our clients. It is also a great opportunity to have your say and share information with others. If you haven't already done so, just search for Muscular Dystrophy Queensland from your facebook profile and "like" our page to receive all the latest from MD Qld in your news feed.



MD Qld is committed to keeping our costs low so we would like to keep in touch by email as much as possible. If we have your email address you will have received the link to this update in your inbox - thanks for clicking!

If you received this update in the post, we probably don't have a valid email address for you. Please let us know if you have an email address or would like to update any of your details to suziz@mdqld.org.au or call 3243 9700.



Thu 16 - Sat 18
June 2016

Sydney Olympic
Park

Building for the future neuromuscular conference is all about planning now for the future! Presentations will include research updates, clinical care updates, school and beyond, assistive technology, registries, the NDIS and self-managing your supports, exercise considerations in neuromuscular conditions and sexuality.

The conference will include presentations from a wide variety of medical and scientific professionals in the neuromuscular field, researchers, clinicians, NDIS representatives, people living with a neuromuscular conditions, NGO's and many more.

Find out more on www.nmconference.org.au

PREPARING FOR THE NDIS

The National Disability Insurance Scheme will commence in Queensland on 1 July, 2016. That is only 127 sleeps away, so call Muscular Dystrophy Queensland to help you to prepare.

Remember Knowledge is Power! There are some great ways you can increase your knowledge of the NDIS and your confidence in this wonderful scheme which gives you more choice and control over your funded supports. Attend one of the NDIS Readiness Workshops that are being held throughout Queensland (see list opposite for some upcoming workshops)

- Attend a special Muscular Dystrophy Qld Readiness workshop. We understand your needs the best and we are travelling throughout Queensland to provide workshops. When one comes to your area, come along and learn good things and meet new people.
- Be a frequent visitor to NDIS websites (listed below)
www.ndis.gov.au
The participant section is the place for you.
www.communities.qld.gov.au/disability
For information about the NDIS coming to Queensland.
The NDIS is constantly evolving and these websites continually update information so please be a frequent visitor - or sign up for their email notifications.
- Call or email Muscular Dystrophy Queensland with your questions. Our Case Management Officers can answer your questions and advise you about the NDIS.

You don't get what you don't ask for! Your relationship with the NDIS starts with the planning meeting. At your planning meeting, you will need to know your current supports (funded and unfunded); have an idea of what you want to achieve in your life in the next 12 months; and what you might need from the NDIS to get there. Muscular Dystrophy Queensland can help you to be prepared.

Consider including MDQ in your NDIS Support Plan If you want to continue your case management relationship with Muscular Dystrophy Queensland, it is important to contact us before your planning meeting and talk about the number of case management support hours you will need in your NDIS Plan. This is important.

We would love to hear from you for a chat about the NDIS. The NDIS is an exciting opportunity for you and we would love to help you to understand, have confidence in, and get the reasonable and necessary supports you deserve from the NDIS. Call us on 3243 9700!

WEAR RED FOR MUSCULAR DYSTROPHY

This year, Muscular Dystrophy Queensland is aiming to inspire schools across the state to hold a free dress day and "Wear Red for Muscular Dystrophy". Our aim is to raise awareness of muscular dystrophy and other neuromuscular conditions.

If you would like a brochure to give to your local school, please contact our events team by email at events@mdqld.org.au or call 07 3243 9700.

UPCOMING NDIS WORKSHOPS

There are many NDIS workshops happening all over the State - these are just some of the workshops coming up in March. We highly recommend that you keep an eye on the NDIS calendar on www.communities.qld.gov.au for workshops in your area.

Paving the Way

Pave the Way invites people with disabilities and their families to a presentation about preparing for the National Disability Insurance Scheme (NDIS). To register, visit www.pavetheway.com.au

March 1 - Mackay
March 2 - Airlie Beach
March 3 - Ayr
March 10 - Mt Isa
March 22 - Moreton Bay

YFS Get Ready Workshops

Topics covered: Overview of the NDIS and how it will affect you, planning the supports you need to live a good life, how to be a confident and savvy consumer, navigating the NDIS and ways to start preparing. The forums are 2.5 hours in duration.

March 1 - Cleveland
March 9 - Robina
March 11 - Wellington Point
March 12 - Logan Central
March 15 - Jimboomba
March 16 - Upper Coomera
March 22 - Victoria Point

Opportunities for a Good Life

This one day forum showcases stories by and about people with disabilities and their families who have been involved in the NDIS trial sites will talk about: Preparation, Creating a vision and planning for a good life, Self-directing and self-managing, Staying well connected in their community and Day-to-day experience of the NDIS.

March 4 - Toowoomba
March 5 - South Brisbane

Making the Most of the NDIS

Information about the NDIS and help people to think about how they can best use the opportunities offered by the new scheme. People who have attended a "Getting Informed" session or "Taking Charge of Change" workshop can start to identify the funded supports needed to complement and strengthen informal, community and mainstream supports that help create and sustain a good life. How can you blend funded NDIS support with natural supports that come from family, friends and community?

March 2 - South Brisbane
March 14&15 - Rockhampton
March 17 - South Brisbane



SOME MEMORIES FROM THE 2015 CHRISTMAS GATHERINGS

BRISBANE: Our South East Queensland Client Christmas Party was held at The Community Place in Stafford thanks to the funding from the Lord Mayor's Community Benefit Fund. Much fun was had by all as we enjoyed a BBQ together and messed around in the photo booth (we just had to share some of these terrific photos with you) - there was even a visit from Santa Clause!



CAIRNS: Friends, families & supporters of Muscular Dystrophy Queensland met for a Community Christmas Party on the Cairns Esplanade at the Fun Ship Parkland. Our Case Management Officer Maryanne Dover flew up for the occasion and everyone enjoyed some fun in the sun along with a delicious BBQ. Special thanks to BDO Cairns, Trinity Auto, Marsh's Butcher and Telstra Cairns for helping to make the day so special!



WAYS YOU CAN HELP OUR MD COMMUNITY

Have you ever wondered how you and your friends and family can get involved to raise awareness and much needed funds for Muscular Dystrophy Queensland?

WEAR RED FOR MUSCULAR DYSTROPHY: Don't let the school kids have all the fun! If you would like to host your own 'Wear Red for muscular dystrophy' day please contact our events team on 07 3243 9700.

MORNING TEA 4MD: Muscular Dystrophy Queensland will again be encouraging everyone to participate in our 'Morning Tea 4MD' campaign which coincides with our annual Red Bow Appeal in March. Get out your recipe books and plan to host you own tea party or encourage your friends and family to get involved.

ART UNION TICKETS: Great prize packages are always up for grabs in our quarterly Art Union draws. How would you like a \$20,000 shopping spree at Harvey Norman, a dream holiday, or would you just take the gold? Tickets are only \$10 each and limited to only 10,000 tickets. If you'd like an order form for you or your family and friends, or maybe a poster to put up on your work notice board, please let us know.