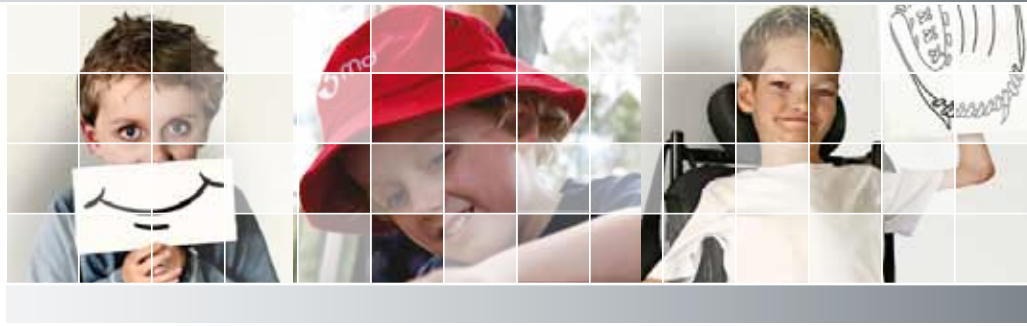




MUSCULAR DYSTROPHY QUEENSLAND

NEWSLETTER • ISSUE #11



Personal Message from the Client Services Manager



Since the last issue my greatest joy has been meeting many clients through our Christmas Parties that were held during November and December. There's nothing like putting faces to names and being able to connect in person. I hope that those who attended found it to be an opportunity to meet with other people who, whether new or previous acquaintances, are part of our Muscular Dystrophy Queensland family. It's amazing how connecting can sometimes make a big difference knowing that there are other people in similar circumstances who can share their experiences.

As a result of the increased need for services and support, the Client Services Team has reached a caseload level beyond the capacity of the number of staff currently providing case management. It

has therefore become necessary for Muscular Dystrophy Queensland to review the method of our current Client Services delivery so we are able to continue to respond to clients effectively and within a timely manner.

Commencing on Monday 31 January the Client Services Team has operated on the basis of responding to individual requests based on a Priority of Need. Through discussions with individuals and families/carers, assessments will be made to identify their high, medium or low needs. This will be done in an equitable manner by considering State-wide needs through implementing a Priority of Need Service Wait List.

The current Client Services Team comprises of Dianne Robertson, Jane Airen, Nicolas Velez and our newly appointed Case Worker, Rebecca MacKenzie. We are delighted to welcome Rebecca to our team. She is currently in the handover process. With the Priority of Need approach we ask that clients requiring any support should contact Muscular Dystrophy Queensland by asking for their assigned Case Worker. In cases where an assigned Case Worker has not been clarified, please ask for the Intake Person (each Case Worker is on Intake one week per month on a rotating basis) who will identify your Priority of Need and explain to you how your specific request will be handled within a timely manner.

Please let the Client Services Team know if there is anything we can do to assist you if you were affected by the recent floods or cyclones. We

understand that, due to evacuation and electricity failure, it has been difficult for some of you to contact us but nevertheless we would urge anyone who has been adversely affected to contact us. We are here to assist in any way we can including offering advice on financial support available through the State and Commonwealth Governments and the Premier's Appeal.

On behalf of the Client Services Team I would like to thank those clients who were involved with our Triennial Audit. As a result of your valuable feedback the auditors highlighted some recommendations that we can take forward and continue to improve our services to meet your needs. We are thrilled to advise that Muscular Dystrophy Queensland passed our audit with flying colours.



Rebecca Mackenzie - Case Worker

Art Union 60
supporting families living with Muscular Dystrophy in Queensland.



To purchase tickets phone 1800 676 364.

Win \$30,000
in cashable gold bullion or have your choice of other great prizes.



LIMITED TICKETS

Muscular Dystrophy Queensland Ride 4 MD



In August 2011 we will see the first ever Muscular Dystrophy Queensland 'Ride 4 MD'. The event will be a 100km cycle from Brisbane to Caloundra.

Muscular Dystrophy Queensland is looking for cyclists, volunteers and sponsors to get involved

in the event. If you are a complete novice, a Lycra Legend or a cycling expert, we would like to invite you to become involved to help us reach our fundraising targets. To register your interest or for more information regarding the event please email events@mdqld.org.au or call Samantha Cox on 1800 676 364.

'Give us More to Smile About' Campaign

Muscular Dystrophy Queensland is proud to present the 'Give us More to Smile About' campaign. The program has been launched by our comedian friend and living legend, Jerry Lewis. For more information regarding the 'Give us More to Smile About Campaign', please visit YouTube and search for Jerry Lewis Muscular Dystrophy Australia and read some of the great stories.

In conjunction with the 'Give us More to Smile About' Campaign, this year Muscular Dystrophy Queensland will be placing thousands of our smile donation boxes in retailer outlets throughout Australia. If you know of a business in your area who may be interested in taking a box, or if you would simply like one in your home for your spare change, please contact Muscular Dystrophy Queensland on 3607 1800.



Australian National Duchenne Registry Launch

The launch of the Australian National Duchenne Muscular Dystrophy Registry took place on Monday, 15 November 2010 at Parliament House in Canberra with guest speaker Senator Jan McLucas. In addition to the national launch, co-ordinated launches were held in several States, including Queensland, to promote and celebrate this monumental achievement.

Muscular Dystrophy Queensland held its National DMD Registry launch at its office in Hendra, with guest speakers Dr Anita Cairns, Paediatric Neurologist at the Royal Children's Hospital and Troy Smyth, Duchenne Foundation Director. The Registry collates the patient's clinical and

genetic mutation data to improve the care of DMD patients and accelerates the recruitment process for Australian DMD patients into international multi-centre clinical trials. The Registry links into the TREAT-NMD global network of registries, opening up opportunities for Australian DMD patients to participate in clinical trials being undertaken anywhere in the world.

The TREAT-NMD global network of national registries has proven effective in improving the health and management of boys with DMD. If you would like more information or wish to be placed on the Australian National Duchenne Muscular Dystrophy Registry, please phone 07 3607 1800.



Proposed Neuromuscular Clinic

The Neuromuscular Alliance Queensland (NMAQ) was established on 29 January 2010 and is comprised of a diverse group of specialist physicians and allied health professionals as well as representatives from various neuromuscular organisations, such as Muscular Dystrophy Queensland (MD Queensland), Montrose Access (MA), Duchenne Foundation (DF), SMA Association of Australia (SMAAA), The Myasthenia Gravis Association of Queensland (MGAQ), Cure CMD and other individuals.

The purpose of the NMAQ was spearheading the drive for a co-ordinated multi-disciplinary neuromuscular clinic for the people of Queensland. Since its inception in January 2010, the NMAQ has been involved in the development and submission of a business proposal to the Queensland Government for the establishment and funding of a neuromuscular clinic at the Royal/Mater Children's Hospital in Brisbane for annual clinical reviews, as well as an additional business proposal for the funding of regular allied community clinics through the Montrose Access Corinda and Strathpine Centres.

Thanks to the advocacy efforts of our Alliance partners and their members who have written letters in support of our clinic proposal to their local MP's, we are currently involved in meetings with Children's Health Services. This proposed neuromuscular clinic would be staffed with a variety of specialists providing all aspects of care including a paid co-ordinator. The clinic would enable families with children who have neuromuscular conditions to minimise the number of hospital visits required each year, with many only needing one annual visit. In addition to the annual hospital clinical visit, NMAQ has proposed that there should be regular community clinics for follow up support and care as required. The hospital based clinic would specialise in the diagnosis and treatment of all neuromuscular conditions and would be able to provide the most current, comprehensive, specialist care available, as well as timely testing and evaluations.

In addition the clinic would foster the education of the broader Paediatric and GP network across Queensland enabling all children to receive the same level of care, regardless of where in the State they live. It would encourage care locally, with visits to the hospitals in Brisbane only when necessary. It would also pave the way for patients to choose to be part of a State Neuromuscular Registry and database linked with national and international registries, ensuring that Queenslanders would be able to participate in clinical trials within Australia and overseas without leaving the State. The NMAQ and its partners will continue its work to realise their dream of a co-ordinated neuromuscular clinic for the people of Queensland.

19th Annual Red Bow Appeal

In March 2011, Muscular Dystrophy Queensland will be celebrating its 19th annual Red Bow appeal. Businesses and individuals across Queensland will once again join forces to raise funds and awareness throughout the community, bringing hope to families living with Muscular Dystrophy and other neuromuscular conditions.

The Red Bow appeal will kick off on Monday 7 March with an inaugural collection day in the Brisbane CBD at 7am. We're seeking volunteers to join the Red Bow Army and to help raise funds by selling Red Bow merchandise. Gather your friends, family and colleagues and join in on this special event. Other key events surrounding the Red Bow Appeal include the traditional All Hallows collection which will take place on Friday 11th of March and will see over 100 dedicated students of All Hallows School working together to raise funds in the Brisbane CBD. The 2010 collection proved to be an outstanding success raising over \$10,500 in only two short hours.

In March, Muscular Dystrophy Queensland will be circulating donation boxes throughout businesses across the State to raise additional funds for the Red Bow Appeal. Since their inception 3 years ago, these space saving, low maintenance boxes have raised over \$100,000 in donations and have

helped us provide services to over 400 families across Queensland. We urge everyone to show their support by taking a box to place in either their business, school or home. Every cent raised from this appeal will make a remarkable difference to the lives of families living with Muscular Dystrophy and other neuromuscular conditions in Queensland.

We would also like to acknowledge the support of our dedicated donors who continue to support the work of Muscular Dystrophy Queensland. Your generosity is greatly appreciated and we thank you for your continued support. For more information or to become involved in the Red Bow Appeal contact Muscular Dystrophy Queensland on 07 3607 1800.



Collaborative Grant by Bradley Launikonis - Muscle Research Lab

This year The University of Queensland opened applications for researchers with 'partner organizations' to apply for moneys from the Collaboration and Industry and Engagement Fund. To accelerate our work on Muscular Dystrophy, we applied to this fund with the support of Muscular Dystrophy Queensland. Our application was centred on Muscular Dystrophy Queensland's assistance in coordinating the approval of Muscular Dystrophy clients to access their archived Muscular Dystrophy biopsies and our subsequent use of these important samples in future research. I am pleased to advise you that we were awarded \$74,120 towards our Muscular Dystrophy research!

The aim of the Collaboration and Industry and Engagement Fund is to support research that will develop and become an application to larger national granting schemes, such as the Australian Research Council and the National Health and Medical Research Council. The Muscle Research Lab will now be able to hire a new research assistant to continue our work on Muscular Dystrophy and, indeed, apply for larger amounts of funding from other agencies as our Muscular Dystrophy projects progress. We wish to thank Muscular Dystrophy Queensland and their clients for their support which enabled us to secure this funding.

Talking with Tristram



In 1994, when I was only 4 years old, I attended a Muscular Dystrophy camp in Coolum. As a young kid who had only recently been diagnosed, it was one of the best things possible. I had the opportunity to ride on a Harley Davidson, play numerous games and activities, and meet people who were facing similar challenges. Generally, it afforded me the opportunity just to be a kid.

But the greatest activity, the one I will always cherish, was an electric wheelchair sports demo. I've been addicted to sports my whole life (as any of my friends would attest), but, even at the age of 4, I had resigned myself to the fact I wouldn't be able to play sport. I naively assumed that, because of my electric wheelchair, it would be impossible. Here it was though... Electric Wheelchair Sports.

The demo included the sports of hockey, soccer and rugby league. The only requirement to be able to play the sports was that you drove an electric wheelchair. No problems there. I soon got involved, played a few games, and quickly discovered that I loved it. Not too many weeks later, I was playing in Brisbane's local competition.

It's slightly daunting to think that it was 16 years ago. A lot has changed since then, but it's safe to say I'm still addicted to the sports. I've even been fortunate enough to play for Queensland Gladiators Electric Wheelchair Sports team and participate at the National Electric Wheelchair Sports competition.

However, the best thing about playing the sports is the camaraderie. By playing the sports, I've met so many wonderful people, who have all helped me along the way—not just in sport, but outside of it as well. It's been a great experience, and an incredibly fun one at that.

These days, funnily enough, I'm now the one helping out with the demos, trying to encourage kids to give it a go. So, if you're interested, please let me know. Hopefully it'll be just as fun for you as it was for me.

LOOKING FOR A GREAT DAY OUT?
Look no further than the MD Queensland HOG Ride.
SUNDAY 15TH MAY
Price includes a full day on the back of a Harley-Davidson, breakfast, morning tea, lunch & a t-shirt.
ONLY \$120
For more information or to book your seat phone MD Queensland on 07 3607 1800

2011 Teleconferences

The first teleconference planned for 2011 is on 23 February 'Getting to know the Muscular Dystrophy Queensland Client Services Team' which will be an opportunity for our team to explain our new Priority of Need Service Wait list and to share information regarding our referral, advocacy, respite, equipment, Community Networks and Outreach Services. We would encourage you to participate so that you can ask the team any questions you may have about our services or to give your comments and valuable feedback.

Our 2011 Teleconference Schedule was circulated with our last newsletter. However, we would like to enclose it with this issue to ensure that, for those clients who may have been affected by the flood or

may not be able to access the internet, you have the full details of the forthcoming Teleconferences for 2011.

For those clients with internet access all our teleconferences from 2010 are available on www.mdqld.org.au. The 2011 Teleconferences will also be uploaded onto our website. Please feel free to contact us on 3607 1800 if you would like a CD with the Muscular Dystrophy Queensland's Teleconferences.

Muscular Dystrophy Queensland were delighted with the client feedback from the audit that the teleconferences were considered a valuable resource.

Muscular Dystrophy Queensland 2011 Board of Directors

We are delighted to include in this newsletter a photograph of the Muscular Dystrophy Queensland 2011 Board of Directors who were elected at the Seventeenth Annual General Meeting on Thursday 7 October 2010:

From left; Top row: Ian Godbold (Director), Graeme Newton (President), Graham Dyer (Secretary), Peter Kearney (Treasurer); Front row: Lorna Peters (Director), Helen Posselt (Director), Clare Besly (Director) Tom Dickson (Director).



'Walk n Roll Ball' hosted by Kirrilli Cowan

When Kirrilli Cowan was inspired by her aunty who faces the challenges of living with Muscular Dystrophy she decided to host the first ever 'Walk n Roll Ball' which will take place on Saturday 12 March at 7pm within the exquisite walls of the Tivoli in Brisbane. Whether you walk or roll, you can be a part of this glamorous event enjoying a 2 course meal (with beer and wine) catered for by a 5 star chef. You will be charmed, entertained, captured

and humbled, so don't miss out on the opportunity to be a part of this truly magical night. Proceeds from the event will go towards Queensland based research and Muscular Dystrophy Queensland services. Tickets are on sale now at \$150 per person or you can enjoy a 10% discount when you book a table of 10. For more information or to purchase tickets contact Kirrilli Cowan on 0424 705 606.

Dates To Remember

23 February 2011

Teleconference - 'Getting to know the Muscular Dystrophy Queensland Client Services Team'

7 March 2011

Volunteer Collection Day
Brisbane Botanic Gardens at 7am

11 March 2011

Red Bow Day Annual Appeal

12 March 2011

Walk n Roll Ball at 7pm
The Tivoli, Brisbane

24 March 2011

Art Union 60 draw

30 March 2011

Teleconference - 'Coming from a client's perspective'

27 April 2011

Teleconference - 'All About Montrose Access'

15 May 2011

Muscular Dystrophy Qld HOG Ride

22 April 2011 - 3 May 2011

Muscular Dystrophy Queensland office closed for Easter

7 August 2011

Ride 4 MD
100km cycle from Brisbane to Caloundra



Would you like to make a donation?

Visit our website: www.mdqld.org.au or Freecall: 1800 676 364



Would you prefer to receive correspondence from Muscular Dystrophy Queensland via email?

Yes? Just phone our office on 1800 676 364.

Unit 13/191 Hedley Avenue, Hendra QLD 4011
Locked Bag 3000, Eagle Farm BC QLD 4009
t: 07 3607 1800 f: 07 3607 1899 e: info@mdqld.org.au
Muscular Dystrophy Queensland ABN 14 908 553 738