



Strong defence earns the Queensland Gladiators rewards at NEWS

Our State's electric wheelchair sports team the Queensland Gladiators, recently travelled to Sydney to participate in the annual National Electric Wheelchair Sports (NEWS) tournament. Now in its twenty-sixth year, NEWS has been held at the Sydney Academy of Sport and Recreation since 2007 and attracts teams from around Australia.

Held over one week, the tournament includes electric wheelchair soccer, hockey and rugby league. A day is dedicated to each of the sports which are played in round robin format to select the finalists. The sports have been adapted to suit the manoeuvrability of an electric wheelchair, making each a fast paced game that requires players with great skill and strategy. Old rivalries and fierce competition making the finals in particular a nail biting, captivating experience for spectators.

The Queensland Gladiators team is selected each year from players involved in local competitions around Brisbane, the Gold Coast and Toowoomba. This year's team included Bryce Castles, Tristram Peters (Captain), Joel Castles, Joshua Merkas and welcomed rookies, Blair Garten and Zac Burley and coach, Tim Merkas.

It was set to be quite a tough competition for the Gladiators this year. Although many of the players had been to NEWS before, the team lacked

experience playing together and would be facing off against very experienced interstate teams. Showing great class, the Gladiators stuck to their defensive strategies and grew stronger with each game, taking out overall third place in the finals. Joshua Merkas was selected for the All Australia Team, the sixth time he received this honour. Tristram Peters was nominated 'Player's Player' for the second consecutive year – an honour never before achieved at NEWS.

Although the on field rivalry can be tense, there is a great sense of comradery amongst the players, officials and carers attending. NEWS is so much more than a sporting event. The players have the opportunity to connect with peers and make long lasting friendships. It is also a fantastic opportunity to take a break from the everyday routine. One parent commented, "After eating dinner, I can get up and walk away. That never happens at home." Knowing there are others around who understand the needs of their loved one and who are willing to jump in and offer assistance enables carers to sit back for a bit and relax.

MD Queensland is proud to support the Gladiators. We've already begun a fundraising campaign to assist the team and their tilt at the 2012 title. Find out more about the players and offer your support online at www.everydayhero.com.au/event/gladiators.



The Gladiators huddle (from left) Zac Burley, Joshua Merkas, Joel Castles, Tristram Peters and Bryce Castles working on strategies with Coach Tim Merkas.

Farewell from Bren Arkinstall

To all my friends in the MD community, I wanted to say a special thank you for all your support and kindness over the last four years and to let you know I will be moving on from my role at Muscular Dystrophy Queensland, having accepted a position with Brisbane Boys College at Toowong as the Director of Development, commencing mid June.

I'm sincerely grateful to everybody I've been lucky enough to meet and spend time with while at MD Qld. I have made some amazing friends and I have learnt so much about courage, compassion and strength from you all. It has been one of the most positive experiences of my life to date and I am most certainly a better man for it. Muscular Dystrophy Queensland has been a great place to work, and I know the tremendous team here will continue to strive for great things.

Once again, thank you for your support, advice, encouragement and most of all your time.

Thanks again! Bren.



Ethical approval granted

We are pleased to announce Dr Bradley Launikonis, Head of the MD Muscle Research Lab at the University of Queensland, has been granted approval from the ethics committee to use archived muscle biopsies in his research.

In coming weeks, we will be contacting our clients who volunteered their muscle biopsies to arrange for signed release forms, enabling Pathology Qld to release the biopsies for use in Bradley's research.

We would like to thank everyone who responded to our call for volunteers. We'll be in touch soon!

MD Queensland farewells our friend - Bill Duyvestyn

Muscular Dystrophy Queensland was saddened to hear of the passing of Bill Duyvestyn, a long term volunteer and supporter of our organisation, on Tuesday, June 7th at the Redcliffe Hospital.



Bill was always willing to assist Muscular Dystrophy Queensland in whatever way he was asked, often helping to pack and send products and donation boxes out to businesses across Queensland to help raise money for our charity.

Bill was perhaps best known as the face of Red Bow Day in the Redcliffe area, having set up a stall to sell merchandise and receive donations in the Peninsula Fair shopping mall for the past several years now. During Red Bow Week 2011, Bill and his best friend, Peter Gray, set a record of \$1,139 collected for the week.

Bill was a member of Bethesda Baptist Church, and is survived by his wife Tracey. He leaves behind a legacy of faith, kindness and compassion and he will be sorely missed by our organisation.

NDIS Latest News - Your stories and your input counts now

Every Australian Counts is a campaign for the introduction of a National Disability Insurance Scheme.

The NDIS would revolutionise the way people with a disability, their families and carers are supported in Australia.

It would be a new support system for people with a disability, their families and carers. It would transform the way services are funded and delivered, ensuring that people's needs are met and are better supported enabling them to have greater choice and control.

For the NDIS to meet the needs of people with a disability, stories of day-to-day challenges

are urgently needed for the final report of the Productivity Commission to be submitted to the Government on 31 July 2011.

If you would like to submit your story or obtain more information on the NDIS, please contact your Case Worker at MD Qld on 1800 676 364 or visit www.everyaustraliancounts.com.au.



Myasthenia Gravis study results to help three fold



Researchers from the University of Queensland, working in collaboration with the Myasthenia Gravis Assoc. of Qld. Inc. (MGAQ) are conducting a survey of people living with MG.

The results will be used to promote greater awareness of the condition as a health issue, data collected will be used to determine the future direction of research into MG and associated health issues and the results will also be presented to government agencies with the aim of sharpening the government's focus on disability related socio-economic issues. As worldwide research into MG is limited, the findings of this survey are expected to stimulate further research and interest.

Although initiated in Queensland, the survey will be available Australia wide with the hope of having as many Australians living with MG complete the survey as possible, and offers people with MG the rare opportunity to fully explain their medical journey and how their condition has impacted on their lives. The findings will be made available on the MGAQ's website and in their newsletters.

Participants of the study will be asked questions regarding their illness, the medical therapy of it and the impact it has had on work, family and lifestyle. An additional medical questionnaire will also require endorsement from each participant's specialist and an extended timeline has been factored into receiving survey results so as to enable participants to wait until their next routine specialist appointment to have the endorsement

FSHD group calling for members

If you have FSHD and are interested in talking to and sharing information with other people living with the condition in Queensland, a new group has now been formed. Members will meet in Brisbane on a regular basis. The first get together will be at Southbank, South Brisbane on Sunday 31st July 2011 at 2pm. Please note we will make sure it is a wheelchair friendly venue and carers are also welcome. To attend please contact Bob McDowell on 0417 440 416 or email gladroad@hotmail.com

Bob McDowell
FSHD Group Coordinator

NILS loans for lifestyle too

Did you know that you can access a No Interest Loans Scheme (NILS) loan for an item that would enhance the quality of your life? A small loan of \$500, for example, may mean the difference between missing out on an opportunity that your family would value if you don't proceed and yet it would have minimal repayments over 24 months of less than \$21 per month.

A loan might help you mark a special occasion by enjoying a day out for the family at a theme park or to purchase an item that you've wanted for a long time such as a DVD player, digital television or computer. With all the bargains coming up in the end of financial year sales – well, it's a great time to take advantage of this opportunity. NILS loans can be approved up to \$2,000.

We encourage you to contact Marianne at MD Queensland or one of the Client Services Team on 1800 676 364 if you would like to benefit from this scheme.

completed. MGAQ will also be providing telephone support to answer any queries raised when completing the survey, in addition to all required documentation and reply paid postage to return the completed forms.

The information collected will be treated with the strictest confidentiality, only available to the three main researchers involved; Prof. McCombe, Dr. Gillis and Dr. Blum, before it is encoded for data entry and further analysis by other researchers involved in the project.

If you have MG and are interested in participating in this confidential study, please contact the Myasthenia Gravis Assoc. of Qld. Inc. directly on freecall 1800 802 568 or visit www.mgaq.org.au.

Growing Stronger update - Phase II commences on 4 July 2011

Regular readers of our newsletter may remember our previous article in issue 10 introducing Growing Stronger, an initiative of the Queensland Government aimed at improving the specialist disability service system so that it is easier, fairer and more sustainable.

We would now like to include an update as Phase II will commence on 4 July 2011. Key features of Phase II are:

- An intake pathway and additional intake officers to take enquiries and determine eligibility for service users, with an aim of completing registration and assessment more quickly.
- In addition to Community Linkers, Case Managers

will be assigned to clients who have been assessed with high needs.

- A new IT system within the Dept. of Communities will include a Service Catalogue showing services offered by funded service providers, including MD Queensland.
- Funding will be directed to services rather than programs.

MD Queensland clients, carers and family members wanting to know more about Phase II of the Department of Communities' Growing Stronger initiative, are encouraged to contact their Case Worker at MD Qld on 1800 676 364 or visit www.communities.qld.gov.au.

Social media helps HOG ride sell out

The annual Harley Owners Group ride for MD offers the paying public a rare opportunity to be a pillion for a day and experience the exhilaration of being part of a group of over 100 roaring Harleys. The ride is organised each year by Brisbane HOG

whose members donate their time and their bikes to support our organisation.

The roar of Harley engines was even bigger this year. Announcements on social media website, Facebook helped sell out the ride with a total of 152 bikes involved on the day, raising just over \$22,000 and making it our second biggest ride ever.

Each year the day begins early, with riders and pillions meeting outside the Morgan and Wacker Showrooms in Newstead and getting to know each other over a hot breakfast which for so many years now has been donated, cooked and served by the always reliable people of the Kiwanis Club of Brisbane.

This year the ride set out for the beautiful border town of Kingscliff via the breathtaking Gold Coast Hinterland, with a quick stop on the way at the Tambourine Community Hall for a delicious morning tea, generously donated by Helen's European Cuisine. After lunch at Cudgen Leagues Club, the pack thundered back up the M1 into an idyllic Queensland sunset. Understandably pillions were already asking to book their tickets for 2012, as they arrived back at Newstead just on sundown.



Talking with Tristram



When I was first diagnosed with a form of Muscular Dystrophy, I was too young to comprehend what it meant or how it might change my life. In all honesty, I didn't give it much thought at all. As my childish mind saw it, my legs simply didn't work as well as they should and I subsequently needed an electric wheelchair to get around. On the plus side, that wheelchair went an impressive 10km/h. My parents, however, were far more pragmatic – as parents always are. Naturally, their immediate concern was to find an organisation that would lend a helping hand. Obviously, as you've probably gathered, Muscular Dystrophy Queensland was the recommendation my family and I received all those years ago.

However, more than a decade on, it occurs to me that I've never really had the opportunity to say thank you—thanks that it has given my parents respite hours, so that they might have a little bit of a break; that it has introduced me to electric wheelchair sports; or that it has provided equipment—electric beds and computers—to make my life that much easier.

And while this gratitude can be directed at the organisation as a whole, I think that it also needs to be directed to the individuals, who toil behind the scenes, making the organisation run smoothly. Sadly, it came to my attention that one such individual shall be leaving Muscular Dystrophy Queensland and I thought, now that I've been given this space in the newsletter, I really should express my thanks.

So, Bren Arkinstall—thanks mate! Through your hard work, more and more people have learnt what MD Queensland is all about. What's more, with the MD Qld team, you've helped the organisation continue to provide support to those who have Muscular Dystrophy. Simply, cheers!

International registry expands to serve more people with congenital muscle diseases

Two years ago, Cure CMD, an organisation dedicated to finding treatments for children with congenital muscular dystrophy, launched the first and only Congenital Muscle Disease International Registry (CMDIR) to identify people with this disease, improve standards of care, and most importantly, prepare for clinical trials to find potential drug treatments.

To reach even more people with similar conditions, the international registry has expanded to collect key information from people affected by congenital myopathies, thanks to the successful partnership of several congenital muscle disease advocacy groups.

"We're very excited about this expansion," explained Anne Rutkowski, chair and co-founder of Cure CMD. "Finding more people with these diseases will enable us to create a critical mass to participate in clinical trials. Simply put, we will not be successful in finding a treatment or cure for these diseases unless we know who the affected individuals are, what the diagnosis is and how the disease is affecting the individual."

"Patient registries provide an essential and important interface between patients, clinicians

and researchers", added Dr. Kathryn North, professor at the University of Sydney in Australia. "Expansion of the registry for congenital muscle disorders is essential in raising standards of care for this rare group of conditions and ensures equity of access to clinical trials for all patients."

The registry includes demographic, health and diagnostic questions. Its mission is to act as a central hub for up to date clinical study and trial information, collect data on baseline medical information and treatment interventions and support genetic confirmation through referral to national centers of diagnostic excellence. The registry is available in English, Spanish, French, Portuguese and German.

"In Australia, State Muscular Dystrophy Associations, are actively spreading the news about the CMDIR to their clients", said Rick Carr, CEO of Muscular Dystrophy Queensland. "By participating in this international registry, our Clients can assist worldwide research seeking to unravel the mysteries of these degenerative conditions".

To register, simply log on to www.cmdir.org and click the 'register now' button.

Current employment opportunities with Muscular Dystrophy Qld

Muscular Dystrophy Queensland is seeking expressions of interest from our clients, carers and families as to whether they would like to apply for current vacancies in our Contact Centre based at Hendra. The area where this work is undertaken has disability access.

We are currently recruiting two part-time Contact Centre fundraisers who will generate donations and sell Art Union tickets to both existing and new customers. Various shifts are available and will require attendance of between 12 and 35 hours per week. Remuneration will include a base hourly

rate plus added incentives and paid training will be made available.

We encourage you to contact Marianne at MD Qld on 1800 676 364 if you (or anyone in your family or network) are interested in these current vacancies. It would be fantastic for us to know if significant interest is shown in working in the Contact Centre on a part-time basis as we can then identify whether further employment and training opportunities for clients, carers and families could be offered in this area by MD Qld in the future.

Dates To Remember

23 June 2011
Art Union 61 Draw

29 June 2011
Teleconference - 'Childrens' Neuromuscular Clinic and its research'

27 July 2011
Teleconference - 'Brisbane North Lifestyle Support - focusing on person-centred approach and current issues'
Guest Speaker - Peter Gregory

2 August 2011
Join us for a DisabiliTEA to raise awareness of the NDIS

28 August 2011
Ride 4 MD
100km cycle from Brisbane to Caloundra

31 August 2011
Teleconference - 'Living actively with Beckers - a client's perspective'
Guest Speaker - Peter Gray

22 September 2011
Art Union 62 Draw

28 September 2011
Teleconference - 'National Disability Services Qld and their latest news'

28 October 2011
Teleconference - 'Helpful advice from a GP'

30 November 2011
Teleconference - 'Latest News from researcher Dr. Bradley Launikonis'

Next teleconference 11am Wednesday 29 June Childrens' Neuromuscular Clinic

The date of this teleconference is very timely as the Childrens' Neuromuscular Clinic is expected to commence operating in July 2011. Please join us for this important teleconference to hear the latest news regarding the clinic and to have the opportunity of asking questions and giving your valuable feedback!

Phone: 1800 246 489 Security Code: 405882#

RIDE 4 MD 100 km cycle Brisbane to Caloundra
SUNDAY 28 AUGUST Ride 4md

REGISTRATIONS OPEN! RIDE4MD.ORG.AU



Would you like to make a donation?

Visit our website: www.mdqld.org.au or Freecall: 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