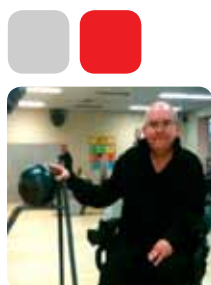




MUSCULAR DYSTROPHY QUEENSLAND

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MAY SUPERSTAR!

JOSH MERKAS: REPRESENTS IN RIO!

Sport: Power Wheel Chair Sports

Josh and his Queensland team mate Bryce Castles recently represented the Australian power chair football team in Rio, competing in the 2014 Copa Americas tournament, run by the Powerchair Football Confederation of the Americas (PFCFA). They played against the USA (the world's number one team), Canada, Brazil, Argentina, and Uruguay.

Australia made the Grand Final, sadly losing to USA. What an amazing achievement for Josh and Bryce!

How did you first get involved with Power Wheel Chair Sports? I found out about it by chance through a stranger while on holidays, that's why I think it's so important to keep promoting the sport.

When did you start playing Power Wheel Chair Sports? I first started playing wheelchairs sports when I was 9 years old. The first National powerwheelchair sport I ever competed in was two years later in the National Electric Wheelchair Sports (NEWS) competition in 2004. I started playing Power Soccer in 2011 at a development workshop in Sydney and competed at the Power Soccer Nationals that same year. My first international competition for Power Soccer was at the APO Cup in January 2013.

Highlights: Queensland Cyclones 2011 – 2013 (Silver 3 years in a row)

Queensland Gladiators 2005 – 2009, 2011 – 2013 (Balloon Soccer Champions 2007, 2012, 2013) (Hockey Champions 2007) (Rugby League Champions 2005, 2007, 2008)

Represented Australia Hockey World Cup 2010, APO CUP 2013 Power Soccer, Copa America Cup 2014, Ditch Cup

Playing Power Soccer for Australia in Brazil was one of the most amazing experiences of my life. It was great to be part of the Powerroos and play along side Chris Suffield (Captain), Jacob Cross, Chris Turnbull, Moustafa Ardati and Bryce Castles (Queensland Teammate) and coached by Peter Turnbull.

What do you like most about Power Wheel Chair Sports? Power Wheel Chair sports has given me the opportunity to play for my state and my country. It shows that I am still able to play sports even though I am in a wheelchair and it is a lot of fun to play alongside my friends and team mates.

Future Goals: My future goal in Power Soccer is to represent Australia in the World Cup in 2015 and beat the USA. I Also really want to win the National competition and beat NSW to bring the trophy back home to Queensland.

I also want to continue to grow and expand the sport in Queensland so that more people get the opportunity to play.

If you would like to get involved in Power Wheel Chair Sports please contact Tristram Peters on 0438 948 802 or email tristram.peters@uqconnect.edu.au

SMARD SUPPORT REQUEST:

We have received a request from the mother of a young man who has been diagnosed with SMARD1 who would like to talk to anyone else who may be affected by the same condition.

Spinal muscular atrophy with respiratory distress type 1 (SMARD1) is a rare inherited disorder characterized by distal muscle weakness and respiratory distress. It is caused by mutations in the IGHMBP2 gene and is clinically and genetically distinct from classic spinal muscular atrophy type 1 (SMA1). SMARD1 is also known as distal spinal muscular atrophy type 1 (DSMA1), and hereditary motor neuropathy type 6 (HMN6).

You can contact Roslyn Rasmussen on 0412 182 861 or email rozandpaul@bigpond.com





OUR CLIENT SERVICES TEAM VISITS REGIONAL QUEENSLAND

Thanks to some very generous funding from the ANZ Staff Foundation, the Muscular Dystrophy Queensland Client Services Team has been able to meet up with some of our regional clients in Central, North and Far North Queensland.

Starting off in Cairns on 29 May and Townsville on 30 May, Client Services Manager Susan Ball and Case Worker Maryanne Dover met up with clients to provide information about the services available from MDQ and the latest news on the rollout of the NDIS. It was great to discuss and share information with everyone and enjoy guest speakers.

Thanks to everyone who came along. It's wonderful to be able to meet you all face to face and get to know you better.

Other trips to regional Queensland are scheduled for the next few months and we will keep you informed about dates and venues. We hope to see you soon!

COUGH ASSIST MACHINES

With the arrival of winter we want to remind you that Muscular Dystrophy Queensland has access to several cough assist machines. These are primarily based in hospitals around Brisbane but we can ascertain availability for our clients use if required. Sometimes, in cases where we are not able to obtain one due to demand, there may be other options available that we can explore for you to have a machine on loan. If you should require one, please contact our client services team and they will try to organise one for you.

QUEENSLAND GOVERNMENT WEBPAGE ON PREPARING FOR THE NDIS

The Queensland Government has announced that their webpage on Preparing for the National Disability Insurance Scheme (NDIS) has been redeveloped with the aim of clearer communication for all users. The webpage will be updated regularly with information on the Department of Communities, Child Safety and Disability Services' preparations and progress on the NDIS.

www.communities.qld.gov.au and select national disability insurance scheme from the left hand menu (near bottom of page)

You can also keep up to date with the latest Queensland NDIS news by subscribing to the e-newsletter Pulse: getting Queensland ready for the NDIS. If you have any questions or comments, please email: NDIS@communities.qld.gov.au



PROPELLED - AVAILABLE SOON ON DVD!

For those of us who were unable to see Doug perform live at the Jute Theatre earlier this year, we now have the opportunity to see it on DVD.

A funny, revelatory and inspiring play based on the experiences of, and starring, Doug Robins. Take a ride in someone else's wheels.

Coming of age is a tricky business, especially when you're on wheels and life keeps throwing roadblocks at you.

Doug is 25 years old. He likes football, partying with his mates, and girls. He's pretty much your average guy except for one big difference. Doug has Duchenne muscular dystrophy, and negotiates life's twists and turns in a wheelchair; not always an easy feat despite the help and support of friends, family and well-meaning strangers.

Life is no blithe spin in the park; stairs aren't built for wheels, and some doors are easier to get through than others.

Armed with a whole lot of smarts, an impressive capacity for patience and a keen awareness of life's absurdities, Doug takes a heroic journey into the liminal worlds between boy and man, man and machine, the real and the fantastical, to discover who he is, and in the process finds a path uniquely his own.

'Propelled' offers a rare insight into an inspiring life through the eyes of an extraordinary man on a remarkable journey. Take a ride and be transformed...the differences may not be what they seem.

Please contact Muscular Dystrophy Queensland for details if you would like to purchase a copy of the DVD.

AN INVITATION FROM MULTICAP

This free community focused event will have entertainment, musical performances, street performers and art exhibitions from the North Brisbane community. There will be stalls, food and activities for young and old. The festival helps increase awareness of Multicap, strengthen our community links, and raise vital funds for the people we support.



26 July 2014, 10am - 3pm, 487 Ellison Road, Aspley

We are inviting you to attend or participate, if you are a stall holder drop us a line and book a stall site. If you would like to participate as part of the entertainment, volunteer or perhaps become a sponsor for the event please contact us at pinerivers@multicap.org.au or alternatively your nearest Multicap Site.

To receive updated information for the event please email staceyh@multicap.org.au and let us know, we will be able to keep you informed of entertainment, stalls and activities as they are confirmed over the coming weeks.

INTRODUCING MYOSITIS SUPPORT AUSTRALASIA

We are pleased to be able to tell you about an exciting new group that has been set up to offer support, friendship and information to those living in Australasia and all over the world.

The Facebook group is a closed group where members can share and discuss their journey with those who understand. The website is currently under construction and is scheduled to open in June. They welcome any members who have been diagnosed with a myopathy or any form of neuromuscular disease, even family members and carers who are affected by muscle-wasting conditions.

Myositis Support Australasia is part of the global family of support groups for people affected by Myositis. They are mutually supportive with Myositis Friends Support Group (UK) and Muscular Dystrophy Qld.



www.myositissupportaustralasia.com

A place for all those touched by Myositis to find connection and support.

Vision: To reach out to people in Australasia who have a direct or indirect connection with Myositis and provide support of the kind you require as individuals and as a minority demographic.

Mission: To grow these affiliations with mutual and reciprocal support throughout the network so that members feel immediate connection even if living remotely.

- Aims:**
- promote dialogue between members for tips/hints/practical suggestions
 - provide links to specialist medical practitioners in their regions
 - provide a safe forum for sharing one's journey with Myositis
 - provide links via our "Files" to research studies being undertaken, and
 - be only a couple of keystrokes away on Skype or a Facebook post or message.

YLYC WORKSHOP

Muscular Dystrophy Qld will be holding another "Your Life Your Choice" workshop on Wednesday 16 July, 10am to 12 noon at the Toombul Shire Hall, 1141 Sandgate Road, Nundah. If you have recurrent funding and are interested in finding out more about "Your Life Your Choice" and self direction please come along.

If you would like to come, or would like some further information, please RSVP to Kim McNab on 07 3243 9700 or email kimm@mdqld.org.au by Monday 14 July.



DID YOU KNOW? - QADA



QADA is a free advocacy group that provides services to anyone receiving aged care or community care services, their carers, or any adult whose decision-making capacity is being questioned, with guardianship and administration matters.

You may need an advocate when you are:

- feeling pressured to make a choice
- not satisfied with the care you are receiving
- not satisfied with decisions made about you
- wanting information regarding accessing services or additional support

QADA can support you to express your views and wishes.

THE NEWS FROM N.E.W.S!

The Queensland Gladiators travelled to Sydney on 21 April to compete at the National Electric Wheelchair Sports (NEWS) competition, eager to continue their recent successes.

The team consisted of Zac Burley, Blair Garton, Tom Latcham, Jeffrey Morrish, and Tristram Peters, and was coached by Warren Strachan. Sadly, Queensland veteran Kirk Patrinos had to pull out of the team due to health reasons, but the team were determined, despite the early setback, to do it for Kirk and bring home the silverware.

Day 1 saw the hockey competition get underway. The Gladiators improved with each outing. Although they didn't pick up a win, and failed to make the finals, they never lost a game by more than two goals, and drew with South Australia in the very last game. The experience will ensure the team push for a finals berth in 2015.



Day 2 was always marked as the Gladiators' day to shine: the balloon soccer competition. Having won the trophy in the previous two years, the Gladiators picked up where they left off, and went through the day undefeated. The teamwork was exemplary, with every player notching a goal. The grand final would see the Gladiators against the Western Australia Wasps, who battled out a 1-1 draw during the day.

Day 3 proved the toughest, yet most rewarding, with rugby league. Having played the entire competition without a bench player, the Gladiators lost more players during the day, with wheelchair issues and health problems. Often defending with a player down, the team's defence was amazing, demonstrating Queensland's 'never surrender' attitude. Because of this, the Gladiators still managed to make the three-four playoffs—to be played, once again, against the Western Wasps.

With such a positive end to the round robin, the Gladiators' attention turned to the finals. The balloon soccer grand final against Western Australia was the big one, and the game began with the team on attack, trying to force an early goal. They missed the opportunity, and the Western Wasps countered, scoring a goal at the end of the half. Despite seizing control of the second half, the Gladiators failed to clinch the equaliser, going down 1-0. It was a terrific game, and every player held their head high.

The rugby league three-four playoff began with a man down, Zac Burley's chair having broken during the soccer final. The Wasps scored two early tries, a deficit the Gladiators could never overcome, despite the return of Zac to shore up the Gladiator's defence. Despite all the adversity during the week the Gladiators knew they had given their all and had done the state proud.

The Gladiators would like to extend their thanks to all their supporters, particularly Muscularly Dystrophy Queensland, Stateside, and Inala PCYC. The team is also indebted to all those who helped with training. Thank you!

If you would like to help out, or even give electric wheelchair sports a go, please contact Tristram Peters on 0438 948 802 or email tristram.peters@uqconnect.edu.au

IN OTHER SPORTING NEWS... BOCCIA PLAYERS TAKE ON AUSTRALIA - AND THE WORLD!

Our very own Jean-Paul has been busy jetsetting to National and International boccia competitions. J-P found himself up against the world number 2 player Marco Dispaltro and took a win, making it into the quarter finals in Montreal. They were to face off again in the Quarters but this time the Canadian was victorious.



Next stop was the Australian National Championships in Sydney where he teamed up with MD Client Bikash Chapagain. They were a winning combination and brought home the gold in the BC4 pairs event. Jean-Paul also went on to win individual gold with Bikash narrowly missing the quarter finals in a nail biting game.

Our "May Superstar" Max Macourt also shone at the Nationals, his juniors team were victorious in the teams division and I'm sure Max is ecstatic about his first National gold medal. Max was also able to add a bronze medal to his growing collection from the individual rounds.

Well done to all our amazing boccia players!

To get involved in Boccia as a player, referee or volunteer, please visit the Boccia Australia website www.boccia.com.au or contact the President of Boccia Australia, Robert Marshall on 0413 120 290.



Bikash, Max and Jean-Paul with their medal haul from the Nationals and inset, J-P with boccia legend Dirceu Pinto.

SENSORY MOVIE DAYS

"Sensory Movie Day" was created for Families with Special Needs. Children are free to try every seat, lighting stays on dim. Fire exit doors are monitored for those escape artists. This movie experience is a positive, non-judgemental experience. Free membership cards are required to purchase tickets, which can be handed out on the day of the screening. Tickets cost between \$6 and \$8 depending on the venue, children 2 years and under are free and companion I.D. cards are accepted.



"The Lego Movie"

2pm Sunday 22nd June

"Rio 2"

2pm Sunday 27th July

Movie changes are possible due to unforeseen circumstances.



Venues: Morayfield Birch Carroll & Coyle
Maroochydore Birch Carroll & Coyle
Capalaba Birch Carroll & Coyle
Browns Plains Event Cinema

Ipswich Birch Carroll & Coyle (Tickets only \$6 each)
Coolangatta Birch Carroll & Coyle
Bundaberg Reading Cinemas (Start time 1.30pm)
Lismore Birch Carroll & Coyle

Contact Chanelle Avison sensorymovieday@hotmail.com or phone: 0422 416 509.

NDIS TELECONFERENCE



Our next NDIS Teleconference will be held on Wednesday 2 July at 11am. This teleconference will feature guest speakers and all the latest news from the Griffith University Symposium.

To join a teleconference, dial 07 3102 8950 or 1800 246 489 then slowly enter security code 405882#

LIFETEC REGIONAL VISITS

Are you or someone you know having difficulty performing daily tasks? Would like some information on how to make life a bit easier? Maybe Lifetec can help.



LifeTec is a specialist information and advisory service that can provide you with unbiased professional advice to help maximise independence through assistive technology. And because they don't sell the assistive technology equipment, you will have the opportunity to trial a range of items to make daily tasks easier without any pressure or obligation.

Individual Services: LifeTec's Health Professionals are available for one-on-one sessions to identify, demonstrate and trial the most suitable assistive technology solutions for everyday living. They cater to individual clients; health professionals and their clients Life Tec's services are not just limited to providing free information and advice. They are also able to provide a range of private allied health services including functional assessments, equipment prescriptions, CAEATI prescriptions, VOSS prescriptions and DVA assessments.

Teleconsultations: LifeTec Health Professionals are available to provide teleconsultations outside of the outreach trip at any time throughout the year. An example of a teleconsultation may include a client working with a local health professional and linking with a LifeTec Health Professional based in Brisbane or Townsville via a computer. For more information, or to make a booking for a teleconsultation contact LifeTec. They are also able to provide talks and presentations to groups via teleconsultation at any time throughout the year.

Region	Including	Trip Dates	Closing Date
Darling Downs	Dalby, Miles, Chinchilla, Jandowae, Wandoan, Taroom, Oakey, Pittsworth, Warwick, Goondiwindi, Stanthorpe, Inglewood, Texas, Millmerran.	14-18 July	13/6/14
South West	Roma, Mitchell, Charleville, Quilpie, Surat, Injune, Augathella, Cunnamulla, Wyandra, Dirranbandi, Thargomindah, St George.	28 July - 1 August	27/6/14
Mackay	Mackay, Collinsville, Whitsunday, Proserpine, Moranbah, Dysart, Clermont, St Lawrence.	4-8 August	4/7/14
Central West	Longreach, Jericho, Barcaldine, Tambo, Windorah, Birdsville, Bedourie, Boulia, Winton, Alpha, Aramac, Muttaburra.	15-19 September	15/8/14
Mount Isa & Flinders Highway	Hughenden, Richmond, Julia Creek, Cloncurry, Mount Isa.	27-31 October	26/9/14

Appointments are essential. Please call LifeTec on 1300 885 886 or mail@lifetec.org.au before the closing date.

JUNE SUPERSTAR!



GORDON WHITE: BOWLING THEM OVER!

Sport: Ten Pin Bowling

How did you first get involved in Ten Pin Bowling: I first heard of the sport through some friends and simply decided to have a go. Beginning at Redcliffe Bowling Centre I played for 3 years then moved across to play League at Strathpine Hyper Bowl in 1994. I've played on most weekends for 20 years and I still enjoy playing just as much now as when I first began.

Bowling Highlights: I have won several trophies throughout my career and scoring a high of 266 in one game was particularly memorable! Bowling also gave me the opportunity to travel through Queensland, competing at representative level.

Why should others get involved? Bowling is a great social opportunity and you can unleash that competitive streak or just have a good time.

What are your future goals in Tenpin Bowling? I just want to continue enjoying the sport I have played for so long. I love the atmosphere and the friendly competition. I would also like to get that elusive 300 one day!

For information on how to get involved with Tenpin Bowling as a player or volunteer, please contact Tenpin Bowling Association of Qld Inc 07 3876 5400 www.tbqa.org.au or contact your local Tenpin Bowling Club.

FARA(A) FUNDRAISERS

Friedreich Ataxia Research Association (Australasia) is a not-for-profit organisation whose sole purpose is to fund research into finding a cure for Friedreich Ataxia.



On June 28 Sarah Skelton will again take on a daunting hand cycle through Cairns but will be joined this time by fellow FAer Terry O'Hanlon who's coming up from Brisbane for the occasion. Another Australian Ride for FARA event.

Please support FAers Sarah and Terry. Make a donation and come join us for a ride to the esplanade and finish with a sausage sizzle!

Donations can be made via <https://give.everydayhero.com/au/ride-for-fara>



...or you can purchase a cool t-vest for \$40 + postage from sarma1000@hotmail.com



REGISTRATION FORMS



Thank you for the overwhelming response in sending in the Registration Forms that went out with our last Client Update. We trust that you should by now have received any information that you requested and Nicolas and Maryanne are currently working through all other enquiries.

SURVEYS

Many of you (those with email addresses) will have received a very short survey regarding the service you receive from Muscular Dystrophy Queensland. Thanks to all who have responded to this anonymous survey.

A paper copy of this survey has been attached to this update for all clients that we do not have email addresses for. Please DO NOT respond if you have already completed the survey on-line. If you received the on-line survey but were unable to complete it and would like a paper copy, please let us know and we will send you one.

WHAT'S ON



Wed 16 June 2014
YLYC Workshop
1149 Sandgate Rd, Nundah

Sun 22 June 2014
Sensory Movie Day
The Lego Movie
see page 2 for a cinema near you

Wed 2 July 2014
NDIS Teleconference
Ph: 07 3102 8950 or 1800 246 489
security code #405882#

14-18 July 2014
LifeTec Visit - Darling Downs
see page 5 for details

Sat 26 July 2014
All in Affair
487 Ellison Road, Aspley

27 July 2014
Sensory Movie Day
Rio 2
see page 2 for a cinema near you

28 July - 1 August 2014
LifeTec Visit - South West
see page 5 for details