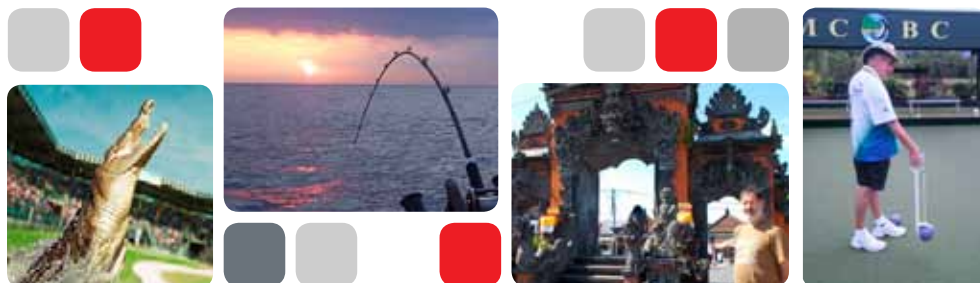




**MUSCULAR DYSTROPHY
QUEENSLAND**

1149 SANDGATE RD, NUNDAH
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BRENDAN DAWSON: FUN IN THE SUN

Recreation: Fishing & Dune Buggy

Brendan's Story: I wasn't really sure about being Star of the month, it's not really my thing and prefer to stay behind the scenes, but I decided to accept and will give a shot at a few words.

It was just last year when my older brother and I were looking at a way to make access to fishing spots that require a Quad bike to reach, such as a place known locally as the Point, a ride of 20kms. So with the help of his railway friends, my older brother built a special chair trailer out of an old Marlin chair to tow behind his Quad bike. It may not be the most comfortable of rides but it is a lot of fun getting out and seeing places that I've wanted to see.

And then a few months back, after saving up my pension for ages, I purchased a beach buggy to do the same but with a lot more fun.

I like to 4WD with my parents and younger brother. Have a big interest in fossils and went on trip around Australia's dinosaur trail last year.



Life was never meant to be easy but you just push through the bad and focus on the good. Don't give up on trying things because they seem unlikely. I do everything beneficial for better quality of life with MD; the breathing exercises, stretches, and wearing leg braces and have found after simpler ways to do them with the same results.

I've also joined online dating to look for a partner, unfortunately haven't found anyone yet but in the end it isn't as important as I originally thought.

Anyway I'd like to thank MD Qld for allowing me to be Star of the Month.



TEN PIN BOWLING PARTY!

Our friends at Cystic Fibrosis have very generously offered some free tickets to 2 Ten Pin Bowling parties. Tickets are available for special needs children and their family for the following dates:

- ◆ Sat 13 Sept 2pm: AMF Bowling Centre, Hyperdome Shopping Centre, Loganholme.
- ◆ Sunday 14th September at 2pm: AMF Bowling Centre, 403 Elizabeth Ave Kipparing.

Tickets are limited and each person attending must have a ticket. Please contact Marianne Hall at MD Qld by 6th August on 3243 9700 if you would like to go.



CALOUNDRA FISHING TRIP IS BACK ON!

We are happy to announce that the fishing day that was originally planned for March this year is back on!

Come and meet us at the Fraser Park Pier in Golden Beach, Caloundra for a fun day. We will enjoy a day of fishing from the pier as well as on Sporthand's awesome wheelchair accessible charter boat. Muscular Dystrophy Queensland will bring some bait, rods and tackle (or BYO if you like) and we will have a BBQ lunch in the park.

There are limited places available on the boat so contact our Sport and Rec Coordinator Jean-Paul on 3243 9700 to make sure you get a place (priority will be given to anyone who was confirmed for the day in March that was unfortunately cancelled due to the wild weather).

The whiting should be biting so come along and have a great day!



FINDING MY PLACE FORUM

Date: Saturday 16th August, 9.30am - 4:30 pm (Registration at 9:00)

Venue: Carrara Community Centre, Nielsens Road, Carrara, Gold Coast

Cost: \$50 (Fee is subsidised to allow as many people as possible to hear these stories)

RSVP: Thursday 7th August at: <https://findingmyplacegoldcoast.eventbrite.com.au> or www.cru.org.au



A one day forum for sharing stories by and about people with disabilities who have taken their place in their community.

People will share their experience of moving into their own homes; having jobs; following their passions and contributing to their community. The presenters who live with disability and the people who support them will also share the thinking and down to earth strategies they have used to get started and keep going. There will be speakers from the local area and further afield.

This forum will continue from themes presented at the recent "Taking Charge of Change: What do we need to be ready for the NDIS?" seminar. Participants will be inspired and encouraged to think about what is possible in the broader context of self-direction and the NDIS.

This will be of interest to people with disabilities, their families, friends, allies and circle members as well as people who support people with disability in paid roles.

Themes covered will include:

- ♦ Living in a home of one's own ♦ Self direction ♦ Ways of building natural supports ♦ Contributing to community
- ♦ Employing your own workers ♦ Working it out one person at a time

Community Resource Unit exists to create and promote positive change so people with disabilities can belong and participate in community. If you have any problems registering on-line please call CRU on (07) 3844 2211.



NDIS TELECONFERENCES

Muscular Dystrophy Queensland has regular teleconferences to keep you up to date with all the latest news about the NDIS. You can listen to all our past teleconferences on line at www.mdqld.org.au or call our office on 3243 9700 if you would like one posted to you on CD.

IMPORTANT INFORMATION FOR VENTILATOR USERS

MD Qld would like to share this vital information with you after the shocking and tragic loss of two fine young men with Duchene after a severe storm hit Perth causing power failure and subsequent loss of their valuable lives.

From all of our MD community, our sincere condolences go to their families and friends.

MD Qld is very grateful to Dr David Hillman, Head of the Department of Pulmonary Physiology at Sir Charles Gairdner Hospital and Director of the West Australian Sleep Disorders Research Institute, for the following advice.

1. Please be aware that overnight power failure can occur. Ventilator malfunction and accidental disconnection of the ventilator hose from the mask or machine can also happen.
2. Please ensure that you have a method of detecting these problems and responding to them quickly. The following can help:
 - a. household power failure alarm
 - b. ventilator alarm either inbuilt or a separate device plugged into the breathing system (consult your ventilator supplier)
 - c. communication method with carer (call bell with easily activated switch, voice communication eg. intercom)
3. Where power failure does occur use the wheelchair or battery back-up systems available to you.
4. Consider purchasing an uninterruptable power supply.
5. Ensure that you check that the alarms are working from time to time.
6. Also ensure that your back-up battery is charged and ready for use in case it is needed.
7. Newer ventilator technologies that combine some of these features will be investigated.

Please feel free to contact MD Qld if you have any concerns about power failures and essential equipment.

BECOME A ZOO KEEPER FOR A DAY!



Muscular Dystrophy Queensland is inviting 8 children to participate in The Sensory Zookeeper Program at Australia Zoo in Beerwah on the Sunshine Coast. It has been specifically designed for those aged 6 to 16 who, due to their specific health or medical requirements, may not be able to participate in the regular Zoo Keeper programs at Australia Zoo. This special program will be fun for the children and their carers!

Activities include: Brushing the tortoise's shells, learning to pat an echidna, feeding the kangaroos, saying hello and patting a koala, pat the wombat, watch Crocoseum Show and much more.

What you will receive on the day: Exclusive design "Zoo Keeper for a day" hat and water bottle, lunch, individual 6x8 photo with an animal and the experience of the day.

Costs: There is no cost for admission (includes 1 carer per child), lunch is provided for clients but can be purchased for the carer at a subsidised rate.

Eligibility: At this time, only available to children who are clients of MD Qld. Strictly limited to 8 clients, RSVP essential.

Don't miss out on this amazing opportunity. Contact Jean-Paul our Sport & Rec Co-ordinator at Muscular Dystrophy Queensland on 3243 9700.

REGIONAL QUEENSLAND VISITS - DARLING DOWNS

On Saturday 26th July our CEO Rick Carr and Case Workers Nicolas Velez and Maryanne Dover took a road trip to Toowoomba to meet with the Darling Downs Support Group.

It is always wonderful to meet face to face so that we can get to know you a little better. Through sharing information on the day we have also been able to connect with some excellent service providers in the region.

A big thanks goes to the Morrish family who hosted the day and made everyone feel most welcome in their lovely home.



NEXT STOP MACKAY!

Client Services Manager Susan Ball, Sport & Recreation Coordinator Jean-Paul LaFontaine and Case Worker Maryanne Dover are heading to Mackay on the 12th-13th September. It will be a chance to meet up with clients to provide information about the services available from MDQ and the latest news on the rollout of the NDIS.

AND COMING SOON...

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

- Gold Coast: Saturday 27th September (to be confirmed)
- Gympie: Friday 17th October
- Caloundra: Saturday 18th October, BBQ and fishing day at Fraser Park Pier, Golden Beach
- Bundaberg: Fri 7th November – Sat 8th November (to be confirmed)
- Greater Brisbane Region: Sat 29th or Sun 30th of November (to be confirmed)

We will keep you up to date with more details as they are confirmed.



Don't forget to follow us on facebook for all the latest updates and news from Muscular Dystrophy Queensland.

WHAT'S ON



12-13 Sept 2014
MD Qld visit Mackay

15-19 Sept 2014
LifeTec Visit - Central West

Sat 27 Sept 2014 (TBC)
MD Qld visit the Gold Coast

Fri 17 Sept 2014
MD Qld Visit Gympie

Sat 18 Oct 2014
Caloundra BBQ & Fishing

Sun 19 Oct 2014
Australia Zoo Trip

27-31 October 2014
LifeTec Visit - Mt Isa & Flinders Hwy

7-8 Nov 2014 (TBC)
MD Qld Visit Bundaberg

29 or 30 Nov 2014 (TBC)
MD Qld Greater Brisbane Region Gathering

DR LEANNE GAULD: TAKING ON THE BRIDGE TO BRISBANE FOR MUSCULAR DYSTROPHY!

Dr Leanne Gauld is training for the Bridge to Brisbane Fun Run to be held on 7th September 2014. We are very grateful that she has chosen Muscular Dystrophy Queensland to be her charity.



I am a paediatric respiratory and sleep physician, working at Mater and Royal Children's Hospital. I joined forces with the neurologists, MDQ and MontroseAccess a couple of years ago to form the Neuromuscular Alliance that was integral in conceptualising and founding the Queensland Children's Neuromuscular Service at RCH. Hospital staff partner with MDQ and MontroseAccess to provide multidisciplinary care. That service continues to grow today, and aims to provide holistic and coordinated medical care to children with neuromuscular weakness throughout Queensland. Many of the children with neuromuscular disease in Queensland, and their families will know me as a doctor within this service.

I began working with children with neuromuscular disease while undertaking my general paediatric training, more than a decade ago. They inspire me with their incredible stories, their smiling faces and their ability to keep motivating me to work harder for them. I undertook my Medical Doctorate on Respiratory Assessment of Childhood Neuromuscular Weakness, and have been hooked on improving medical care for this inspiring group of children, ever since then. Their wonderfully supportive families cannot help but make me proud of the community I live in. The children have many needs that do not come cheaply, and MDQ does a wonderful job of supporting them. This is my way of supporting the children and families outside the hospital. I hope I make it to the end!

You can encourage your friends and family to support Leanne by sponsoring her on the Everyday Hero website: <https://b2b2014.everydayhero.com/au/leanne>



Leanne in training, her training buddies and top, the Dr Gauld many of you will recognize.

CLIENT STORY: PETER KRUIDENIER

Peter asked us to share his story after noticing improvements in his health which he believes is due to making some lifestyle choices and taking the health supplement laminine*.

How's your health been over the past twelve months?

It has improved. My health feels more like it was 3-4 years ago.

What improvements have you seen?

I can do more things such as walk again and I'm not as reliant on a wheelchair now which is an amazing feeling. Through this independence I have been able to travel to more places such as Bali.

Two years ago when I went to Cairns on my first major holiday with my wife, Tina, we took the motorized-wheelchair 'Big Mac' and I didn't have the energy or the endurance to go out every day in the wheelchair. On the second last day I was bed-ridden from exhaustion and my muscles went into spasms.

The difference between the Cairns trip two years ago to the holiday to Bali in May this year was huge. I didn't take my motorized wheelchair at all and I was able to go out every day and sometimes walk a few kilometres. On one day I actually walked 4 kms! Bali was the turning point for me as I knew that my body was doing more than it had done for years.

Since coming back from Bali, with my renewed invigoration and confidence, I started driving again for short trips, which is quite remarkable, as I had to give up driving years ago when I was a threat to myself and anyone else on the road. It was quite a blow to my self esteem. Now I feel much safer and in control as a driver. It just feels great to have my independence and mobility back – as I used to say 'have wheels will drive' – and now it's possible again to drive short distances to see my friends.

My speech is a lot better. My endurance is a lot better. I'm walking straighter and I feel more confident in myself. Physically and mentally I feel so much more alive. My blood tests also show a marked improvement.

I am trying to keep my health the best it can be as I hope that there will be a medical breakthrough in the next few years with Myotonic knowing there is current research and trials being done in America.

If you would like any further information, Peter can be contacted on 07 5438 7924.

***Note from Muscular Dystrophy Queensland:**

These are the personal views of Peter, and do not reflect an endorsement of this product by MD Qld. Medical advice should always be sought before taking any type of supplement.



Peter at the 2012 NDIS rally and this year in Bali

AUGUST SUPERSTAR!

COLIN NEYLAND: PREPARING FOR QLD STATE TITLES!

Sport: Lawn Bowls

How did you first get involved in Lawn Bowls: In 1997 I started playing "Bare Foot Bowls" on a Tuesday night at Marlin Coast Bowls Club, Cairns. My muscular dystrophy symptoms first appeared in 1971. I started bowling in the conventional style, but since the progression of my FSHD I now use a "bowling arm" apparatus - which means I don't have to bend. As I deliver the bowls standing upright, my balance is not compromised. Other bowlers are often amazed at my prowess with the arm and have threatened to do nasty things with it on many occasions.

Bowling Highlights: Club pairs title 2013.

What are your future goals in Lawn Bowls? To win more club titles and to get into the Queensland disabled team.

Why do you love Lawn Bowls? The sport is a great leveler, anyone can play and do well, from teenagers to elderly, fit or disabled, everyone has a chance.

Each game involves about one kilometre of walking in twenty-five metre lengths, which is good gentle exercise and keeps me mobile. I bowl at least three times each week.

Most clubs provide disability access, in the form of steps or ramps, for access to and from the green and facilities within the clubrooms. I am on the committee of my local club and play competitively in open tournaments around Cairns. I compete annually at the Queensland Multi-Disability State Championships. This year they are being held at the Aspley Memorial Bowls Club, on the 31st of August till the 4th of September, with sections for people with vision, hearing, intellectual or physical disabilities. There is a great camaraderie between competitors, even across the disability sections and a great chance to catch up with old friends from previous years' competitions. The bowling standard is very high and the spectators who have not seen disability bowls before are quite often amazed.

Lawn bowls requires a set of bowls and suitable shoes. Specialised equipment that assists players to pick up their ball can be purchased from most bowls shops. Sporting Wheelies has specialised bowls wheelchairs for hire and can provide more information on guidelines for wheelchairs and a list of suppliers and manufacturers.

For more information to join a Lawn Bowls club or how to get involved as a player, umpire or volunteer, please go to www.bowlsqld.org Tel: (07) 3355 9988 or www.sportingwheelies.org.au Tel: (07) 3253 3333. or simply contact Jean-Paul LaFontaine our Sport and Rec Coordinator here at MDQ on 3243 9700 or jean-paull@mdqld.org.au

LIFETEC REGIONAL VISITS

Are you or someone you know having difficulty performing daily tasks? Would you 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. LifeTec'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
Central West	Longreach, Jericho, Barcaldine, Tambo, Windorah, Birdsville, Bedourie, Boulia, Winton, Alpha, Aramac, Muttaborra.	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.

THE LAST WORD...

Gordon White has penned a song that he would like us to share.



MD song by Gordon White

*I have Muscular Dystrophy,
That's not gona stop me,
Some people may stare,
I don't care I'm going out there,
I can't stand I will fall over,
But I'm my baby's lover,
When I put my wheelchair up a gear,
I go faster but my shoes won't wear,
I need someone to help me fill a glass,
But people telling me don't do this don't do that is a farce,
Sometimes I might make a blunder,
But my life will always be like heavy metal thunder,
I can't lift anything heavy,
That's something to put up with like a tax or levy,
I can't climb a stair,
But a ramp will get me there,
I can't play football or drive a racing car,
Our sports we play are just as thrilling by far,
I have Muscular Dystrophy,
Noth'n is gona stop me,
I have Muscular Dystrophy,
Ain't nothing is going to get the better of me,
The better of me.*

SHARE YOUR STORY

If, like Gordon or Peter, you would like to share a story, or if you would simply like to recommend a topic for the client update, please email suziz@mdqld.org.au or call 3243 9700.