

talking point

NEWSLETTER OF MUSCULAR DYSTROPHY NEW SOUTH WALES

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Season of Change

 **md**
muscular dystrophy
new south wales

Hello friends

Easter is one of my favourite times of year, less stressful than Christmas and who can resist a bit of chocolate goodness? I hope you enjoyed a few days break and some treats over the long weekend. For those of you caring for a loved one, ensure you also take some time out by using Flexi-rest or other respite programs, or even just schedule in some 'me' time where you can. MDNSW has some great events scheduled so hope you can attend, get information and meet other members.

In February I attended the second day of the *Towards a Better Future* Conference at the University of Sydney, organised by the Duchenne Foundation. I was asked to give a presentation from the perspective of living with a neuromuscular disability which I found a confronting yet empowering experience. I attended some practical sessions on occupational therapy, hydrotherapy and stretching – all important in the lives of people with a neuromuscular condition.

The overarching message I took from the conference was **hope**. There are some amazing developments in the research field and new treatments for the muscular dystrophies and other conditions. It was heartening to see the scientists, doctors, health professionals, advocates and families all come together to discuss the issues and share developments. The feeling that 'you are not alone' is reassuring. A young mum with a son with Duchenne cried as I told her that my late husband made it to age 40 and had a **good life**. For more details on the speakers and their presentations take a look at www.parentproject.com.au

In this edition our theme is that of **change**. Change although at times scary but can bring about new growth and learning. Change is healthy for any organisation and personal change can be challenging yet rewarding. A big change for the MDNSW is as we farewell our dynamic Client Services Manager Renee McBryde. As you will read Renee is about to embark

on a huge change in her life, and we remember Renee as a real change-maker for the Association. We thank Renee for her enthusiasm, commitment and 'can-do' attitude, and hope that the many strong relationships she has built with the MD family will continue into the future.

Hope you enjoy this edition of Talking Point, and might even be inspired to write your own piece for the winter edition.

Stay well as the weather changes,

Carolyn Campbell-McLean



All contributions can be sent to The Editor, PO Box 1365 Meadowbank NSW 2144 email: cazza74@iinet.net.au tel: 9684 6443

contents

EDITORIAL	2	RECENT DEVELOPMENTS FOR MYOTONIC DYSTROPHY	12
HELLO FROM THE PRESIDENT	3	TADNSW ARTWORK COMPETITION	13
RIDE FOR A CURE	4	AFTERNOON OF CREATIVE DESIGN	14
HOW TO BECOME AN EVERYDAY HERO	4	ACCESS ALL AREAS	15
CARERS CORNER	5	MAKING CHANGES – HELP ON-LINE	16
SEASON OF CHANGE	5	DISABILITY ACCESS ON-LINE	17
INTRODUCING OUR NEW TEAM MEMBERS	6	ROBERT LAMB – 10 YEAR DIAGNOSIS	18
CLIENT SERVICES	8	NATURAL THERAPIES WORKSHOP	19
NATIONAL NEUROMUSCULAR CONFERENCE 2010	10	CONTACTS, CLINICS & CLASSIFIEDS	20

Hello from the President

Welcome to the start of another propitious year, and I hope a very productive one. I think it will be one that we can approach with more confidence, as having established a new platform of services that are so much more relevant to our members, it is now our job to refine and add to them.

There have been 2 major staff changes at MDNSW. While I am sorry to lose Renee, who is going to work in Kenya, I am also confident that we have found an excellent replacement for her in Pene Hodge, who I'm sure you will be delighted to meet.

The receipt of a substantial bequest from the Laube Estate has provided substantial financial security to MDNSW, which has been very timely, arriving during a period of expansion with a background of financial uncertainty.

We had decided that after receipt of the bequest a well chosen fundraising/marketing person was essential to secure a more reliable income for our future. I'm sure Rebecca Scelly is the right person to achieve this.

I am particularly pleased that our board members are becoming increasingly involved and engaged with activities that have enabled the staff to do what they do best. And I'm sure the staff are more aware that the board is not only assisting with direction setting, but is strongly supportive of their role, whatever it may be.



Some of the board achievements to which I refer are:-

- Ian Williams initiated and oversaw a new and much more relevant MDNSW constitution prepared pro bono by Mallesons Stephen Jaques
- Colin Gunn has been adding to and maintaining both the MDNSW and MDF web sites in a very dedicated and professional way
- Graeme Troy has dedicated a great deal of time to the successful introduction of MYOB, and a much clearer and easier understood set of accounts, along with monitoring our investments. He also took a major role in negotiations regarding the Laube bequest which were both protracted and difficult
- Ross Parker has been very actively supporting fundraising events with the assistance of an impressive list of corporate contacts
- Percy Baptiste has assisted Michael with annually raising funds for and organising 9 successful National Electric Wheelchair Sports days to date, has now added the overseeing of the NSW Red Rooster receipts
- Dr Kristi Jones, has updated the staff with several very popular presentations on neuromuscular disorders; and also assisted and enabled us to acquire cutting edge database software at no cost
- And of course Heather Johnston continues to give invaluable advice in response to equipment applications, and to provide ideas and speakers for medical seminars. Heather, Dr Alistair Corbett and Dr Kristi Jones, all gave important presentations at the recent Towards a Brighter Future Neuromuscular Conference at Sydney University
- My establishment of the Spotless collection box connection at Sydney airport terminals, and new initiatives with volunteers, whose support I value greatly (particularly Mick Watkins who assists in no small way with Spotless).

I look forward to 2010 with confidence that we are engaging more closely with members, and providing increasingly more relevant services to them.

It is no accident that our membership is growing exponentially and stands at about 50 new members each year at present. This must be an indication that we are providing better and more relevant services to our members.

Rob Ferguson

President, Muscular Dystrophy New South Wales

Ride for a Cure



Duchenne Muscular Dystrophy affects the muscle function of boys, and some girls in a devastating way. One father of a beautiful boy with Duchenne has taken up the fight to find a cure for this condition that will likely see his son in an electric wheelchair by the age of 12.

Tour Duchenne is the result of one man's passion. It is three simultaneous bike rides starting from Brisbane, Melbourne and Adelaide and culminating in Sydney. There will be 25 riders on each leg with a total of 75 riders crossing the line at Darling Harbour on the 19th September.

Each rider has a goal of \$25,000 to raise, with 70% of the overall total going to Australian research of Duchenne Muscular Dystrophy and the remaining 30% going to State based programmes and support of people with a neuromuscular condition.



Tour Duchenne has teamed up with Muscular Dystrophy Foundation Australia to help make the ride happen this year. This has been a very successful partnership and as a result we are striving to raise as many funds as possible for boys with Duchenne Muscular Dystrophy.

The three legs of the ride still have places for riders left. If you, or someone you know is looking for a challenge, then jump onto www.tourduchenne.com or email rebecca.scelly@mdnsw.org.au (02 9809 2111) for further information.

If cycling really isn't your thing, then you can still support the riders by going to www.tourduchenne.com and choosing a rider to give your support to. Our very own CEO, David Jack is cycling the Brisbane to Sydney leg and you can show your support for him by going to the Tour Duchenne website, or directly to David's fundraising page at: www.everydayhero.com.au/david_jack.

This ride will bring media exposure to neuromuscular conditions and the families who live with them every day, and much needed funds to find a cure.

How to become an **Everyday Hero**

Muscular Dystrophy NSW relies on donations and fundraised income to provide the vital services and support to our members. 75% of our income is derived from fundraising and so you, our supporters are pivotal in ensuring people with a muscular dystrophy and their families are supported in their journey.

Muscular Dystrophy NSW has teamed up with Everyday Hero to make hosting your own fundraising events, or joining in a public fundraising event very easy. Public fundraising events include the Sydney Morning Herald Half Marathon (16 May) and the City2Surf (8 August). If you decide that you would like the challenge of one of these events, or you can convince a group of mates that entering as a team would be lots of fun, then you can choose Muscular Dystrophy NSW as your charity of choice and your fundraising income will come directly to MDNSW.

Another way to raise funds for Muscular Dystrophy NSW is to organise your own gathering or event and raise funds through your own Everyday Hero page. Some examples of this include a trivia night, a scrapbooking group, or a party where your guests bring donations in lieu of gifts.

The fundraising pages are quick and easy to set up and come with tools to help you promote your occasion. So check out, www.everydayhero.com.au and look for Muscular Dystrophy today!



A big thank you to all our **supporters!**

Last Christmas we sent out an appeal to all of our members and supporters asking for financial support for our Camps and Retreats. Through this appeal we raised almost \$42,000.

Thanks to your generosity, and some government funding, we are well on our way to running another Retreat in May, and another Camp in September. MDNSW is able to keep our overheads quite low and we are lucky to be driven

by a fantastic Board. A result of this is that we are able to put most of your donations straight into support for our members.

So, we would like to extend a big thank you for your generosity, you are wonderful people and together we can make a difference.



Regional visits, respite and recreational events

Welcome to the Carer's Corner of Talking Point. I hope you've enjoyed the Christmas / New Year break and are easing back into the business of another year. Many of you would have recently received a fairly bulky envelope of information detailing some upcoming events planned by Client services. We have received such a strong interest in these events; we would like to encourage you to apply soon, as places to some events are limited. There are no limits to how many events you can attend, so call the office or e-mail me your interest at carers@mdnsw.org.au

For members living in our regional areas, I have visits planned in The

South Coast on Tuesday 11 May, New England Regional Visit planned for late April, Members Meeting planned at the Newcastle City Hall on Thursday 10 June and a first time visit to the Far West - Broken Hill region in June Wednesday 23 - Friday 25 June.

On another note, it's been wonderful to see an increase in Flexi-rest respite applications during the past year. I would encourage you if you have not yet applied for these funds to call me in the office to discuss respite options for you and your family. Sometimes change is as good as a holiday.

To enquire about your eligibility for respite funds or with questions on current events or interest in having MDNSW visit you in your home, contact me on 9809 2111

I anticipate seeing many of you at some of MDNSW upcoming client events.

Kind Regards,

Georgina Christofis
Carers Program Coordinator

change

Season of change

Autumn represents change of seasons and like nature we are experiencing a change of season at MDNSW. Rebecca Scelly has joined us in an additional position to work on fund raising and events. Hulya Ucan has left us to pursue a new business and we welcome Sandra Stavrou as our new Bookkeeper.

We will miss Renée McBryde who leaves us in April to take on a volunteer tour in Africa with her husband John. Renée who has been Carer and Client Services Manager for the last eighteen months is well known to all MDNSW, members and stakeholders will be sadly missed but leaves us with the inspiration she embodies to always help others.

Change is necessary in all cycles and always brings new growth. Rather than leaving and joining we see these changes as 'passing the torch' to new torch-bearers who bring their own new energy to the MD cause.

Inspiration is never lacking at MDNSW to keep giving and getting better. Our members provide us inspiration each day with their lives and give us all energy to keep expanding what we do and what we give. One such inspiration featured in the Sun-Herald on 7th March, where Tom Barrett whose son has Muscular Dystrophy told of how he 'sold his bed, tables and chairs' to pay for the framing of a signed football jersey which raised \$1100 toward helping a fellow cancer sufferer to get a wheelchair. He states that 'I cannot expect others to donate unless I do it myself. What an inspiration!

To those who are leaving please remember that we have to say goodbye before we can say hello again.

Maralyn McCann
Office Manager



Introducing our new team members



Rebecca Scelly Fundraising Manager

Working to support people in the community is something I have been passionate about doing for most of my working life. Prior to starting at MDNSW I was working as the Communications, Fundraising & Marketing Manager for Australian Foundation for Disability (AFFORD). Before that I was in New Zealand working as a Fundraising Manager for Presbyterian Support Central (Elderly Care and Social Services).

Becoming the first Fundraising Manager for MDNSW has presented me with an

amazing opportunity to grow fundraising income which directly benefits all of our members.

My first few months are concentrated on increasing income from philanthropic grant-making bodies, making plans to achieve short term and long term goals, and supporting others in their established fundraising events.

Please feel free to give me a call if you are interested in helping out in any way or would like opportunities to raise funds for this great organisation.



Pene Hodge Client Services Manager

Hi my name is Pene Hodge and I am the new Client Services Manager. I recently moved to Sydney from Auckland with my husband, two teenage children and our dog Ralph.

I have previously worked as a social worker and manager for several government and community organisations. My most recent role was as a director of a counselling, budgeting and community services agency.

I have had the privilege of spending the last few days with Renee McBryde and can see that she will be greatly missed. I look forward to meeting you all and am very excited about my new role at MDNSW.



Sandra Stavrou Accounts

I have recently come on board at MDNSW as the new bookkeeper.

I am excited about joining the MDNSW team ... I have a passion for work in the not for profit and charity sector. Before MDNSW I spent the last four years working as the Accounting and Administration manager at a not for profit specialising in the membership/education sector.

My aim in my first 6 months at MDNSW is to ensure that there are sound procedures in place around the accounting function.

On the weekends and after work you will find me running around a soccer field or spending time with family and friends.

I'm Really No Good at Goodbyes...

It is with a sheepish grin that I write Happy New Year Everyone; acknowledging that we are already fast approaching the end of March!! I really hope you enjoy this edition of Talking Point – the first for 2010. This edition is themed around change, which as many of you will know is really very fitting for the Client Services Program at present, as this is sadly my last post to you all as the MDNSW Client Services Manager. My husband and I are relocating to Kenya to work in an Internally Displaced Persons Camp which, in line with the theme of this edition, is going to be a very big and exciting transition for me on a personal level. My last day in the office is on the 8th April and I do hope I will get to say goodbye to many of you before then.....

Before I leave though it is of course important to tell you what has been happening in the Client Services Program this year. A major part of this year thus far has been centred on

planning and consolidation. This has seen the implementation of a whole range of new events and activities available to members and carers throughout this year. Some of the new opportunities coming up soon include the natural therapies workshop, the multicultural luncheon and my personal favourite: the Easter show family day out!

As some of you already know Georgina and I recently had a week long trip visiting the mid and far north coast where we were able to meet with virtually all our members in those

regions either through the seminars run or through home visits. Georgina and I would like to thank all of the families and members who made time to have us in their homes and we look forward to more frequent visits to the area.

The Home Support Program has also been a major focus of the New Year and we are working very hard to expand on the program's capacity given its overwhelming feedback from our members to date. Here is what some members have had to say about the program thus far:

"I wanted to say a huge thank you for your support, understanding and insight yesterday when you visited me. Thank you so much for being so genuine, reflective and spot on with your analysis of the issues I am having. Your visit left me feeling better and clearer on some of the emotions and thoughts, Mum as my carer, may be experiencing. I also felt empowered and reassured about my decisions and plans to move forward with things."

(Member with SMA)

"Last year I received a call from you, you said you were in the area and you could come to have a chat with me, I must admit that I was very surprised as I had not had this offer prior to then. I was a little apprehensive as I was feeling very alone with the issues of caring for my son Tod that has FSH MD, but I agreed to the visit.

...After you came and visited me at home, I was surprised at my feelings. I felt that I had a person, that I felt I knew who was not that far away - someone that seemed like they understood, and cared. I did not feel so alone in the world.

You offered me some respite in the form of Flexirest; a dream that for the last 17 years has not been possible, you offered to help me with my sons transfer for housing, you offered me some hope, and I reiterate, I had an empathetic, real person to support me in my role as carer.

I believe this home visit is truly important to those who become so limited in the things they can do when they care for a person with FSH MD – such as me. So many people out there do not know, or do not want to know, how difficult it is or how restricting it is to care for a sick person (this includes doctors and other professionals).

To have you come to my home and offer your help was appreciated more than you know.

I thank you and hope this type of service will continue to be available for people like me"

Mother of boy with FSH

Finally I just want to encourage all our members to keep up to date on all that is happening at MDNSW – it is really going to be a very exciting year with quite a few surprises in store for everyone. Before I sign off, I really want to thank all of you for welcoming me into your homes and letting me share in your lives. I am very fortunate to have collected some wonderful memories during my time at MD, which many of you have played a major part in. Without launching into an Oscars speech, I quickly want to thank some people specifically. Thanks to Carolyn for being a great partner in Talking Point crime; thanks to all of the campers and carers who came to our first camp – you will always be in my fondest working memories - it still makes me smile thinking about all the fun we had!

On a larger scale - a huge thank you to all the families who have made every Client Services event bigger, more fun and more amazing than the last – the 2009 Christmas party water fight is still making me laugh..... and finally before the thank you's get utterly ridiculous – thank you to David, Maralyn, Georgina, Rebecca, Sandra and the MDNSW Board for being the most wonderful colleagues anyone could ask for.

I promise to send an update for TP soon.

**Much Love,
Renee**



Funding opportunities!

Two grant-making bodies are calling for applications from individuals with a disability to support them in their every day living.

The first one is provided by Technical Aid to the Disabled NSW. They provide assistive devices that allow people with disabilities to maximise their opportunities and live their lives more fully. Services provided include: Custom Designed Aids, the POSH Chair, Freedom Wheels, and TAD/Gale Computer Support Services. For more information call 1300 663 243 or go to: www.tadnsw.org.au

The second opportunity is provided by Telstra's Disability Equipment Program. They are looking to provide eligible customers with specialised equipment to access the standard telephone service. To access this equipment you need to complete an application form and have it signed by an authorised professional, for example, Doctor, Occupational Therapist or Speech Pathologist. To apply, please call 1800 068 424 or go to:

www.telstra.com.au/abouttelstra/commitments/disability_equipment_program.cfm

Both applications for funding are ongoing and can be applied to at any time. MDNSW will endeavour to keep you up to date with any other funding opportunities that may be available.

Be a Carer Representative for Carers NSW

The Carer Representation Program provides training, information and support to carers to enable them to act as Carer Representatives, representing Carers NSW and the wider body of carers. In order to inform a range of professionals and the broader community about carers' perspectives, activities include: participation on committees / advisory groups etc; guest speaking; forums; conferences; media interviews; and focus groups.

Carers NSW is seeking the involvement of carers from diverse communities and backgrounds, throughout metropolitan, regional and rural NSW. Service providers are encouraged to inform carers of this opportunity. No experience is required, but an interest in getting the carers' perspective heard is a must. For information, phone Alison Parkinson on 9280 4744 or email alisonp@carersnsw.asn.au.

Update on National Disability Insurance

The Disability Care and Support Inquiry Last week the Productivity Commission inquiry into a National Long Term Care and Support Scheme for people with a disability and their families received its terms of reference. These are deliberately broad and wide ranging to allow a thorough exploration of the complex issues which would be thrown up by the introduction and implementation of a National Care and Support Scheme.

The Productivity Commission will hold public consultations as part of its inquiry, and is intent on hearing about the experiences and needs of people with a disability and their families, as well as the organisations that support them. This is your chance to say how you would like the system to change for people with a disability, their families and carers in this country.

If you want to be kept informed by email or post, or to make a submission on the issue, you can register on www.pc.gov.au/projects/inquiry/disability-support. Or you can also download a registration form, to be sent to Disability Care and Support inquiry Productivity Commission, GPO Box 1428, Canberra City ACT 2601.

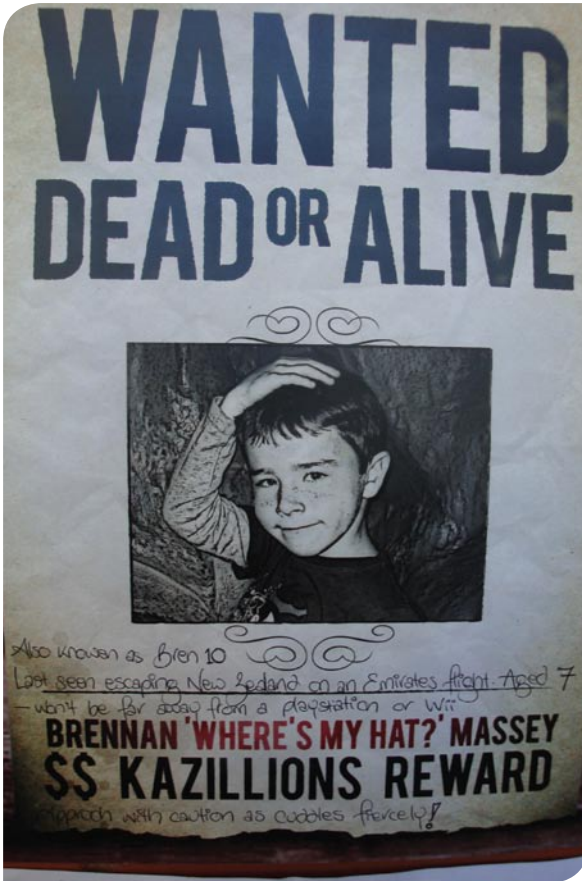
DVD "Starting School" Stories from 6 Families of Children with a Disability

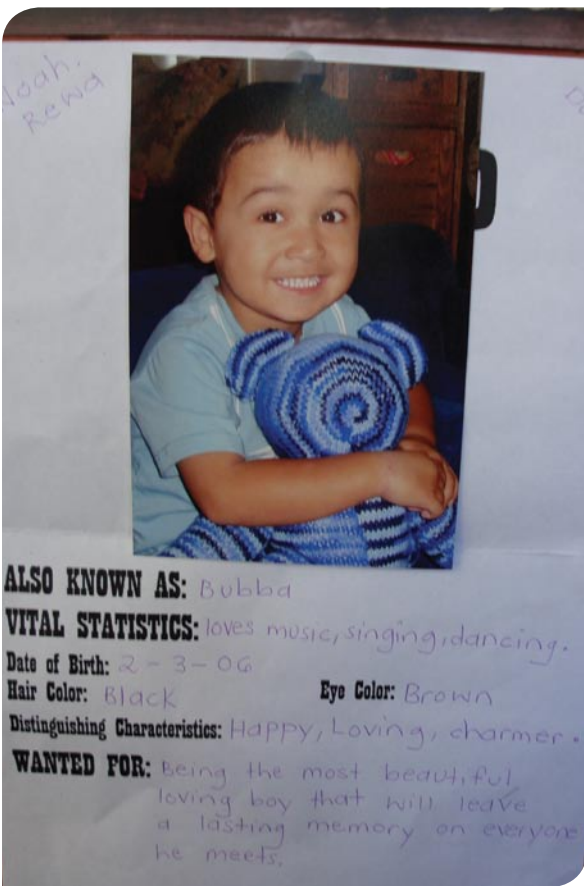
This 25-minute DVD identifies strategies to ease the transition into school for the first time. It will be useful for families from the earliest stages of thinking seriously about choosing a first school - it is realistic, encourages flexibility and cooperation, acknowledges the expertise of parents. It includes both mothers and fathers, grandparents and siblings, and a number of principals, teachers and learning support officers are interviewed. Produced by the Lady Gowrie Childcare Centre with funding from the NSW Government, the single disc includes information in English, Cantonese, Dari, Dinka, Korean, Mandarin, Vietnamese. Request from Early Childhood Intervention Infoline on 1300 65 68 65.



TOWARDS A BRIGHTER FUTURE

National Neuromuscular Conference 2010 • University of Sydney, 26-27 February 2010





TOWARDS A BRIGHTER FUTURE
National Neuromuscular Conference 2010 • University of Sydney, 26-27 February 2010



Recent Developments For Myotonic Dystrophy

Myotonic Dystrophy is the most common adult form of muscular dystrophy. There are two types of myotonic dystrophy. Myotonic dystrophy Type 1 which is common, involving at least one person per 8,000 and myotonic dystrophy Type 2 which is rare. Myotonic dystrophy Type 1 results in weakness of the hands and ankles and muscle stiffness (myotonia). Patients may also have involvement of the heart with heart beat irregularity and reduced heart output, cataracts, difficulty speaking and swallowing and most importantly fatigue and sleepiness. Later in the course of myotonic dystrophy they may develop diabetes and sleep apnoea.

Both myotonic dystrophy Type 1 and myotonic dystrophy Type 2 are due to large expansions of repeat base sequences of DNA. For myotonic dystrophy Type 1 this is an expansion of the triplet base repeat sequence CTG close to the myotonic dystrophy protein kinase gene and for myotonic dystrophy Type 2 a quadruplet base expansion CCTG related to the ZNF9 gene. Unusually both of these repeat sequences occur just outside the part of the gene that is translated into protein. Most genetic disorders are due to defects occurring within the translated part of the gene.

Recent research in the laboratory of Professor Charles Thornton,

University of Rochester New York, has demonstrated that the repeat sequences are transcribed from DNA into RNA but not translated into protein. For both disorders the long repeat sequences which for myotonic dystrophy Type 1 contain anywhere from 50 to several thousands repeats remain trapped in the nucleus and form nuclear inclusions that can be seen under the microscope. These repeat sequences then trap a protein that is involved in the process of splicing RNA called Muscleblind. Genes are region of DNA that code for proteins. Each gene consists of a number of protein coding regions, exons, and between these non coding regions, introns. This is like a series of words with nonsense letters between them. The DNA is transcribed into RNA and before this is translated into protein, the introns or nonsense letters are removed. The words which are the protein coding regions are then joined together to form a sequence of words that makes sense, like a sentence. This can then be translated into a functioning protein. The protein Muscleblind is important in this process of splicing and insuring that the genetic material produces a sensible protein. In myotonic dystrophy, this process is interrupted and the coding regions often fitted together (spliced) in a way that does not make sense. This produces a protein that does not work properly. In myotonic

dystrophy a number of proteins that do not work properly have been identified including the muscle chloride channel. The abnormal chlorride channel results in muscle irritability and instability causing myotonia. Some heart proteins are affected as well as brain proteins and the insulin receptor which can result in diabetes. Professor Thornton has recently been able to construct small sequences of RNA call antisense oligonucleotides that bind the abnormal repeat sequences in myotonic dystrophy Type 1. He has demonstrated that these are able to release Muscleblind and break down the nuclear inclusions formed by the abnormal expanded repeats. This in tuurn has led to the production of normally spliced and normally acting proteins. He has demonstrated that this will work in both mouse models of myotonic dystrophy and in individual human cells. At the present time these antisense oligonucleotides need to be injected directly into the muscle to work. Research is proceeding to produce similar antisense oligonucleotides that may be suitable for delivery by intravenous injection or possibly even as a tablet. This could allow potential treatment of myotonic dystrophy that would prevent progression and possibly produce significant improvement in strength, myotonia and other areas of function.

FREE to Good Home

Thanks to a very generous donor - MDNSW member Ruth Flood, MDNSW has a scooter available to give to a member in need.

If you are a current member of MDNSW and need a scooter for mobility purposes, please contact the office for details on how to apply.

Applications will be accepted by all current members and will be assessed by the equipment committee on a needs basis.

For more information please contact the Client Services Manager on 9809 2111.



TADNSW Artwork Competition

DRAW IT
PAINT IT
SNAP IT
CREATE IT!



To celebrate 35 Years of Service, TADNSW is putting together a commemorative calendar for 2011 - and we want YOUR help.

The Theme is: 'Practical Solutions, optimising abilities'.

Each month of the calendar will highlight a different artwork and client story. We are calling out to clients of all ages and their families to show us - **CREATIVELY** - how TADNSW has helped them. It's nice and flexible too - you can draw, paint, take a photo of something - or perhaps you have an even better idea. Whatever it is, we want you to submit it to us.

All entries will be considered for inclusion in the calendar. Entrants will be notified if they have been chosen. A \$50 gift voucher will be awarded to entries selected for the calendar.

For more information and entry forms visit www.tadnsw.org.au or phone (02) 9912 3400 and select option 3.

Entries close April 24th, 2010.

ENTRY FORM

First name: _____

Email: _____

Last name: _____

AGE: Under 10 11-20 21-30 31-64 65+

Address: _____

MY ENTRY IS: A photograph A Drawing A Painting

Other _____

Contact number: _____

TITLE of your entry: _____

By signing this form, you agree to have your original work published by TADNSW, with your name, photo and short bio (each winner will be consulted prior to publishing). Your work may be circulated through TADNSW networks and to the general public. Once your work has been submitted to TADNSW, copyright will then belong to TADNSW. Your original work will not be returned. Decisions of the judging panel are final.

Signature: _____ Date: _____

SEND YOUR ENTRIES TO communications@tadnsw.org.au or Mail to 'TADNSW Artwork Competition', Locked Bag 2008, Wentworthville NSW 2145. Entries close April 23rd, 2010.





Ladies Event
MDNSW invites you to an

Afternoon of Creative Design

Learn How to Scrapbook your albums, Learn How to Paint and Decorate Pottery
Afternoon Tea will be served for all guests

When: Friday 7th of May, 2010

Where: Shepherd's Bay Community Centre
3a Bay Drive, Meadowbank

Time: 1:30 to 4:30pm

To RSVP for this event contact Renee or Georgina on

9809 2111

carers@mdnsw.org.au



Great Southern Land

In January my fiancé and I travelled to Victoria for a ten day city and country escape. I use a power chair and Steve uses a scooter for mobility so access is paramount. One of our carers Anna accompanied us on this big trip to explore our Great Southern Land, and this is our Access All Areas report. If you've been to an accessible destination recently why not drop us a line and share your experience with other members.



With some of the bad publicity our airlines have been receiving lately I'm happy to report that Virgin Blue www.virginblue.com.au provided excellent service for our flights to Melbourne during the summer holiday period recently. Booking in advance, telling them all your needs over the phone, and again upon arrival and using my own sling for transfers meant that things went quite smoothly. The use of the 'airplane wheelchair' although uncomfortable and annoying is part of flying so taking a check of your own expectations and being prepared is helpful in these situations.

The Virgin staff were friendly, accommodated our 'special needs' and communicated well. Everything was on track, except for when our return flight was cancelled – oh no!, but the staff then worked hard to get us on the earlier flight so we had no delays. The hardest thing I find about flying is the worry

when you have to say goodbye to your power wheelchair for it to travel in the cargo, and you cross your fingers that it will arrive in the same location as you, with no damage! This time no dramas..... so well done Virgin Baggy Blues!

In Melbourne we stayed at the gorgeous Mantra on Little Bourke www.mantra.com.au, a medium size hotel right in the heart of this vibrant city. We booked the interconnecting family rooms with a good disabled access bathroom. The manager was very helpful and ensured our bed was raised to allow the hired hoist to run underneath. Both rooms were quite large, more like suites, and although there was no view, there was in-room cooking facilities, plus a bar and restaurant with the best big brekkie ever!

Staying in the heart of the city was so convenient, it meant we could drive

our chairs around all the attractions and save money on transport. We also boarded the big red free tourist bus (wheelchair accessible but very full!) and caught the number 96 Tram to St Kilda – it was my first time on a tram and it was so exciting I texted everyone in my phone to share the joy! Melbourne is a very accessible city, we loved exploring Fed Square, Southbank, the MCG, all

the groovy restaurants and laneways and of course the shopping! The crew at the Old Melbourne Gaol made our tour of the Old Watchouse very interactive and we had an awesome view 88 floors above from the Eureka Skydeck (and got to skip the queue!).

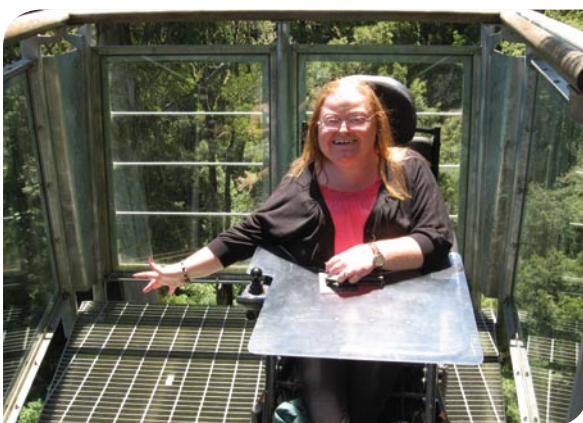
For the next part of our adventure we hired a Toyota Hiace from the friendly team at Wheelaway Van Rental www.wheelaway.com.au The leisurely 3 hour drive down the coast along the Great Ocean Road was definitely the highlight of our trip, superb scenery - the camera got a good workout! Travelling through the holiday villages of Torquay, Airey's Inlet, Angelsea and Lorne led us to a sleepy little place called Skenes Creek, just 5kms out of Apollo Bay. The cabin we stayed in was called Fisheye 9 www.fisheye9.com.au, with soaring views of the deep blue and peaceful tranquillity to enjoy. Fisheye 9 is wheelchair accessible, designed and owned by an Occupational Therapist.



Small but homely the cabin has a few nice access features including ceiling hoist rail and commode chair. Terrific accessible bathroom, and a lovely base to explore the delights of the area. Our top picks if travelling the Great Ocean Road are the accessible Otway Fly treetop walk www.otwayfly.com.au and the viewing platform for the Twelve (now 8.5) Apostles – just breathtaking!

They say a change is as good as a holiday but I really don't think so!

Caz and Steve



THE 25TH NATIONAL ELECTRIC WHEELCHAIR SPORTS TO BE HELD IN SYDNEY

The National Electric Wheelchair Sports (N.E.W.S.) tournament will once again be hosted by Muscular Dystrophy New South Wales and will be held at the Sydney Academy of Sport and Recreation, Narabeen, from the 12th to 18th April 2010.

This year marks the 25th Anniversary of N.E.W.S. which will be celebrated throughout the week so N.E.W.S. 2010 will be extra special.

Your NSW Colts will be defending the Roger Melnyk Trophy for the overall best team, along with the Hockey and Rugby League championships, while Victoria hold the Soccer trophy. This year the teams, along with the Colts, are ACT Wheelers, Victoria Pride Warriors, South Australia Scorpions, Queensland Gladiators and Western Wasps.

The NSW team is Peter Dalrymple (Co-Captain), Steve Webb, Dean Crane, Chris Suffield (Co-Captain), John Shepherd and Jordan Crane. I once again have the honour of coaching the team.

NSW squad members, Hamish Armitage and Alex Scollard will be representing

ACT, while our newest member to the squad, Kieran Watts, will be representing Queensland.

The games commence on Tuesday, 13th April, and will be proudly opened by Mr David Jack, CEO of MDNSW and MDF. The first sport played will be Hockey. Wednesday, 14th April is the Rugby League, while Thursday, 15th is Soccer. The finals of all sports will be played on Saturday, 17th April. Generally all sport days run from 10am to 5pm, while the times for the finals run from 9am to 4.30 pm.

If anyone is interested to watch the event, you are most welcome and there is no charge. The team's progress will also be updated on the MDNSW website.

For more information about the event please feel free to contact me on (02) 9643 1429 or email MBaptiste@bigpond.com or call the MDNSW Office.

Michael Baptiste
National Director (N.E.W.S.)
& NSW Coach

Making Changes – Help Online

A range of options are available on or via the making changes website if you would like to help yourself and/or get professional help. www.makingchanges.com.au

This website has a number of options, at no cost, including **free weekly tips, information/fact sheets and tip sheets.**

In addition, it offers Australia's most comprehensive online clinical and coaching psychology service with a

variety of internet based treatment options to consider. Simply go to the **"Online Treatment"** section, at the menu to the left, for more information.

Finally, for those of you based in Sydney Making Changes offers traditional, face-to-face psychological therapy and counselling from 3 locations (CBD, Parramatta and Bondi Junction). Just call our Head Office on (02) 9231 2522 to find out more information on how to make an appointment.

DISABILITY ACCESS

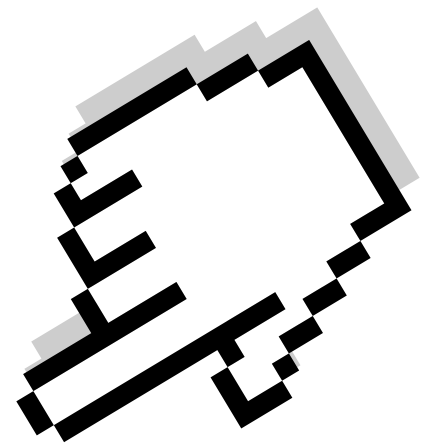
<https://www.det.nsw.edu.au/disabilityaccess/>

Whole of Life - All of Life

Welcome to the Disability Access pages, focusing on whole of life - all of life disability support services.

This is a one-stop online shop providing lots of information on disability programs and services in public education and training in NSW, with links to employment and related disability services. Information includes:

- **Education and Training**
- **Employment**
- **Housing and Accommodation**
- **Community Support Services**
- **Government Support**
- **Disability Consumer Groups**



The **Department of Education and Training's Disability Community Consultative Committee (DCCC)** is the key mechanism by which DET consults with the disability community on matters associated with education and training for people with disabilities in NSW. Members of the community seeking support to write to senior officers, the Director General or the NSW Minister of Education can contact the Disability Programs Directorate for advice on such assistance.

Phone: 02 9244 5085 TTY: 02 9266 8189

FOR SALE – Toyota Hiace with Hydraulic Lift for Wheel Chair Access



Price	\$27,000.00
Address	6 Alverna St, Rooty Hill NSW 2766
For Sale By	Owner
Make	Toyota
Body Type	Minivan/Van
Year	2003
Kilometers	89200
Transmission	Automatic
Drivetrain	Front-wheel drive (FWD)
Air Conditioning	Yes

6 seater capacity with space for electric or manual wheel chair. This van is specifically modified for wheel chair access which includes floor hooks/belts for wheel chair security while driving as approved by the RTA. Registration is valid till 23 May 2010. The van is in great condition, please view attached photos and call Andy on 0408 476 875 if you are interested and make an offer.



10 years is a long time for a diagnosis

Dear MD members,

My story begins in January 1985, when Sharon my wife, our children Craig and Michelle and I returned from a two week holiday down the south coast of NSW. I just did not feel right, with difficulties in concentration and visualising in the mind's eye. This concerned me as my chosen field in Engineering required me to be very good with these abilities along with cognitive reasoning.

I went to my local Doctor who said that I was "depressed", and put me on a course of Serepax to help with the depression. But as a precautionary alternative he referred me to a Neurologist at Westmead, where I explained my symptoms. He organised for me to have a cat scan of my head at Westmead Hospital that afternoon. After receiving the results, the Radiologist suggested that I go straight back to the Neurologist, which I did, and he explained to me that the ventricles' in my brain were about the size of a duck egg and not pea size, this was called Hydrocephalus.

My Neurologist strongly suggested that I go straight to Westmead Public Hospital with a covering letter and book into the Neurological ward. After arriving at Westmead Hospital at the booking department, I was told that no beds were available in the Neurological ward, and to ring again the next day. The pressure in my head increased dramatically during that afternoon, it felt as though my brain was exploding from the inside out.

I went back to Westmead Hospital later that evening and collapsed in the waiting room. They could see that I was very sick, and admitted me to an Ear Nose and Throat ward, as there still were no vacancies in the Neurological ward. That evening I was rushed into theatre for an emergency procedure to have a VP shunt inserted in my brain to reduce the pressure.

It was explained to me later that as an adult my skull was hard and that the increase in intracranial pressure had no where to go. And that this shunt was like plumbing that would open a pressure relief valve in the back of my head and the excess intracranial fluid would drain away into my abdomen.

After the operation I found it difficult to return to work, as my ability to do the same tasks required a lot more concentration. I had a revision of the VP shunt in 2002 and two operations in December 2004 and at each time it affected my ability to perform just that little bit more difficult.

My swallowing difficulties started in 1997. I visited an Ear Nose and Throat Specialist, who said that I had a piece of loose skin hanging from the bottom of my uvula which the food became lodged on. So he removed it and cauterised the area in his surgery. He indicated that once the surgery settled down my swallowing should return to normal; it never did.

Over the years I have gone from GP's to Specialists to Professors trying to get a diagnosis. At some of these visits the Doctors would ask me did I have any relatives in Canada. MY ANSWER WAS NOT TO MY KNOWLEDGE. So it was dismissed as a possible course.

As the years progressed my difficulties of dysphasia slowly worsened, and the Specialist's would send me for all sorts of tests of which all came back negative. **STILL NO DIAGNOSIS.**

In 2001 and 2002, I attended a feed - back trial with a Gastroenterologist at St George Hospital. I explained my dysphasia to him essentially it was as though I had a pocket in my throat, in which food would lodge. Professor Cook suggested that I have my throat stretched, which I did, but to no benefit.

In April 2003 I had a left biolateral eyelid P tosis and in December 2003 on my right lid and in May 2006 my left eye lid again as the eyelids continued to droop, **STILL NO DIAGNOSIS.**

In November 2006 I had another appointment with Prof. Cook as my dysphasia was slowly worsening. At this appointment we got onto the subject of relatives in Canada. He asked me did I have any family members with swallowing difficulties and droopy eyelids. I said to my knowledge I had no family members had difficulties in swallowing, but my maternal Grandmother had drooping eyelids along with three of her children. After this appointment I was able to supply the Doctor with photos of the family members affected by the droopy eyelids.



Bob and his wife Sharon.

The Doctor commented to me that the only way to rule out a probable cause of my droopy eyelids and dysphasia was for me to be genetically tested. An appointment was made on the 13th February 2007 with a geneticist at the Prince of Wales Hospital. At this appointment a sample of my blood was sent to Queensland for DNA analysis. On the 13th of March 2007 the geneticist had received the results, and wanted me to go and see him again at his rooms at Prince of Wales. At this appointment we went through the results, and in gene 14, I had 10 on one side and 13 on the other. This was a definite diagnosis of (Oculopharyngeal Muscular Dystrophy) OPMD.

Finally I now had a diagnosis after **10 long years** of many Doctors saying it was it was caused by my Hydrocephalitis or I was imagining my symptoms.

Prof. Cook had been to Quebec in Canada on a conference concerning gastroenterology; He found out that there was a large cluster of OPMD sufferers there. This was why I was asked did I have any relatives in Canada as there was a cluster of OPMD sufferers.

From my research that I have done, in 2004 in Quebec there were quite a number of sufferers with the same symptoms of drooping eyelids and dysphasia. And none of the Doctors were able to come

up with a definite diagnosis. They thought it may be genetic!!!!, so they asked each one of the sufferers to do their family tree. Surprisingly each of the family trees' went back to two sisters that emigrated from France in the early 15th century and brought the defective gene with them. An effected person will not show any symptoms until late forties to late sixties even though they are born with the defective gene. I started to have my symptoms in my late forties.

I have now a "diagnosis" which is really good, but how do I live with it. From the research that Prof. Cook and I have done, the Specialists in Quebec have been trilling different procedures to help with the disphia. The first was to sever the cricopharyngeal muscle, this would help for a period of time but the disphia would return. From the research that I have done, if one got an infection in the throat after surgery there could be up to a 25% mortality rate. With the hospitals of late, I have decided to put up with my disphia, and steer clear of the foods that would stick in my throat.

At this stage it is taking me longer and longer to have my meals, and this will worsen in time. I have been consulting with a neutrinist about keeping up my nutrition. And if I was to loose a lot of weight, it may be necessary for me to have a peg inserted in my stomach. And I would be feed by a tube. **NOT LOOKING FORWARD TO THIS.**

As my ancestry is Scottish and English, and that the distance from France to Scotland is only across the English Channel. I feel that it has come down from my Scottish side of the family.

As to my drooping eyelids, I have been advised that it is no longer possible to do the Tosis operation and I would have to have the sling done (Blepharospasm). And this procedure would elevate my eyelids when I frowned. A direct cousin of mine has had the sling procedure and is quite happy with it (time will tell). It wasn't until I went to his father's funeral that I noticed that he had the drooping eyelids as I did not know which side of the family my defective gene came from. I contacted him later, and he told me, that like me, he had been sent for all sorts of tests but no diagnosis. My mother died of cancer in 1980 at the age of 56, she too had the drooping eyelids, but it was diagnosed as old person's disease, and to live with it. Just plain Muscular dystrophy but no diagnosis as to where it came from.

I have contacted my direct relatives with my concerns; some of the response was positive and some negative. My reason for the contact was to alert them to the possible cause of their dysphasia and drooping eyelids. If they wanted to be tested, the decision would be there's. The defective gene is not a male or female carrier, it can be either. If a child upon conception does not have the defect it will not come out in later generations from his or her's children.

I am a member of the Muscular Dystrophy Association and see others with the crippling and debilitating disease. Mine is insignificant as compared to some. If you think this letter is of benefit to you, I feel pleased that at least I have helped in some way.

Robert (Bob) Lamb



MDNSW presents a

Natural Therapies Workshop

When: Friday 28th May 10

Where: Shepherd's Bay Community Centre
3a Bay Drive, Meadowbank

Time: 1-4pm

Lunch will be provided around 1pm

Guest speakers will talk about what treatments are available, and how they may compliment current treatments for people with a Muscular Dystrophy



To RSVP for this event contact, Renee or Georgina on:
9809 2111
carers@mdnsw.org.au





muscular dystrophy
new south wales

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We could not do all we do for our members without the generous support of individuals, community organisations and companies. If you would like to make a tax-deductible donation as a once-off, or on a monthly basis, simply complete this form and return to: Muscular Dystrophy Association of NSW, PO Box 1365, Meadowbank NSW 2114.

Yes, I would like to make a tax-deductible donation to help those with muscular dystrophy

name _____

address _____

phone _____ email _____

I enclose my Cheque/Money Order made payable to Muscular Dystrophy Association of NSW for \$ _____, or

Please debit my card: once only every month **amount \$** _____ card type: Visa Mastercard

cardholder's name _____ card No _____

cardholder's signature _____ expiry date _____

Thank you. All gifts of \$2 or above are tax-deductible.

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