

“Island Ties”

Newsletter of the

MUSCULAR DYSTROPHY ASSOCIATION OF TASMANIA Inc



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A Message from the President

MEETINGS

Meetings have been held by phone as required as it has been a difficult year for several committee members with family commitments and health problems.

CLIENTS

Since our 2007 Annual General Meeting seven new clients/families have contacted us. Most at this stage only required information and support. One inquiry led to finding that there is a support group with some 25 - 30 members in Tasmania for a particular form of Muscular Dystrophy - Charcot Marie Tooth (CMT). I attended a full day seminar run by the group. If you know of anyone with this form of MD please get them to contact me and I will put them in touch with the group.

EQUIPMENT

We had three electric wheelchairs returned to us. One was just right for one of our adult members so has been passed on and allows him much more freedom and independence. Another is being assessed for suitability for a client. The third is available and if anyone needs a large electric chair please let me know – it is in good order but basic in its features. The last of our old electric wheelchairs was modified, had new batteries and tyres provided and given to a member family. It has proved very useful but was only ever to be a temporary fix until a new chair could be funded. This is now done and the chair should arrive shortly.

FUNDING ASSISTANCE

We provided funding, in part or in full for:

- service and repairs to two electric

wheelchairs;

- camp fees for one member and his carer;
- the Steve Forrester Prize at Prospect High School;
- top up funding for an electric wheelchair.

Three more electric wheelchairs will be up in for consideration later this year.

FUNDING

During November a collection box project ran in Queensland, New South Wales, South Australia and about 100 boxes in Tasmania. Any profit from funds collected here will come to MD Tasmania. Some mainland businesses asked for extended time to have the boxes so results have no been finalised yet.

Graeme and Marie continued with chocolate sales and we are very appreciative of their efforts raising over \$2000.

Our funds are diminishing rapidly – we desperately need some ideas and assistance!! This is a challenge especially in these difficult economic times.

MUSCULAR DYSTROPHY THE NATIONAL SCENE

This year has seen Muscular Dystrophy at the national level become active through the Muscular Dystrophy Foundation. A CEO has been appointed on a time share basis with MD New South Wales. He has been extremely proactive and much has been achieved. The current priority is to source funding on a national level – again a challenge these days. See our new website at www.mdf.org.au - it is still under construction and a link to an MDTasmania site is to be added.

GENERAL

The Neuro Muscular Alliance (NMTA

– MDTas is a member) submitted papers to the House of Representatives Inquiry – “Better Support for Carers.” NMTA was one of three organisations, and 10 carers who were able to meet with the House of Representative Committee members at hearings in Hobart. I and the Client Services manager for MS represented NMTA. I also attended, on behalf of MD Tasmania and NMTA, a session for disability organisations to meet with Bill Shorten the Minister for Disability in Launceston.

NMTA continues to monitor the program “Young People in Residential Aged Care (YPIRAC)” set up as a federal/State government initiative to provide more suitable accommodation for people under 50 now in an Aged Care facility. A new special purpose home – with four bedrooms and two separate units is to be built in the northern suburbs of Hobart with completion by February 2010.

Special purpose care packages have been provided for others remaining in their Aged Care facility to be near friends and family and to 6 others to prevent them having to enter an Aged Care facility.

Anne Ashford, President



This newsletter of the Muscular Dystrophy Association of Tasmania Inc. is

YOUR newsletter and we encourage you to submit your contributions in the form of articles of interest, stories, poems, news items, personal anecdotes or any items that you feel would be of interest to the Muscular Dystrophy family in Tasmania.

Please forward any submissions to Anne Ashford or John Salmon at mdatas@hotmail.com

Together we will beat Muscular Dystrophy



MY TIME

My Time groups provide local support for Mums, dads, grandparents and anyone caring for a young child under school age with a disability or chronic medical condition.

My Time gives parents the chance to socialize and share ideas with others who understand the rewards and intensity of the caring role., to find out about available community support and get research-based parenting information.

Each group has a play helper who can lead the children in activities so parents can spend time focusing on catching up with others.

Contact Association for Children with Disability (ACD) 1800 244 742, or 621 2466 (Hobart), 6343 0344(Launceston) 0400623121 (North West)



ACD also offers Advocacy, support and case management to parents/families with children up to 18.

It was founded by parents and is managed by parents. It also publishes "Finding Your Way" a comprehensive guide for parents and families of children with disability to services available in Tasmania. There is also a quarterly magazine PEP Talk.

Care Bears Cottage in Mornington recently held a fundraising night. The profit from the night is shared between Cancer Plus and Muscular Dystrophy Tasmania. We received a cheque for \$820 for which we are extremely grateful.

We sincerely thank the Care Bears staff and all who attended thus contributing to this donation.

Tour Duchenne, a fundraising and awareness event has been happening during March 2009. Funds raised will go to supporting research into Duchenne Muscular Dystrophy in Sydney and Melbourne.

25 riders left Sydney on Saturday 7 March headed for Melbourne. They have raised over \$600,000.



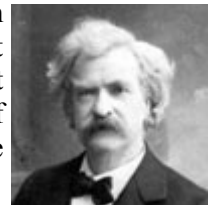
What a great effort.

Impossible things

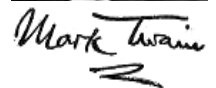
In the latest issue of The Adelaide Review, Mark Twain's visit to Adelaide in 1895 is remembered. He is reported to have stated, "Truth is stranger than fiction because fiction is obliged to stick to possibilities; truth isn't."

In a similar vein, an article in a recent issue of MDA USA's magazine Quest, quotes Lewis Carroll's writings from "Through the Looking-Glass and What Alice Found There" which followed his better-known children's book, "Alice in Wonderland". In the quotation, Alice is saying to the Queen, "There is no use trying ...one can't believe in impossible things." The Queen replies, "I daresay you haven't had much practice."

We all need practice at believing in impossible things. We can raise impossibly more funds than we do right now. We must think impossibly. We can achieve the impossible with respect to the services we provide and with respect to the amount of research that we support. And above all, those impossible treatments and cures can be achieved.



As Mark Twain is saying, impossible things can be true.



From MDA SA Website

Since we have been informed recently that there is number of people affected with Myotonic MD in Tasmania we include a brief description of the condition

MD Tasmania has a book - Myotonic Dystrophy - The Facts - which can be borrowed.

MYOTONIC MUSCULAR DYSTROPHY

This disorder is unique in that myotonia - delayed relaxation of muscles after voluntary contraction - is a significant feature. This particularly affects the small muscles of the hand so that after making a fist or gripping an object the muscles relax slowly - especially in the cold.

Secondly unlike other dystrophies other organs and tissues are frequently affected. Cataracts may develop as well as various glandular problems - including reduction in fertility, increased likelihood of spontaneous abortion, stillbirths or death of a newborn. In males frontal baldness is common. Some children can be severely affected from birth with facial weakness, feeding and breathing problems and mental retardation.

A third difference is in the structure of the muscle - it has increased nuclei in the centre of muscle fibers not as is usual at the periphery.

There can be muscle wasting and weakness affecting the face and neck, lower leg and forearms, and small muscles of the hands. The heart can be affected with some degree of heart block (slowing of the heart rate). However Myotonic Muscular Dystrophy is a more generalized disorder. Only occasionally do all these features occur in one person.

It follows an autosomal dominant genetic pathway. The disorder frequently increases in severity from one generation to the next. Thus a grandfather with cataracts and mild myotonia may have a daughter with myotonia and muscle weakness who in turn has a child with serious congenital form of the disorder.



The outlook for congenital myotonia is poor, mildly affected adults survive into middle age and beyond.



SOME PUBLICATION INFORMATION THAT MIGHT BE OF INTEREST AND HELP

Do you need help to stay at home – to live independently? - contact a **Commonwealth Carelink** centre on 1800 052 222 or

www.commcarelink.health.gov.au

Carers who need a break and help with respite contact - Commonwealth Carer Respite Centre - 1800 059 059.

Hobart City Council has a “**Hobart CBD Mobility Map**” available - a guide to access and facilities for people with limited mobility.

“**Places to go, People to Meet**” – a booklet put out by the **Glenorchy City Council** giving recreational options for Southern Tasmanians – not necessarily those with a disability.

Have trouble getting shoes that fit problem feet!! – men, women and children.

Specialists in comfort and orthopedic footwear – try Ms Lesley Fisher at 6 Station Road, Moonah, 6228 3551- open Tues/Wed/Thurs 9.30 to 4.30.

“**The Wheelie Good Guide of Tasmania**” – published by **Paraquad Tasmania** – listing places around Tasmania with wheelchair access.

Centrelink have commenced a news sheet for Carers - contact **Centrelink** - not sure how often it will be published.

Are you having trouble with speech or hearing when making a phone call. **National Relay Service** can help - 1800 555 660

Physical Disability Council of Australia is now Physical Disability Australia (PDA). They will be publishing a monthly Bulletin keeping people up to date with disability issues in Australia and overseas. The PDA Board now has a member from each State each of whom have a disability.

Two items in the first edition - Jan 2009 - interested me and I quote from them.

“In December 2008 the Federal Government launched a paper outlining its strategy for improving employment opportunities for people with disability and mental illness.

Six priority areas for action were identified –

- Improving disability employment services
- Supporting and encouraging employers

- Engaging people with disability
- Innovation
- Direct government employment of people with disability
- Better access to education and training.

Comment by PAD

“... It still remains to be seen how these areas will be addressed and whether the government will provide the financial backing to really make a significant change. The largest challenge will be in changing the attitudes and culture of discrimination with employers and the workforce.”

An item headed **Migration and Disability** refers to a case where residency was refused based on the person’s son’s disability. This sort of decision making discriminates against the whole family and denies the potential of the disabled person. It is not only offensive to many people with a disability in general but inaccurate.

They then listed some ways a person with a disability befits his/her community.

- Many people with a disability are able to contribute via employment and improving the access and attitude of workplaces will assist others to find and keep employment
- People with a disability often play an important role within a family taking on tasks that enable other family members to work and contribute to society than was otherwise possible.
- People with a disability contribute significantly to the cultural and social diversity of this nation.
- People with a disability also improve the lives of many others through creating and providing employment to many caring and skilled individuals.
- People with a disability contribute financially to Australian society through paying GST and other taxes like everyone else.

Disability is so often spoken of negatively – I thought it good to hear some positives!

Membership of PAD is free to people with a disability and family members/carers/supporters can have free Associate membership.

PAD, PO Box 38, Willawarrin, NSW 2440 - Phone: 02 6567 1500 - email pda@pda.org.au or www.pda.org.au

History

The first historical account of muscular dystrophy appeared in 1830, when **Sir Charles Bell** wrote an essay about an illness that caused progressive weakness in boys. Six years later, another scientist reported on two brothers who developed generalized weakness, muscle damage, and replacement of damaged muscle tissue with fat and connective tissue. At that time the symptoms were thought to be signs of tuberculosis.

In the 1860s, descriptions of boys who grew progressively weaker, lost the ability to walk, and died at an early age became more prominent in medical journals. In the following decade, French neurologist **Guillaume Duchenne** gave a comprehensive account of 13 boys with the most common and severe form of the disease (which now carries his name - Duchenne muscular dystrophy). It soon became evident that the disease had more than one form, and that these diseases affected people of either gender and of all ages.

Principal symptoms include:

- Progressive Muscular Wasting (weakness)
- Poor Balance
- Frequent Falls
- Walking Difficulty
- Waddling Gait
- Calf Pain
- Limited Range of Movement
- Muscle Contractures
- Respiratory Difficulty
- Drooping Eyelids (ptosis)
- Gonadal atrophy
- Scoliosis (curvature of the spine)
- Inability to walk

Few or none of these symptoms may be present before diagnosis. Some types of Muscular Dystrophy can affect the heart, causing cardiomyopathy or arrhythmias.

ACKNOWLEDGEMENT

Island Batteries gave us a very nice discount on batteries we bought for a wheelchair.

Thanks guys.



A letter to my daughter

Hello Emily

It was an indescribable joy to finally meet you. You are the result not only of the love your parents have for each other, but also of the precise planning of a team of medical professionals. Most Mums don't know for certain they are having a baby until a few weeks into their pregnancy, but we knew you were a distinct possibility long before the three days you spent in the Sydney IVF lab, where you grew from four cells to around one hundred cells.

After a systematic series of medical procedures that began weeks previously, you were transferred into my body when you were five days into your existence. A few days later, your Dad and I happily knew for certain we had another 36 weeks (more or less) to wait before we could see you face to face.



We knew before the embryo transfer procedure that you were a girl. I also already knew you would have something in common with me, and my mum (your grandmother), and your grandmother's mum (and her mum, too) – something more than ordinary family ties. You are a carrier of Duchenne muscular dystrophy (DMD).

The difference for you and me is that we are aware of it. You will have choices to make (as I did) about whether to have children, and how to go about it, armed with the knowledge of your carrier status. In addition, in your future there could be amazing leaps ahead in technology and research to help you along the way.

How do we know you are a carrier?

DMD is an X-linked recessive disorder – every son has one chance in two of being affected because of the defective gene contained in the X-

chromosome from his mother, and every daughter has one chance in two of being a carrier.

The reason why we underwent “in vitro fertilisation” (IVF) was that it could be done in combination with “pre-implantation genetic diagnosis” (PGD). With PGD, the choice of which embryo to implant is made on the results of genetic tests on the embryos, in our case to exclude those with DMD. As it happened, the only embryo available to test... was you!

It seems strange to think of now we know you, but if there had been another embryo (male or female) unaffected by DMD available to implant, you might now exist as a frozen embryo sibling waiting in limbo, just one of several complex medical and moral issues that

I hope to discuss with you in the future. One thing that is very important for you to know, is that although I did not wish to risk having a son affected by DMD, I would never wish away being my brother's sibling. Your uncle Mark was a wonderful person, and I am a better person now because he was my older brother for 16 years. I wish you could have met him.

When our Sydney IVF doctor told us that the only embryo we could possibly implant was a carrier female, we were worried. We know there is a tiny possibility that you might be a manifesting carrier (female carriers who show symptoms of the X-linked disorder they are carrying).

Even without that possibility, I still worry that we have placed a burden on you (of being a carrier) that might have been avoided. Now that I've met you, I wouldn't swap you for the world, just as I would never swap the time I spent with your uncle Mark, as difficult as it sometimes was.

Within the few hours that your Dad and I had to make a decision about whether to implant our only available embryo, we were asked by a wise advisor, “Do you want to be parents, or not?”

We hope you are happy that we decided the answer was “Yes!” We certainly are.

With much love,
Louise West (your Mum).

Reprinted with kind permission of Louise West and MD New South Wales.

Beach Wheelchairs



Children's Beach Buggy

- Carries up to 75kgs
- Lightweight – only 12kgs
- Folds into carry bag 800x800x200mm
- Easy to assemble/disassemble
- Adjustable handle for pusher



Beach Wheelchair - Adult

- Lightweight (35kg)
- Quick release wheels
- Fold away arm rests
- Quick release footrest
- Fold away safety bar
- Slimline design allows access through normal doorways
- High traction tyres
- Free form mesh seating



All Terrain Wheelchair

- Light Weight (25kg)
- Drain through mesh chair (Enabling occupant to dry while seated)
- 100% Water Friendly (Simply hose off after salt water use)
- Removable footrest
- Fully and easily collapsible (No tools required)
- Quick and easy to assemble
- Highly manoeuvrable (Turns 360 degrees on the spot)
- Suitable for all terrain types



For more information or bookings please contact our Head Office

Phone: 1800 001 141 Fax: (03) 6228 4564 Email: admin@cptas.org.au

Cerebral Palsy Tasmania wishes to thank



for giving us the opportunity to purchase these chairs

Pictures kindly reproduced with permission from Accessible Concepts

Cerebral Palsy Tasmania is in the process of collating a wide range of resources relating to cerebral palsy for our member clients, families, carers and health professionals to borrow.

Resources are available from our **Head Office at 21 St John's Avenue, New Town.**

Phone: 03 62284488

Email: admin@cptas.org.au

Items from the Lending Library can be delivered or mailed to people outside the Hobart area.

There are no fees or charges for the hire of our Beach Wheelchairs but we do ask that you might like to make a donation to Cerebral Palsy Tasmania.

Please contact Sally-Anne Sherman on: 6228 4488 for further information.

Link to Beach Chair Flier:
http://www.cptas.org.au/images/stories/downloads/media/bchair_flier.pdf

You or members of your family may be thinking of making or updating your will.

Have you considered a bequest to Muscular Dystrophy?

If so we suggest the following as an option for inclusion in your will.

“I give and bequeath to the: Muscular Dystrophy Association of Tasmania Inc. [...% of my estate] OR [the sum of \$] for the general purposes of the Muscular Dystrophy Association of Tasmania Inc.

I declare that the receipt of an officer of the Muscular Dystrophy Association of Tasmania Inc shall be a full and sufficient discharge to my trustee.”

