

NEWSLETTER DECEMBER 2009

Highlights from President's 2009 Report

Most of the work this year has been advice and support to members. Meetings have been held by phone as required. Since our last Annual General Meeting five new clients/families have contacted us. They have been given information about MDTasmania, disorder specific information and other assistance as required.

We provided funding, in part or in full for: One electric wheelchair, camp fees for one member and carer, the Steve Forrester Prize at Prospect High School.

The exciting news for MD Tasmania is a partnership with the New Town cricket Club. One of our members is their coach. He has a young son with MD and when the club was looking for a charity to link with as part of their community involvement he nominated MD Tasmania and the club accepted. We are starting small but plans are in hand for events which will support and/or include MD members. (see MDTas website)

Our new website is up and running – www.mdtasmania.org.au – use this link not a generic search.

As a member of the Neuro Muscular Alliance (NMAT) MD Tasmania is supporting the NMAT survey of Tasmania to find out how many people there are with a neuro-muscular condition, what services they are receiving, who from and what services they need but are not getting. (see article GETTING in TOUCH)

NATIONAL NEWS

This year, the Muscular Dystrophy Foundation (MDF), our the national MD body, has been very active. Three events have been held.

- **Jerry Lewis – see separate article**
- **Motown in Mudgee**

This was held at the Gooree Park Winery and Thoroughbred Stud and featured James Morrison and his band. Approximately 900 people attended. MDF CEO had the opportunity to speak about muscular dystrophy and MDF and receive some generous donations.

- a collection box project running for MD Month- November - in Queensland, New South Wales and South Australia, and some in Tasmania.



Helping families with Muscular Dystrophy

Virgin Blue becomes more accessible



Disability Discrimination Commissioner, Graeme Innes, recently congratulated Virgin Blue Airlines on the increased accessibility of their airline for Australians with disabilities.

"Travel is something that we are all doing more and more of, and it is important that people with disability can participate equally in this activity," Commissioner Innes said.

Virgin Blue have been working productively with peak disability and advocacy organisations to improve access and their Independent Travel Criteria. The result is a policy which is far less restrictive.

"Australians with disability make up 20 percent of the population, so I am pleased that this significant segment of the travelling market will now be able to share in use of Virgin's facilities more equitably," Commissioner Innes said.

"I congratulate Virgin Blue on these changes, and the way that they have worked with people with disability to achieve a positive result."

LIVEWIRE

Are you aged over 10 and under 21 looking for a free and fun way to spend your time

Livewire Members (members.livewire.org.au) is a safe online community designed especially for young people aged over 10 and under 21 living with a serious illness, chronic health condition or disability.

It's a supportive place for you to hang out online and features chat, blogs, forums, competitions, games, music, and entertaining content.

To join Livewire members today:

- Go to <http://members.livewire.org.au> and click 'Join'
- Contact the Livewire Support Team on (02) 8425 5971

Livewire is an initiative of the Starlight Children's Foundation and is supported by funding from the Australian Government under the Clever Networks program.

wheelies.net.au

Another new website which has been launched.

wheelies.net.au has been released to enable people who use wheelchairs to meet, talk and swap houses which they know are suitable for their holidays

wheelies.net.au will provides a free community service for people who use wheelchairs and who find it difficult to have holidays because of cost or lack of suitable accommodation.

The brainchild two people living with multiple sclerosis wheelies.net.au is proudly sponsored by the MS Society of Tasmania; gifted by the Tasmanian Community Fund; and made by Ionata Web Solutions.

Merry
Christmas
from
your
MD
Committee



GETTING IN TOUCH 2009 –
WE NEED YOUR HELP!

Thousands of Tasmanians suffer from debilitating and sometimes life threatening, neuro-muscular conditions. These include Multiple Sclerosis (of which Tasmania has the highest incidence in Australia), Motor Neurone, Parkinson's, Spina Bifida, Huntington's Disease and Muscular Dystrophy. However, we have no full picture of exactly how many Tasmanians suffer such conditions or who they are. The Neuro Muscular Alliance of Tasmania (NMAT) in conjunction with IMC-Link are conducting a survey to gather more detailed information about these conditions in order to develop a body of data that will influence future planning and provide empirical evidence for advocacy on behalf of people living with neuromuscular conditions in Tasmania. To make this survey successful, we need as much information as possible.

Officially launched on 30th November, "Getting in Touch" will be the first comprehensive survey of this type ever conducted and will provide wide ranging information on who is affected (how many people and their demographic profile); how they are affected (the extent of debilitation) and what their needs are (Current support services, identification of gaps in services).

The collective information will support relevant associations to understand client needs and align their strategies and/or use the data to lobby government for improvement of client services.

The survey is completely confidential and impartial – once completed, all survey forms are sent to an independent organization for collation.

Copies of the survey are available from participating organisations on the numbers listed below, or on the IMC-Link website at www.imc-link.com.au. If you are a registered client or member of one of the following organisations, you will be sent a copy of the survey.

- **Australian Huntington's Disease Association** (Tasmania) Inc - Ph: (03) 6431 3403
- **Muscular Dystrophy Tasmania** – Ph: (03) 6231 3273
- **Motor Neurone Disease Association of Tasmania** – Ph: 1800 806 632
- **Multiple Sclerosis Society of Tasmania** (03) 6220 1111 (South) or (03) 6343 1240 (North)
- **Parkinson's Tasmania** (03) 6295 1395 or (03) 6375 1734
- **Spina Bifida Association of Tasmania Inc.** (03) 6275 0987

COLLECTION BOXES

If any of you – or your family members- have a workplace or other venue where we could put one of our collection boxes I would like to hear from you.

I have spare boxes

Just ring me on the number below or email me at the address below and I will send you a box.



For information please contact:

**Muscular Dystrophy Association of Tasmania
Inc.**

26 Goulburn Street
Hobart TAS 7000

Email: ashfords@dodo.com.au

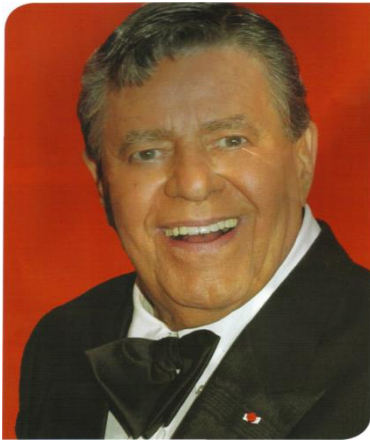
Phone: 03 6231 3273

www.mdtasmania.org.au

MDTasmania is a member of the Muscular Dystrophy Foundation
and



The Neuro Muscular Alliance Tasmania



A Promising Future

SEPTEMBER 2009, SYDNEY

What an amazing week it was!

And what an amazing guy is Jerry Lewis!

In a whirlwind week of special events and media appearances, Jerry worked his magic as a legendary entertainer and leading muscular dystrophy advocate, using his compelling combination of humour, charm, passion and determination to forge new friendships, new alliances and new support for muscular dystrophy in Australia.

Only a day after his arrival Jerry stunned, delighted and energised the Australian muscular dystrophy community by pledging through the national media his total commitment to work with Muscular Dystrophy Foundation Australia to achieve here what he has achieved in the USA.

I would love to do here in seven days what I did in 58 years [in the USA] but the point is it has to begin," Jerry said.

Jerry's Annual MDA Telethon in the US has raised over US\$60 million in each of the last two years, and since its inception in the 1960s has raised US\$2.4 billion - that's with a 'b', he says with a big grin.

Jerry announced that he plans to return to Australia in 2011 to stage a muscular dystrophy telethon as extravagant and successful as its US counterpart. He acknowledges this will depend on getting support from Australian television networks, but says he'll put all his resources into making it happen.

"I have a hunch we're going to pull it off [here in Australia]," Jerry said.

The exciting week started with a "Special Afternoon with Jerry Lewis" at Star City in Sydney. Young kids and older 'kids', mums and dads, carers and friends, were all treated to heaps of fun and laughter with the king of comedy showing clips from his favourite movies and shows.

Jerry's newly adopted Aussie kids were in fits of laughter watching the zany antics of the guy on screen (the younger ones probably for the first time) with the man himself following up with more great jokes and quick repartee.

Keen to talk with everyone in the room and hear stories of their lives and answer the many questions there were about his life Jerry not only recounted amazing tales of his life as a star of stage and screen, but also revealed his deep commitment to muscular dystrophy.

**JERRY'S DEEP HUMANITY
AND COMPASSION
FILLED THE ROOM WITH
INSPIRATION AND MUCH
ENCOURAGEMENT.**

At another three fantastic functions at Star City, Jerry went on to entertain and inspire hundreds of committed muscular dystrophy supporters who came from all around Australia to get 'up close and personal' with this remarkable man.

Jerry was supported at the Star City events by marvellous musical performances from Leo Sayer, David Campbell, Mark Spano and Carl Riseley.

TV personalities Jaynie Seal (Channel 9 Weather), Mark Beretta (Channel 7 Sunrise) and Kellie Connolly (Channel 9 Today) kept things moving as accomplished and gracious MCs of the events.

The grand finale to the week was a spectacular show at Sydney's Enmore Theatre featuring Jerry, his 24 piece orchestra and the royalty of Australian comedy. A packed house of more than 1300 people was "laughing for life" as Jerry and his Australian co-stars Peter Berner, Kitty Flanagan, Tom Gleeson, Paul McDermott, Julie Morris, Fiona O'Loughlin and Mikey Robins worked their brilliant comic magic.

For all the laughter and all the fun. Jerry was intent on getting a more serious message across.

"If you make people laugh, I have found that they become very available to thinking good stuff," Jerry had said before the show.

"I'm going to make them aware that they have an enemy [muscular dystrophy] in their midst and I've come to do something about it."

Jerry also had a special message for the muscular dystrophy community of Australia.

"You've got to go national and you've got to be united if you want to be successful," he said.

For representatives, members and supporters of MD associations from New South Wales, Queensland, South Australia, Tasmania and Northern Territory participating in this wonderful week of events, hearing this from Jerry reinforced their commitment to continue to work together to create a cohesive, integrated and collaborative Australian MD community.

"We deeply appreciate the great generosity and true friendship Jerry has shown us" said David Jack, CEO of MD Foundation.

Colin Gunn

From "Talking Point" newsletter of MDNSW