

talking point

NEWSLETTER OF MUSCULAR DYSTROPHY NEW SOUTH WALES

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in this issue: **Meeting a Legend**



md

muscular dystrophy
new south wales

Dear Friends

In thinking about this editions theme of **The Future**, a range of emotions and thoughts were stirred in me. One of them was **curiosity** – what would the world be like in the future? How will my life be different in 5 years? How long will medical advances take? Can we halt environmental ruin? What will life be like for people with NMD in the future?

The future can often evoke feelings of **fear** and worry about change and the unknown. I guess we all fear what may happen, or indeed what might not happen, to some degree or another. Being a person with a neuro-muscular condition, a family member or friend means that thinking of the future can be even more daunting and overwhelming. Perhaps using this fear in a proactive way may be the key, in terms of planning for likely events and scenarios. In recent years my learning

has been that living for today and truly enjoying what you have in your life is the key to dealing with these fears and anxieties.

But importantly when we think of the future we can always hold onto some sense of **hope**. Hope for good things for family and friends, hope for personal goals to be realized, hope in finding your own piece of happiness. We do not know what the future holds, we can not always shape its destiny, but we can take comfort in knowing that there are many wonderful events yet to unfold.

In this edition we celebrate the incredible events over the past few months that have taken the Association to an all time high. HOGS Day and the Jerry Lewis Extravaganza were exciting, unifying events that inspired much awareness of and support for Muscular Dystrophy. My loved ones and I came away feeling a renewed sense of hope

for the future of the support and treatment of people with NMD. I hope you have been able to be involved during this exciting period of time in the associations history. "The future looks bright".

Thank you to the contributors to this edition – we wouldn't have a magazine without you. May I also sincerely thank the efforts of Louise West who generously lent her graphic design skills to this publication over the past few years. All the best with your growing family Louise, may you continue to be a friend of MD in the future. Welcome to our new graphic designer Mardi Arkininstall.

Enjoy your Spring issue of Talking Point, before we know it, it will be the silly season!

Stay strong.

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

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Hello from the President

During the year the Association has achieved several considerable milestones in its Building Strength program.

These include:-

- The commencement of our home visit program
- The running of our first camp at Narabeen Leisure Centre assisted by a NSW Government grant
- The visit to Sydney by world famous comedian and muscular dystrophy supporter Jerry Lewis

These achievements took a lot of planning and effort, and I congratulate David, Renee, Georgina, and Maralyn for their commitment and hard work in making them happen.

In the last 18 months we have moved from ideas, to planning, and finally to reality.

For many years MDNSW provided funds towards essential services:-

- Equipment
- Research
- An office worker who could provide useful information

These services essentially complemented the medical services provided by the medical clinics at Prince of Wales, Concord, and Westmead hospitals.

Today MDNSW provides much more in terms of the social and emotional needs of our members, and carers, so that their life can be more balanced and fulfilling.

Improvement and change always comes at a cost, both in terms of growing pains, and funding. Fundraising has always been hampered by our low profile and lack of public awareness.



As you will know Jerry Lewis spent a week in Sydney recently, at our invitation, which was the best possible way we could raise our profile, and in doing so raise the greater level of funding that we need. There is no doubt Jerry's visit has immeasurably boosted our profile. As a result we are working towards a future telethon along similar lines to the one that has made Jerry and MDA a household word in the USA. If only one of these telethons occurs, the financial commitments for our future operations will be secure.

I look forward to providing ever improving services to our members, and thank our supporters for being so loyal in enabling this to happen.

Cheers,

Rob Ferguson

President, Muscular Dystrophy New South Wales

MAC Needs You!

The Members' Advisory Committee (MAC) is an important part of the Association. If you have any issues or suggestions of how the Association can be of service to you, then feel free to let us know.

The committee is made up of members from diverse backgrounds. MAC also puts forward suggestions for events and seminar topics, as well as reviewing events held by the Association, so that we can make recommendations to the Board and this process helps the Association to continually provide dynamic services to members.

We are currently recruiting new members to MAC, so if you could spare a Thursday afternoon, from 2pm to 4pm, once every two months, then please feel free to get in touch with us.

If you are interested in joining MAC, or putting forward any ideas, suggestions or comments, please feel free to contact Renee McBryde, Manager, Client Services at the office or myself on (02) 9643 1429, or email me at MBaptiste@bigpond.com

Michael Baptiste

Chairperson, Members Advisory Committee



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.

Throughout the week Jerry was supported by a brilliant line up of leading entertainers and comedians including Peter Berner, David Campbell, Kitty Flanagan, Tom Gleeson, Paul McDermott, Julie Morris, Fiona O'Loughlin, Carl Riseley, Mikey Robins, Leo Sayer and Mark Spano.

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, 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 all participating in this wonderful week of events, hearing this from Jerry reinforced their commitment to continue to work together to fulfil the mission of Muscular Dystrophy Foundation Australia of creating a cohesive, integrated and collaborative Australian MD community.

"We can't thank Jerry enough for coming all the way here to support us, and we can't wait to see him back

here to head up a TV entertainment extravaganza", MDF Australia & MDNSW CEO David Jack said.

"We deeply appreciate the great generosity and true friendship Jerry has shown us.

"With new support and awareness already building from Jerry's time here, we at MDF Australia will do everything possible to ensure the momentum continues.

"I hope we will look back on this week as the beginning of a united and vibrant era for MD in Australia, inspired and supported by a man who has spent most of his adult life leading the charge to improve the lives of people affected by muscular dystrophy", David Jack said.

Colin Gunn

Meeting a **Legend** of our Time

Saturday, 19th September, we attended a "thank you" function at Star City Casino where we met the one and only Jerry Lewis comedian extraordinaire. He was in Australia to promote awareness of Muscular Dystrophy. It was a fantastic experience to see and hear some of his exploits on the screen and share his enthusiasm to raise the profile of MD worldwide.

Back in the sixties when my parents and I were first told that I had Muscular Dystrophy there was no information available and precious little hope of a cure in Australia. My parents gained most of their hope from reading about Muscular Dystrophy in the USA through news about what Jerry Lewis was doing.

When I became a member of MDNSW in the eighties I have followed his efforts in the US to raise funds for the Muscular Dystrophy family where the children with MD are often called "Jerry's Kids".

It was absolutely amazing when David Jack, our CEO of MDNSW and CEO of the Muscular Dystrophy Foundation of Australia said he had secured Jerry Lewis to visit Australia.

Jerry Lewis had just finished his 44th national telethon on the 7th September in Las Vegas, Nevada where over \$US60 million was raised, bringing to date a total of over \$US2.4 BILLION !!!

I look forward to meeting him again when next he visits Australia.

Do I have favourite Jerry Lewis movies? Yes

1. The Nutty Professor (1963), where one of his characters sings 'that old black magic'.
2. Which Way To The Front? (1970) is where Jerry's character takes on Hitler with riotous results.

Bruce Ellison



MEETING A LEGEND OF OUR TIME





JERRY LEWIS SEPTEMBER 2009 SYDNEY



Wild Hogs

As one of the key organisers for the annual MDA-HOG Picnic Day it gives me great pleasure to be able to give the MD community an insight of what it means for the HOG members.

It was in the year 2007 that I first attended this day out at Warragamba as a fairly new member of the New South Wales HOG Chapter, the day was explained to the members as just a fun day to help raise money in support of MD NSW. This was for my partner and I a real eye opener as to how important a day like this really is. Although this day was attended by only about 50 people including MDA and HOG members alike it was still a very touching day.

The following year was the first for me as the Activities Officer for the NSW HOG Chapter which meant that I could add a little something to all the chapter events including the MDA Picnic Day.

The HOG committee really wanted to bring new life to the MDA day and worked in conjunction with MDA NSW to find out what sort of day they wanted this event to be, and after a number of discussions the new format was born. This format would include the starting convoy from Fraser Motorcycles to Warragamba



which allowed for a longer journey on the back of the Harley for anyone that was up to the trip as well as give everybody the feeling of being a part of something pretty awesome as they travelled down the M4 motorway.

The 2008 day saw the numbers rise from 50 in total to over 200 which were made up of about 80 from MDA and 120 from HOG chapters around the Sydney area. This gave those involved in putting this day together a feeling of success and let them know that we were back on the right track to

organising a great day out for all those who attend.

This brings me to this year's event, which again was very well co-ordinated by both MDA NSW and NSW HOG Chapter, and which saw attendance grow to over 350 people made up of 160 from MDA and about 200 HOG members from around NSW.

We again had the convoy leaving from Fraser's at Concord which saw 163 Harley's and 7 Trikes ready to take pillions and make their way to Warragamba in what would only be described as one "hell of a convoy" down the M4. Once the convoy arrived at Warragamba they were entertained for the day by the boys from Servinitup Australia (check out their work at www.servinitup.com) doing their amazing stunts on those motorbikes as well as Airbrush Tattooing for anybody who wanted some "tuff stickers" for the day, and of course the culinary delights of spit roast beef with salads and cold drinks all laid out for everyone to enjoy. There were also rides provided on the back of a Harley or a Trike as well as plenty of prizes up for grabs in the raffle.

Again as one of the key organisers due to the success of this year's event I can tell you that it gives us great pleasure to be able to share our passion with the folks from MD whilst at the same time give support both monetary as well as socially. Whilst a lot of hard





work and planning goes into this day it is made worthy by the attendance of everyone on the day.

I am also happy to be able to inform the members of MD that we have already been working towards an even bigger day for 2010, and I would like to encourage any type of feedback from those that attended this year's event so as to improve the day next year. If you would like to comment on the day please forward those comments to me (the Secretary) via our website www.nswhog.com.au and we will do our very best to implement those things.

Whilst you are there check out the Photo Gallery and all the photos from this year's MDA DAY.

Todd Le-Grand (Zorba)
Secretary

New South Wales Chapter
Harley Owners Group (HOG)

mob: 0433 434352 fax: (02) 4733 1073



Dear MD Team

I wanted to tell you how valuable you are to the MD and what a super duper job you and the team have done in organising all the events recently. You are probably exhausted - or on adrenalin til the camp is over, but I want you to know how much we all appreciate the efforts and hard work you are putting in to our association - a fabulous team!! The HOGS Day and Jerry Lewis event we attended were both really fun, exceptionally organised and a great chance to meet other families and enjoy some time out from our busy lives. Lets hope the momentum gained from Mr Lewis visit can continue to achieve awareness and lots of funding for the MD Foundation.

Carolyn Campbell-McLean



Hi Caz

Jeff and I went to the Jerry Lewis function on Wednesday and it was really good. What a truly wonderful human being he is and let's hope this is the beginning of something big for the MDA Foundation. How was the cocktail evening last night? We also had the chance to meet Totti Goldsmith who sat with us for about ten minutes downstairs after we had left the function and were having a coffee. Despite my preconceptions about her, which weren't very positive she proved me very wrong! A lovely warm woman who seems genuinely committed to our cause. You came across really well in the DVD package, what a star! I also finally met David Jack and Renee McBryde. The whole day left me feeling positive and inspired.

Hope you and Steve are well, take care

Love Sandie x



congratulations!

Cheeky Dogs: Deaf Indigenous Teen with MD has Flourishing Business

Dion Beasley is both profoundly deaf and has muscular dystrophy. He spent his early years

living with family in the Barkly region, then moved to Tennant Creek aged 11. His love of drawing grew into a business at 14, and now the art royalties and sales of his T-shirts, bags and cards are placed in a trust fund for his benefit.

See www.cheekydogs.com.au for his story and products.



Craft for a Cause

This is my third fundraiser for MDNSW. Each year I hold a scrapbooking day at Edgeworth Bowling Club (Newcastle) and attract between 75-80 ladies to the day. I charge an entry fee of \$20 per person, this includes entry, tickets into the luck door prize raffle and a home made morning tea (thanks to Aunty Jennie, Aunty Lorna and Mum) with the whole \$20 going to MDA.

The ladies spend the day scrapping, chatting and making new friends. We also run 3 work shops at an additional cost of \$12 each. Marion Werren, Jen Hall and Peta McBeth all donate their time to run these workshops allowing the money from each student to go directly to MDA. The ladies love the workshops and they are usually booked out well before the big day. I also run raffles and guessing competitions on the day to raise more money. Donations are sought from online scrapbooking stores and stores in the Newcastle region. It is amazing the generosity that is out there even in these hard times.

We have a local scrapbooking store Shop and Crop come to the event each year to sell products that the ladies just have to have to complete their amazing scrapbooking pages.



Each year the store donates amazing prizes and a percentage of sales made from the kits sold to the ladies taking part in the workshops.

I could not get through the day without the help of my oldest and closest friend Lisa Bramble. We are looking to hold another event next year and will post details here <http://www.newcastlefundraiser.blogspot.com/> - this year we managed to raise \$3154!

Mandy Gilchrist

Cremorne Cinema

A very special thank you to Alana and Fleur Garton and Matt Taylor for the truly wonderful fundraiser they put together at the Cremorne Orpheum on the 2nd of September. Over 100 people attended the screening of Ang Lee's 'Taking Woodstock' in support of Muscular Dystrophy NSW. The evening was a great success raising close to \$15,000 dollars. This is an outstanding result particularly for Alana, Fleur's and Matt's first ever fundraiser – Thanks guys!



Packed To The Rafters!

Well what a HUGE three months since the last Client Services Report! Of course you could not have missed that we had the WONDERFUL Jerry Lewis here in a whirlwind week of activity raising the profile and awareness of Muscular Dystrophy nationwide – which was a truly spectacular week to be apart of. Aside from all of the madness of the Jerry Lewis week we have also had a huge number of other things happening for members.

The warmer weather called for another ladies pamper day complete with manicures, pedicures and of course a champagne luncheon. The afternoon was spent in lovely company, with a great turnout and a lot of beautiful looking hands and feet for the trip home. Fast forward to the following week – same venue but perhaps less attractive hands and feet, we had another great day for the Nutrition Seminar. This year's medical seminar had a diverse group of presenters, allowing for both the professional and personal perspective. I think we all came away from the day knowing a great deal more about the importance of nutrition. I also must say a very special thank you to all our presenters who gave up their Saturday to be apart of the medical seminar:- Heather Johnson, Alastair Corbett, Hanan Saleh, Michael Baptiste and Susan Adams.

Another very special MD day and for me personally one of the highlights of the client services program was HOG'S Day. On the 13th September we had a hot summers day of 35 degrees out at Warragamba Dam – which did nothing to stop everyone turning up for the fun filled day of mayhem with the Harley Owner's Group. There were over 400 people that took part in the festivities at the dam - making it the most memorable HOG's day yet! Thank you to everyone who came along and most importantly a HUGE thank you to Roy Rogers and all the HOG's who continue to supersede all our expectations in making HOG's day the event of the year! One reminder for next year is to make sure that all grown ups bring a water pistol so that we can pay the kids back for all their water pistol activity!! Look out kids!



By the time you read this the first ever Muscular Dystrophy NSW Camp will sadly be over! As I write this article, the official camp countdown is well and truly on with only a few days left until 85 campers and carers embark on a week of adventure and fun at the Sydney Academy of Sport. It has been 9 short months in the making but the week of camp is finally here, all camp carers are trained and ready and all that is left to do is enjoy the week of fun activities and of course find a Halloween costume for the big party!

Following camp, I hope to see you all at the big Melbourne Cup luncheon at the MDNSW office on the 3rd November and of course the annual Christmas festivities in December... Who can believe it is almost that time again!!

See you all soon

Renee McBryde
Manager Client Services

PS Look out for all the camp photos in the Christmas edition of TP!!



MDNSW'S 2009 MAGIC CHRISTMAS PARTY

DATE: Sunday 13th December 2009

TIME: 11.00am – 3.00pm

VENUE: Bicentennial Park, Australia Avenue, Homebush Bay.

Site number 4 Education Centre with shade sail (look for the red and white balloons).

THEME: RED & WHITE (come dressed in the Christmas spirit wearing red & white only: prize will be given to the most Christmassy...)

COST: FREE for MDNSW MEMBERS! Gold coin donation from non-members. All food, drinks and activities supplied: **Including a Mad Science Christmas Extravaganza experience: The Spin, Pop, Boom Show (starts 11.30am)**

Santa will also make a special appearance and bring presents for children under 16.

RSVP:

To Renee at MDNSW

By Friday 4th December 2009

Renee.McBryde@mdnsw.org.au

Or on (02) 9809 2111





Family Day Out at Featherdale Wildlife Park

Spend the day at Featherdale Wildlife Park and Visit the World's Largest Collection of Australian Animals

Meet Wallabies, feed the kangaroos and take a photo with the koalas.

See emus, crocodiles, dingoes and much more!

When: Saturday 28th of November 2009

Where: Featherdale Wildlife Park Sydney

Time: 10:00am

Important: Please RSVP by Friday the 20th of November 2009

Call Georgina Christofis on 9809 2111

Come and join the fun

Women's Lunch Out at Oliveto's Restaurant

When: Friday The 13th of November 2009

Where: 443 Concord Rd Rhodes (Close to the MDNSW OFFICE)

Time: 11:45am – 1:30pm

Come and Enjoy the Italian cuisine and peaceful water views of the bay with the staff at MDNSW and it's members

RSVP to Georgina at the MDNSW office on 9809 2111 by the 10th of November

Cost: Free for Members of MDNSW



Upcoming Regional Events



- **Riverina Carers and Members Forum**
Thursday 29th of October, 2009
Wagga Wagga RSL Club 10:00am
- **New England Carer's Meeting**
Tamworth Community Centre
17th of November, 2009 10:00am
- **Hunter Carers and Members Christmas Party**
5th of December, 2009
- **South Coast Carers and Members Christmas Party**
Tuesday 8th of December, 2009

Diary Dates



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."

National Disability Strategy

The report 'Shut Out: The Experience of People with Disabilities and their Families in Australia' was launched by the NPWDACC on 5 August 2009.

The report provides detail on the key barriers and issues facing people with a disability, their families and carers and highlights the solutions offered by the 750 submissions received.

The many views expressed through the transcripts of nationwide consultations have undergone a thematic analysis and the submissions have since undergone an independent

qualitative and quantitative analysis. Together, these two important pieces of work have informed the consultation feedback report from the National People with Disabilities and Carer Council (NPWDACC) to government.

The report also compares the level of interest against a range of themes and issues that have emerged. It identifies the existing strategies that submissions suggest are working well.

Shut Out: The Experience of People with Disabilities and their Families in Australia is available to download by visiting <http://www.fahcsia.gov.au/sa/disability/progserv/govtint/Pages/nds.aspx> The report is available in accessible formats.

If you require another version of this document **please call: 1800 050 009**

Access to Premises Standard

The House of Representatives Standing Committee on Legal and Constitutional

Affairs tabled its report on the inquiry into the draft Disability (Access to Premises - Buildings) Standards in June. The report is entitled Access All Areas, and can be found online here - www.aph.gov.au/house/committee/laca/disabilitystandards/report.htm

The Australian Human Rights Commission is urging the Government to adopt the Committee's recommendations and proceed to finalise the Standards as soon as possible. The recommendations made by the Parliamentary inquiry for

improvement of the draft Standards, include:

- requiring access to the common areas of apartment blocks;
- improving access and safety features on all stairways;
- clarifying and limiting some of the exemptions in the current draft; and
- ensuring a timely and effective review process on the implementation of the standards.

It is expected that the Government will now prepare a finalised version of the Disability (Access to Premises - Buildings) Standards to be tabled in Parliament before the end of the year.

In June the Parliament also passed amendments to the Disability Discrimination Act with the aim of achieving greater economic and social inclusion for people with disability, and the Australian Human Rights Commission was given some responsibilities for monitoring Australia's implementation of the international Convention on the Rights of Persons with Disabilities.

For more information on these, see the Australian Human Rights Commission's Disability Rights website www.humanrights.gov.au/disability_rights/ or call IDEAS on 1800 029 904.

Gilchrist continues to bat for **FREEDOM WHEELS**[®]

Former Australian Test Cricketer Adam Gilchrist has signed on to support the FREEDOM WHEELS Modified Bike Service for kids with disabilities, for another two years.

It was Amway, who sponsor the program through their One by One Campaign, who made him aware of FREEDOM WHEELS, when they put out a challenge to Adam for the 2009 Indian Premier League. His task was to hit 25 sixes and Amway would contribute funding for these modified bikes. Not one to reject a challenge, Adam went beyond his target and hit 29 sixes, up from 19 sixes during the previous season.

After seeing the modified bikes in action and the smiles on the children's faces, Adam was more than happy to continue supporting the service.

"As a father of 3 kids, I know how important it is and the joy a bike means to a child. On behalf of Amway, it is an honour to be a part of this program," Adam said.

The FREEDOM WHEELS[®] Modified Bike Service customises standard pushbikes to give a new kind of independence to children with disabilities by allowing them to ride a bicycle for the first time. Since the program began, almost 400 bikes have been delivered throughout the country.

FREEDOM WHEELS is a joint undertaking between the charity, TADNSW (Technical Aid to the Disabled) and principle corporate sponsor Amway of Australia, whose support has allowed TADNSW to take the program regionally and now interstate.



"We have been modifying bikes for many years now and the initiative brings so much joy to hundreds of kids with disabilities by allowing them to ride a bike for the first time. We want to show the difference these bikes make to these kids and to their families. Suddenly, the whole family can go for a bike ride, which is often a huge achievement," TADNSW CEO Joy Barrett said.

Prior to the sponsorship support provided by Amway's One by One Foundation, volunteers would spend between 30 and 50 hours modifying just one bicycle. This has now been reduced to as little as three hours with the introduction of pre-made components.

TADNSW has been providing services to clients with disabilities for over 30 years and FREEDOM WHEELS is just one of the many services they provide to people with disabilities.



TADNSW is running bike assessment clinics all the time. Parents interested in registering their child for a bike clinic or would like more information about the **FREEDOM WHEELS** program please contact TADNSW on **1300 663 243 or (02) 9912 3400**. Alternatively, visit our website www.tadnsw.org.au



Welcome to Spring!

This is such a wonderful time of the year. The weather is starting to warm up, the days are becoming longer and the countdown to Christmas (and holidays) is getting shorter.

The next couple months are certainly busy around the MDNSW office. The Riverina carers meeting is scheduled for late October and a carers morning tea is also scheduled for our carers and members living around Tamworth NSW on the 17th of November.

We also have our annual regional Christmas parties in the Hunter and South Coast scheduled in Early December. Please refer to regional calendar of upcoming events.

On the 13th of November we also celebrate our end of the year party for the women carers and members of MDNSW. This event will be held at a local Italian restaurant near the peaceful water views of the bay. Please RSVP early to avoid disappointment



I look forward to seeing you at some of these events.

Georgina Christofis
Carers Program

NSW Colts Update

The off season for our N.E.W.S. team is over, with training for NEWS 2010 underway. However, most of the players continued playing in their local competitions which are run at the same venue as NEWS training. These local competitions are open to people with all types of physical disabilities as long as they use a wheelchair to play. The Soccer and Rugby League competitions are run by NSW Push & Power Sports, while the Hockey is offered by the Australian Electric Wheelchair Hockey Association. The regular members of the NSW NEWS Team also play in all competitions in addition to NEWS training sessions.

NEWS 2010 will be held in Sydney, from 12th to 18th April, at the Sydney Academy of Sport and Recreation, Narrabeen. The Colts will be defending the Roger Melnyk Trophy as well as the Hockey and Rugby League titles.

This year we have had a couple of new players join the squad, but we are always looking for new people to get involved in sport. If you are interested in just coming to try the sports to see if you like them, then the NEWS training sessions are a great way to do this.

The NEWS training sessions for 2009/2010 will be held at Kevin Betts Stadium, Ralph Place, Mt Druitt. All training days are Saturdays.

The dates are below:

Oct 2009	10th, 17th, 24th & 31st	1.00pm to 3.00pm
Nov 2009	7th, 14th, 21st & 28th	1.00pm to 3.00pm
Dec 2009	5th & 12th	1.00pm to 3.00pm
Feb 2010	6th, 13th, 20th & 27th	2.30pm to 4.30pm
Mar 2010	6th, 13th, 20th & 27th	2.30pm to 4.30pm



Left to right: Dean Crane, Jordan Crane, Stephen Webb (Captain), Michael Baptiste (Coach), Peter Dalrymple, Chris Suffield (Vice Captain) and John (Donny) Shepherd. In the background is MDA NSW Board Member, Mr Ian Williams.

Please note that the times may be subject to change, so if you are interested in coming along to try the sports, please feel free to contact me in advance.

For more information about NEWS, or if you would like to try electric wheelchair sports, please feel free to contact me on (02) 9643 1429 or email MBaptiste@bigpond.com

Michael Baptiste
National Director, National Electric Wheelchair Sports
NSW Coach



Soccer round robin match, with the Colts vs Western Wasps.

Spinal Muscular Atrophy (SMA) Developments

Spinal muscular atrophy (SMA) is one of the two most common inherited children's neuromuscular diseases. It causes weakness and wasting of the muscles in the arms and legs of infants, children and adults. The type of SMA (I, II, or III) is determined by the age of onset and the severity of symptoms. There is currently no cure or disease modifying treatment. Treatment guidelines for patients with SMA have recently been established based on expert consensus. A multidisciplinary approach focusing on managing the symptoms and preventing and treating the complications of weakness for the respiratory, gastrointestinal and orthopaedic systems is used.

There have been significant insights into the mechanisms of disease. SMA is caused by reduced levels of the survival motor neuron (SMN) protein in motor neurons. Insufficient SMN protein levels results in the degeneration and death of motor neurons in the spinal cord. There is an emerging picture concerning the selective function of the SMN protein in motor neurons. It has been proposed that SMN might function in the splicing (processing) of specific gene (or genes) and proteins important to motor neurons. A second hypothesis suggests that SMN is important for the transport of substances in motor neurons and that disruption of this function results in SMA.

In most cases of SMA, there is an abnormal or missing gene, known as the survival motor neuron gene (SMN1), which is responsible for the production of the SMN protein. Humans and chimpanzees have a second survival motor neuron gene (SMN2), which is able to produce a small amount of functional SMN protein and partially 'rescue' the motor neurons. Disease modifier genes, which alter the disease severity, have been recently identified. Molecular genetic tests have also provided advances in the diagnosis, which allows doctors to be able to diagnose the majority of cases and provide advice on family planning.

Encouragingly, SMA has been selected for accelerated drug discovery efforts and is considered "of many neurological diseases,

the disease closest to treatment" (National Institute of Neurological Disorders and Stroke, USA). A number of approaches have been assessed in clinical trials, although to date the results have been variable. Encouraging approaches include increasing the level of SMN protein expression from the SMN2 gene.

Gene therapy and stem cell transplantation remain potential future strategies.

Attaining sufficient patient numbers for clinical trials for each potential therapy is expected to be a significant challenge, requiring multiple centers.

Additional research is focused on the development of biomarkers; these are objective and sensitive measurements that should reflect disease severity and also function to monitor disease progression and response to potential therapies. They will therefore be used as outcome measures in future treatment trials. The development of biomarkers for SMA may also provide further insights into disease processes and lead to the development of novel therapeutic strategies.

Dr Michelle Farrar MBBS FRACP

Paediatric Neurologist
Sydney Children's Hospital
Neuromuscular Clinic and Prince of Wales
Medical Research Institute,
University of New South Wales.



Destination My Future

When you think about the future, what do you think of? Is it just thinking about the weekend? Or maybe wishing that school holidays would arrive quicker? Maybe you're eagerly waiting the release of your favourite band's new album, or an upcoming concert. Whatever the case, we are always thinking about the future.

I often only think of the future in a short-term sense. Often I'm wishing the week would fly by so I can play some sport on the weekend. I'm currently half way through second semester at university this year and I'm already thinking about the summer holidays (after the dreaded examination period!). However, I also think it is valuable to think of the future in the longer term.

I think it is important to set goals for yourself when considering the future. I believe that if you give yourself something to work towards, then you will be able to achieve more. When I was in my final years of high school, I set myself the goal of getting enough marks for my course at university. I knew that I wasn't going to top the state or anything like that or achieve a UAI of 99, but I still thought I could do enough to reach my goal. I set my goal a little bit above the UAI I required and ended up surpassing this goal. I think the reason that I was able to achieve my goal was because I set something that I could realistically achieve. Of course, to gain some personal satisfaction, it is important to extend yourself, to show your potential, but you can do this without trying for more than you are capable of.



When you set goals for yourself, whether they be short or long term tasks, it is important not to set yourself up to fail.

I've seen it before, specifically in the HSC setting, where students have set goals so high that they were destined to fail. At the same time, it is also important not to set goals that are too easy to achieve. Where is the satisfaction in achieving something well below your potential?

Remaining motivated is essential in achieving your goals. One way to do this is to set yourself small goals along the way to something bigger. Rewarding yourself for these small steps may also be a good idea. For example, in the quest to find a cure for Muscular Dystrophy, many small steps have been taken. When your goal is something so complicated, it is even more important to set small steps. Research into genetic conditions has come a long

way in the last couple of decades, but there is still a long way to go. There is not so much a struggle for motivation in this area, as I'm sure the aim of a cure for such a condition is motivation enough in its self. But at the same time, it is illogical to think that a cure is just around the corner. I believe there will be a cure in the future. Whether that is in 10 years, 20 years, a lifetime or longer, but those working in this field won't give up on the fight. It is tough, but continuing to work for a goal, no matter how difficult it is, will eventually yield results.

It is part of human nature to think of the future. This is not a bad thing at all. But I think it is important to give yourself a goal for the future. Everyone needs a destination, but it is how you get there that is the challenge. My next challenge is to decide what to write next time. But for now, I hope everyone continues to enjoy the rest of spring. Bring on summer!

Chris Suffield

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 FEATURED MEMBER - Kate Hepton, Spinal Muscular Atrophy – Type 2 SMA

What are your favorite things?

Friends, family, Livewire, my phone, music and MSN.

What are you really good at?

Creative writing – when I can concentrate, talking to people and technology.

What are some of the things you really dislike?

Math, hospital, my disability, and insects. Math is boring. Insects creep me out. Hospital is stressful for my whole family when I am in there. My disability is annoying because I can't do things.

Have you had to spend a lot of time in hospital or at home, away from school and friends?

Having Type 2 SMA means I miss a lot of things like sport, spending time with my friends at home and at school. I talk on MSN with my friends after school and on weekends, because I can't do many activities with them.

What do you like about being a member of Livewire?

It's awesome! Learning something new from other people. But also making friends with people who have a similar disability to me. As well as socialising in the comfort of home.

How do you spend your time on Livewire?

Chat, competitions, blogs and news. It is good to find out more about others.

How often do you use Livewire?

At least once a week. More if I'm allowed – homework first.

Have you made any new friends on Livewire?

Lots! My bestie (I don't usually single one person out).

What have you learned from joining the online community?

I have learnt many new things about other disabilities. But that I'm not alone either. I get to make friends elsewhere than school.





muscular dystrophy
new south wales

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

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