



MUSCULAR DYSTROPHY ASSOCIATION OF NSW

Talking Point

fight for muscular dystrophy

VOLUME 67 AUTUMN 2008

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What MDANSW does for its members:



Bruce's Brainteaser

by Bruce Ellison.

See page 7.

*provides hours
of entertainment...*



Your chance to own an original Monica Ellis work on paper!

See page 24.

*gives their ventures
shameless plugs...*



*... and
most
importantly:*

*makes a
difference!*



Dear friends,

Hope this edition of *Talking Point* finds you happy and healthy, pulling up the doona and getting the most out of this wonderful time of year. It's hard to believe Easter has come and gone and we

are into April 2008. A friend recently wrote that Easter is the time of forgiveness and new beginnings.

She shared a definition of "forgiveness", which had nothing to do with right or wrong. It simply said **forgiveness is giving up all hope of a better past.**

It seems that holding onto our past grief and injustices hurts us, and forgiveness can be a wonderful gift to ourselves.

From the bush behind me I can hear the familiar sound of a Kookaburra laughing. In Animal Dreaming wisdom the Kookaburra shows us how to effectively heal ourselves. A symbol of new beginnings, Laughing Kookaburra tells



us to take responsibility for our own healing and to cease all pretence. Silent Kookaburra guarantees that our desire to heal has been initiated and is set to be effective. May the coming months take us all on a journey to forgiveness, healing and new beginnings in our life.

The association is embarking on new beginnings with the appointment of a new CEO and new strategic directions from the Board. Chris Suffield shares how he is going with the next chapter – university. We welcome the new Carers Coordinator and share the newest information, research and events for members. Finally, on behalf of the members, I thank Ian Dear for his dedicated service over the past three and a half years, and wish him well with his 'new beginning' of retirement.

Enjoy and take care,

Carolyn Campbell-McLean

NEW BEGINNINGS FOR TALKING POINT

In this edition of *Talking Point* we invite readers to help shape the future of the publication. My idea is to try to theme future TPs so that they have a focus.

The regular content (editorial, fundraising round-up, research, President's and CEO's pieces, etc) would continue to be included. The upcoming themes are:

- Healthy Family, Friendships, Relationships, Sexuality
- Education, Employment and Finance
- Leisure, Sport, Rec, Transport, Travel

I would welcome and encourage TP readers to contribute pieces of interest, weblinks, poems, write stories, letters, artworks, be interviewed – just about anything at all – you'd like to share with others. We are also happy to hear what you like in TP and what you'd like more of. It would be good also if we could find some regular contributors who might be happy, for instance, to do a film or book review or an interview with someone of interest. All you budding journos, writers and artists, here is your chance to shine!

All contributions can be sent to The Editor, Locked Bag 1005, Rosebery NSW 1445 **email:** cazza74@bigpond.net.au

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FROM WHERE I SIT



Hello friends.

After almost four years as CEO of the Association I will be leaving around the

end of May or June. I will do so with mixed feelings, knowing that a lot has been achieved but that a lot more still needs to be done. I will certainly miss seeing many of the members whom I have come to know over the years and sharing the many ups and downs that are so familiar to the people we represent.

I will certainly also continue my membership of the Association and to have a special interest in all its ongoing activities.

The Association, after many difficult years, is potentially at the threshold of an exciting new phase of its development. It now has a more optimistic and realistic outlook for the opportunity to develop a long term national initiative in conjunction with other State MDAs. This will not happen immediately but there are early signs that this prospect is a real one and there for the taking. It has always been the case that a national initiative is necessary if we are to be able to maximize our profile, exposure and fundraising ability. The Board, under the presidency of Rob Ferguson, and the new CEO will be very keen to exploit this initiative.

There are too many people to thank for the help, advice and guidance they have provided during my tenure. I have tried to thank as many as I can individually and I can only assume that there will be some whom I will miss. To them, my sincere apologies, but also my gratitude. You know who you are!

I wish you all good health and look forward to catching up in the future. Bye for now.

Best regards

Ian Dear, CEO

HELLO FROM THE PRESIDENT



Dear members,

Ian Dear has made the difficult decision to move on from MDANSW after a highly successful three and a half years as CEO.

Ian has laid a strong foundation for our future and made a very real difference in a variety of ways, which was what he set out to do. The job of CEO entails a huge commitment of both time and effort, and Ian gave his all to the job.

Some of Ian's numerous achievements include:-

- the bedding down of the State Government funded Carer's program
- procurement of the recently introduced State Government funded Flexi Rest respite program jointly with MS and MNDA
- introducing our services co-ordinator's visiting program to the major Sydney clinics
- establishing a workable bequest program
- improving our relationships with corporate supporters such as Red Rooster, Randwick Labor Club, Turramurra High, Best & Less, and major donors
- overseeing major facelifts and making major contributions to our major communications media being *Talking Point*, our web site, and annual report
- organising a variety of highly successful major events including our Luna Park bash, our inaugural charity golf day (scheduled again for May 15 this year – please come along), Pathways to a Cure conference and hypothetical, and the Government House reception for our 50th anniversary
- substantially increasing membership numbers
- maintaining our financial reserves at a healthy level
- implementing a major computer upgrade and switching to a new accounting system (MYOB).

While it will be difficult to replace Ian's numerous skills and talents, we will find a new CEO with other qualities, which will be ideal for the next stage of our development.

I believe that the next stage is vital to our future, in that we must take a variety of initiatives to ensure provision of better services to a greater number of members.

We have recently added and will continue to add skilled people to our board, and among other things we hope to raise our profile, and consequently our income, so that we can provide better services.

During February the directors endorsed a plan of initiatives which will be implemented over the next three years, which they have called "Building Strength". Now we are looking for the right CEO to introduce them in the way they think best.

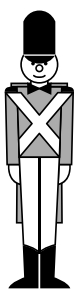
This is an important watershed for the Association, and one which I like to see as a great opportunity to facilitate the changes that we need to make.

Rob Ferguson

Fundraising May '07 – February '08

We received many donations over the last ten months from our very generous donors and supporters. Our sincere thanks go to every one of those donors and, in particular, the following:

- Macquarie Bank Foundation \$22,334
- Dick Smith \$20,000
- Best & Less May campaign \$15,786
- Colin Gunn \$14,798
- Mandy Smith Kokoda trek supporters \$10,800
- Ian and Sue Rodwell \$10,000
- Bilbergia Pty Ltd \$10,000
- Turrumurra High School \$10,000
- Randwick Labor Club \$10,000
- AMP Foundation \$10,000
- Oborn Professional Consulting Group \$5,500
- Horsley Park Soccer Club \$5,125
- Lime Taxis \$5,000
- Myer Community Fund \$4,528
- The Rogers Group \$4,250
- Ian Williams (Chatswood) \$4,000
- Shirley Williams \$4,000
- Anonymous \$3,000
- Yvonne Dreves \$2,000
- Rotary Club of Penrith \$2,000
- Fox Hills Golf Club Associates \$1,650
- Lianne Aramini (in memoriam) \$1,310
- Harley Owners Group \$1,143
- St Gertrude's Primary School \$800
- Entertainment Books (Joanne Murray) \$702
- Lachlan Riley (in memoriam) \$600
- Philip Henshaw (in memoriam) \$600
- John Andrews Insurance Brokers \$550
- Australia's Open Garden Scheme \$503
- Seaside Classic Tennis \$500
- Rotary Club of Parramatta City Inc \$500
- HMAS Penguin Sir David Martin WOSS Mess \$500
- AIB Pty Limited \$500
- Bruce Vaughan \$500
- Merrylands Bowling Club \$500
- Saltaire Pty Limited \$500
- Lioness Club of Camden \$500
- Olive Walker \$500
- Barbara Gunn \$500
- Mark Stanbridge \$500
- R.J. Atfield \$500



fight for muscular dystrophy



Miranda claims top Rooster

During 2007, our total collections from Red Rooster stores throughout NSW were almost \$49,000, an increase of nearly \$10,000 on the previous year. Congratulations to all our friends at Red Rooster, their staff and customers as well as our collectors on a great result.

The top-collecting store this year was Miranda, followed by Lismore and then Carlton in a close finish.

Our CEO, Ian Dear, met with the Red Rooster Miranda staff and their Area Manager, Lube Damcevski, to present a certificate recognising their efforts as well as a few prizes to thank them all. Pictured from left to right are Lube, Andrew, Teagan, Nathaniel and Damien. Well done to you all!

Sandra Allen collects from Miranda and Taren Point and has recently taken over collecting from Bexley and Carlton from our long term collector Dr Jacqueline Morgan. Our sincere thanks to both Sandra and Jacqueline for their invaluable help in this very important part of our fundraising efforts.

YOU'VE GOT A FRIEND IN ME

We have had a very long and happy association with our good friends at Turrumurra High School and have been very fortunate to be one of three chosen charities for their fundraising support.

At the end of 2007, our President Rob Ferguson and CEO Ian Dear attended the school's presentation evening and were presented with a cheque for \$10,000.

As a token of our gratitude, Ian addressed the school assembly in February 2008 and presented the two school captains with a certificate of appreciation for the hard work and support of the Turrumurra High staff and students.



Pictured are the Principal, Graeme McMartin, school captains Stuart Wheatley and Mary Barr, and Ian Dear.

The new Entertainment Books are now available.

The books sell for \$55 or \$65 (depending on the area) plus a small charge of \$7 for postage. They provide extraordinary value for money with substantial discounts for dining, hotel accommodation, theatres, sports and so much more. They can repay the purchase price after only a few uses. But wait, there's more! For every book sold, we receive

\$11 - \$13 towards our fundraising efforts.

So, please contact your friends, work colleagues, sporting clubs, schools, etc then let us know at the office on 9697 9111 how many Entertainment Books you would like to order and which type (Sydney, Sydney North, Parramatta/Hills/Blue Mountains/Macarthur).



THE NEW 2008/2009 entertainment BOOKS ARE WORTH THEIR WEIGHT IN GOLD!

Purchase your brand new 2008/2009 Entertainment™ Book now to receive over \$15,000 in valuable offers, valid through 1 June, 2009. At the same time, you'll be helping community fund-raising!

The Entertainment™ Book is your guide to the best restaurants, hotel accommodation, attractions, sports and leisure activities... all with 25% to 50% off or 2-for-1 offers. Plus, **My Bookings™** ... Compare rates, check availability and book your accommodation online.

Here is a sample of the many well known businesses providing valuable offers in the new Sydney and Sydney North Entertainment™ Books...



Fine and Contemporary Dining

Sydney edition *(the best of the city, east, south and inner west)*

- Cafe Sydney
- Forty One Restaurant
- Astral
- Le Sala
- Manta
- Wolfie's Grill
- Assiette
- Restaurant Sojourn
- Kingsley's
- Coast
- Waterfront Restaurant
- Ecco Ristorante
- Da Gianni Trattoria
- Caveau
- Baydu Seafood Restaurant
- Bavarian Bier Cafe
- Blue Ginger

and many more...

Sydney North edition *(the best of the north, upper and lower north shores, northern beaches and a selection of the city)*

- Watermark Restaurant
- The Bathers' Pavilion
- Pili at Freshwater
- Milson's
- Alchemy 731
- La Grillade
- Terrace on Pittwater
- Orso Bayside Restaurant
- Serowva Waters Inn
- MuMu Grill
- Limani Seafood Restaurant
- Beach Road
- Banjo Paterson Cottage Restaurant
- Nilgiri's
- Bavarian Bier Cafe
- Catalonia
- The Ginger Room

and many more...

Restaurant and Café Dining

Sydney edition *(the best of the city, east, south and inner west)*

- Wagamama
- Hog's Breath Cafe
- Blackbird Cafe
- Bite Me Burger Co.
- The Barn Cafe & Grocery
- Cine Restaurant and Bar
- Löwenbräu Bier Hall
- Cafe Monz
- Mike's Grill and Bar
- The Rocks Cafe
- Encasa
- Nikos
- Cafe Bo Bo
- Clovelly Hotel
- Bay Tinh
- Il Goloso
- Pancakes on The Rocks

and many more...

Sydney North edition *(the best of the north, upper and lower north shores, northern beaches and a selection of the city)*

- Pi Gallagher's
- Cafe Brisa
- Wood and Stone
- The Newport Arms
- The Barn Cafe - Headland Park
- Flying Fox Cafe
- The Moody Chef
- On Shore Cafe Brasserie
- The Claypot
- The Stoned Crow
- Chili Lime Too
- Fink Chocolate Cafe
- Basil and Mint
- Brewhaha
- Ironbark
- Wok on Inn
- Bar Asia

and many more...

The following appear in both the Sydney and Sydney North editions.

Informal Dining and Takeaway Restaurants

- McDonald's
- Gloria Jean's Coffees
- Hungry Jack's
- Domino's Pizza
- Oporto
- Krispy Kreme
- Subway
- Pizza Hut
- Ogalo Portuguese Chicken
- McCafe
- Kick Juice Bars

and many more...

Arts, Sports and Attractions

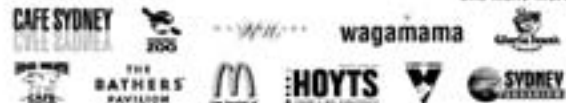
- Greater Union Cinemas
- Taronga Zoo
- Sydney Aquarium
- Hoyts Cinemas
- Sydney Symphony
- Luna Park
- Sydney Wildlife World
- Sydney Theatre Company
- Sydney Tower Skywalk
- Sydney Swans
- The Australian Ballet

and many more...

Retail, Travel, Leisure and Accommodation

- Hamilton Island
- BreakFree Hotels Resorts Apartments
- Golden Door Health Retreats
- Rydges Hotels and Resorts
- Avis/Budget/Eurocar/Hertz/Thrifty
- Movie World, Sea World, Wet n' Wild Water World
- Fountain Cosmetics
- Roses Only/Fruit Only
- Brampton, Dunk, Heron Islands

and many more...



For a complete listing of participating businesses or more information about Entertainment™ Books for other cities, please visit www.entertainmentbook.com.au.

TO PURCHASE YOUR NEW ENTERTAINMENT™ BOOK, CONTACT:

Help raise important funds for Muscular Dystrophy Association of NSW

To order your copy contact: Ian Dear Phone: 9697 9111 Email: idear@mdansw.org

Name: _____ Phone: _____

Address: _____ State: _____ P/Code: _____

I would like to order: _____ x Parramatta/Hills/Blue Mtns/Macarthur @ \$55 each (GST incl.) = \$ _____
 _____ x Sydney North @ \$65 each (GST incl.) = \$ _____
 _____ x Sydney @ \$65 each (GST incl.) = \$ _____
 I have included \$7 per Book for postage and handling **Total amount enclosed: = \$ _____**

I would like to pay by: Cheque - Please make cheques payable to: Entertainment Publications Cash

Or please charge my: Visa MasterCard

Credit Card Number: _____ / _____ / _____ Expiry Date: _____ / _____

Cardholder's Name: _____ Signature: _____

muscular dystrophy association fundraiser luncheon



When
Wednesday 7TH May from 11 am

Where
Aqua function room, Beaches Hotel, Merewether

Cost
\$45 includes champagne on arrival,
Delicious 2 course meal, tea/coffee

Dr Heather Johnston of Sydney Children's Hospital
and Medical Director of MDANSW
will be our Guest Speaker.

Prizes
There will be lucky door prizes, raffles and lucky balloons. Prizes include 2 nights accommodation at the Vineyards, vouchers for wining and dining around Town, girly pamper packs, movie tickets, shopping vouchers and lots more surprises than last year!

Dress
Red, white & black theme optional—prizes for best dressed

Wheelchair access available from the car park entrance in Ridge Street.

For catering purposes we need to know if you will be attending by 2nd May with all moneys paid by 2ND May . Please contact any of the following girls to secure your seat:

Vicki Sciulli	0432 979543	4963 7247
Janene Oborn	0418 687532	4934 4488
Lisa Bramble	0411 774472	4956 5090

fight for muscular dystrophy



Can you name these movie titles?

Answers on pg 21.

- 1 **Charlton Heston** starred in this 1956 Cecil B. De Mille epic. (3,3,12)
- 2 This Alister Maclean novel was made into a film in 1971 and starred **Anthony Hopkins**. (4,5,5,4)
- 3 **James Dean** 1955 classic. (4,2,4)
- 4 **Jill St. John** starred with **Sean Connery** in this 1971 film. (8,3,7)
- 5 **Ronald Colman** and **Shelley Winters** starred in this 1947 Oscar winning film. (1,6,4)
- 6 **Yul Brynner** made this musical a huge success. (3,4,3,1)
- 7 **Bogart** and **Hepburn** classic of 1951. (3,7,5)
- 8 **Omar Shariff** was the star in this 1974 comedy about crime and passion. (3,2,2,6)
- 9 **Mel Gibson** starred and directed this 1995 period drama.(10)
- 10 This **Whoopi Goldberg** film title was inspired by a Rolling Stones hit of the '60s. (6,4,5)
- 11 Alfred Hitchcock thriller of 1959 starring **Cary Grant**. (5,2,9)
- 12 **Mitzi Gaynor** starred in this musical. (5,7)
- 13 **Sophia Loren** starred in this 1961 Oscar winner for Best Foreign Language film. (3,5)
- 14 A 1954 film about a Roman tourist attraction. (5,5,2,3,8)
- 15 **Hugh Grant**'s first starring role in this 1994 film. (4,8,3,1,7)
- 16 **Natalie Wood** starred in this 1961 film version of a smash Broadway hit of the same name. (4,4,5)
- 17 A British horror film made in 1949, starring **Edith Evans** in the title role. (3,5,2,6)
- 18 A film about three generations of Chinese women living in the USA. (3,3,4,4)
- 19 **Paul Newman** starred in this 1967 film set in a prison. (4,4,4)
- 20 A 1958 British drama starring **Rita Hayworth** and **David Niven**. (8,6)

INTRODUCING...



Ross Parker

Honorary Director of MDANSW

I have recently entered semi-retirement after a career in Human Resources at Director level. I was fortunate to have a number of roles with a small number of employers. I commenced work as an Industrial Engineer with Streets Ice Cream, a division of Unilever Australia. I gained experience in manufacturing and warehousing and then entered Human Resources as I had studied Industrial Relations at the University of NSW whilst undertaking a BA. I then accepted a role as HR Director at Tooheys' Limited for six years then moved to Goodman Fielder in various positions including an assignment to the USA. Elspeth and I lived in Philadelphia at the time of the 9 /11 attacks. My last corporate position was with the Crane Group that employs about six thousand people. My working life has exposed me to many people in a wide range of social circumstances, many touching my compassion especially in overseas countries in which I travelled.

At a personal level, I live in the Southern Highlands where I garden under the direction of my wife, Elspeth, play the occasional game of golf and fly-fish for trout. I am gregarious and enjoy the company of good friends. Prior to relocating to the Southern Highlands we had a farm at Bungonia NSW, ran sheep and grew grapes for wine production. We have three children, and four grand children ranging in age from seven to fourteen. We involve ourselves in their busy lives including church activities and viewing netball and swimming events.

When approached by the President of the Association, I was pleased to be considered for a voluntary Director's role. I hope that I can contribute to the successful operation of MDANSW and enhance support to those affected, their families and carers.

OLYMPIC SPIRIT AT LOCAL LEVEL

Northcott sports carnivals give students with physical disabilities the opportunity to represent their school and compete against other young people with similar abilities as themselves.



WHEELCHAIR FOOTBALL: A, B & C Division. School teams in an exciting game of Wheelchair Football. Push and Power Rules apply. There are 6 players on a court at a time. A team must consist of 3 manual wheelchairs. Powerdrive wheelchairs may round off the rest of the team. Divisions cater for different ability levels.

SENIOR CARNIVAL ONLY - TUES 27 MAY 2008

BALLOON SOCCER: The game consists of 6 players on a court at a time. A team must include 3 manual wheelchairs. Powerdrive wheelchairs may round off the rest of the team. Divisions cater for different ability levels.

JUNIOR CARNIVAL - TUES 12 AUGUST 2008

SENIOR CARNIVAL - TUES 26 AUGUST 2008

ATHLETICS: Carnival caters for all physical disabilities.

races - sprint races, obstacle race, bean bag race, relay race

field events -discus, shot put, powerdrive slalom, manual slalom

SENIOR CARNIVAL ONLY - WED 22 OCTOBER 2008

If you would like more info on Northcott's Interschool Carnivals, ring Claire or Mitch 9890 0100. recreation@northcott.com.au

They will add you to the school carnival list to receive info & entry forms.

ideas | Expo
Speak up – be heard

IDEAS NSW is proud to present their latest expo to be held in Queanbeyan in May this year. The Expo titled IDEAS Expo 2008 **Speak up – be heard** is to raise awareness and promote the development of advocacy in the Southern Highlands region.

It will be the perfect opportunity to explore and learn more about the range of organisations, services and equipment available to you. With over 40 companies and organisations, represented and on display, this is an opportunity for you to find out who and what is available to support and assist you when needed.

The Expo is in the Queanbeyan Conference Centre in Crawford Street, which is a very centrally located venue with plenty of parking nearby.

Opening times:

Thursday	22 May 2008	12pm – 5pm
Friday	23 May 2008	9am – 4pm
Saturday	24 May 2008	9am – 12pm

A range of education workshops will held run in conjunction with the Expo at a venue across the road – the Queanbeyan Community Centre. Initial interest to run workshops has come from Public Guardian; NSW Ombudsman - Community Services Division; Intellectual Disability Rights Service and Family Planning NSW.

Visit the website www.ideas.org.au for further details on exhibitors and the range of workshops as they come to hand or call on **1800 029 904** to be added to the mailing list and kept up to date with details of the event.

For further details contact Diana Palmer on 1800 029 904.

SUPPORT NETWORKS



NSW Network of Women with Disability

PO Box 9381, Harris Park, NSW 2150

phone: 02 9891 6400 toll-free call: 1800 629 072

The NSW Network of Women with Disability and the **Pathways to Parenthood Project Team**

present the following website:

www.femability.org.au/parenting_with_disability.htm

ONLINE FORMAT OF PATHWAYS TO PARENTHOOD RESOURCE

Lois Gilmour developed the website format of the Pathways to Parenthood resource. This online format of the parenting resource for parents with disability was completed in late October 2007. This format has the capacity to be added to and updated on a regular basis - so if you have a relevant service, program or information please contact the Lois at webmistress@femability.org.au or the office at women@mdaa.org.au

PRINTED BOOK FORMAT OF PATHWAYS TO PARENTHOOD RESOURCE

A copy of the book has recently been donated to the reference collection of each Central Library branch in all

152 local council areas throughout NSW.

So please inform/highlight this to anyone interested in accessing the book.

For the remaining copies of books, individuals and parents with a disability will still be a priority - we have set aside copies for these people and we welcome any request.

BRILLE FORMAT OF PATHWAYS TO PARENTHOOD RESOURCE

A braille format of the resource is currently in process of being donated to the national and NSW-based libraries of Vision Australia. The NSW Network of Women with Disability office shall also have braille copies of the resource.

NSW NETWORK OF WOMEN WITH DISABILITY NOW ONLINE

The femability website www.femability.org.au has important information about the NSW Network of Women with Disability and its current activities, projects and seminar's for women with disability throughout NSW.



**CASE MANAGEMENT PROGRAM
MEN'S SUPPORT GROUP 2008**

A joint project between **Learning Links & the Health Department**

Learning Links would like to support you as Dad, Step-Dad and Grand-Dad of children with a disability by providing a **Men's Support Group**. Often the men in the family are unable to access support outside of their home and/or work place as they are working and/or are a significant support person. Coming along to a **Men's Support Group** could give you an opportunity to have some time for yourself... and obtain

- support specific to your role as a male carer of a child/children with a disability
- assistance to address issues relating you as carer
- connections with other men who are experiencing similar situations
- some time out
- new friendships
- new experiences
- an opportunity to talk and discuss issues with other men.



Special guest speaker every month.

Come along and join in the discussion & meet other Dads, Step-Dads & Granddads.

If you require childcare contact Julie to organise free childcare for you while you attend the group.

Supper provided.

venue **Learning Links head office**
12 - 14 Pindari Road
Peakhurst NSW 2210

date last Thursday of each month

time 7.30pm - 8.30pm

contact / RSVP Julie Densley

phone 9534 1710

FREE COUNSELLING FOR FAMILIES with a member with a disability

Offered until June 30, 2008.
See www.interrelate.org.au or phone 1300 736 966 for details of **Interrelate** centres across NSW. Metro centres are at Mosman (Thursday afternoon and evening), Dural (anytime) and Burwood.

BUILDING STRENGTH for now and the future

As most *Talking Point* readers are probably aware, MDANSW is governed by a Board of Directors whose responsibility is to ensure that the Association fulfils its mission is to alleviate the impact of neuromuscular disorders in our community and to promote the well being of affected people, their families and their carers.

As volunteers ourselves, the members of the Board are deeply appreciative of the support the Association receives both from within and without. The many and varied contributions made by our members, our volunteers, our staff and our corporate and individual benefactors provide the platform of community, effort and generosity upon which the Association fundamentally depends.

As we look to the future we see many challenges and many opportunities. Our immediate challenge is to find and appoint a new CEO who is able to take over the running of the Association from Ian Dear (see Rob Ferguson's discussion of Ian's considerable achievements on page 3 in this issue of *Talking Point*). This upcoming change in our management has coincided with the Board's desire to consider what strategies might be adopted to improve our ability to serve the interests of the NMD community in NSW.

The Board set aside a Saturday in February to ensure that we had sufficient time to consider all the issues we felt needed to be addressed. We were fortunate to have the generous assistance of professional facilitator Alan Bird to keep us focused and productive, in addition to having the invaluable contribution of Ian Dear.

The first item on the agenda was to agree on a name which would succinctly encapsulate our new strategic program as well as remind us of the core purpose of the Association and its continuity of service. We hope you will agree with us that the name **Building Strength** does just this.

By day's end the Board had agreed to a comprehensive set of issues to be addressed and the goals to be achieved. We are now looking forward to reviewing and refining our program for **Building Strength** with the incoming CEO. In the meantime we would like to share the broader picture with you.

Some of the major goals of **Building Strength** are:

To improve and expand delivery of our existing services including

- the provision of information and support
- advocacy on behalf of members
- fundraising and social event planning and facilitation
- carers' programs
- clinic liaison
- publication of *Talking Point*
- developing and assisting support groups
- funding of equipment

- funding of respite
- funding for emergencies.

To develop new services and programs which

- address the unmet needs of members
- provide and facilitate new social opportunities for members to develop closer relationships
- provide assistance, guidance and support tailored to different stages in our members' lives
- more effectively lobby all levels of government in support of better provision of equipment, services and facilities
- harness the accessibility and flexibility of the internet to educate, inform, communicate and entertain.

To increase our membership as much as possible to represent all people in NSW living with NMDs.

To work with Muscular Dystrophy Associations from other states in Australia to

- achieve greater cooperation and collaboration through dialogue, shared events and common programs
- develop a more united voice and uniform identity
- raise the profile of NMDs at a national level, and thus
- increase the potential for greater funding from government, corporations and philanthropic bodies at a national level.

To increase funding of research into neuromuscular disorders with a review of the most effective and beneficial means of distributing this funding.

To attract skilled and committed people to work with and for the Association in both voluntary and paid capacities including

- seeking and appointing a CEO capable of and committed to implementing our **Building Strength** program
- improving the amenity of our office premises for our staff, members and guests
- attracting directors with the specific skills as well as social, political and commercial networks required to fulfil our goals.

To develop and implement a structured and sustainable fundraising program capable of providing the ongoing financial resources necessary to achieve the goals above.

We hope you will join with us in **Building Strength**. As always your thoughts, suggestions and constructive criticism are always welcome.

The Board of MDANSW

Provided the cost is fair!

In November, 2007 my elderly sister took ill and was placed in a nursing home at St Marys. Having suddenly lost her son and our sister within six days, I was eager to see her.

As I am a pensioner, I contacted the South West Community Transport for help to visit my sister. They quoted me \$37 return trip from Prairewood when I normally travel further to Concord Hospital for \$22! I felt this unreasonable and requested a 'reasonable cost' be applied. This was ignored, so feeling I was being treated unfairly, I contacted Viktoria at MDANSW and the Ombudsman.

When Community Transport was told I had contacted the Ombudsman, they agreed to a meeting on 24 January 2008. Viktoria (MDANSW), Linda (HAAC

Development Officer) and Lyn (Executive Officer with Community Transport) met at my house to discuss my situation. It was agreed I be charged the \$22 fee I normally pay when I go to Concord.

I broke down and cried when I managed to meet my sister on 7 February 2008.

The whole situation with Community Transport was stressful, traumatic and quite unnecessary. I was extremely disappointed with the staff at Community Transport because of their lack of compassion for people in my situation.

Finally, I would like to say that I am thankful for being able to visit my elderly sister and also I am grateful for the support afforded me by Viktoria from MDANSW.

Kathleen Deane

To make a booking

Call on 1300 138 794
General Enquiries 4629 6888
An answering machine is available out of hours for your convenience

Office Hours
Monday to Friday
7.30am to 5.00 pm

Fax:
4629 6800

Email:
transport@swct.com.au

SOUTH WEST Community Transport

The areas we cover

Camden
Campbelltown
Fairfield
Liverpool
Wollondilly

Providing transport for the frail aged, younger people with disabilities, their family and carers

Home and Community Care Program funded jointly by the State and Federal Government

Shopping trips

These trips run one day per fortnight. On arrival you have 3 hours at the shopping centre. Due to the limited room on the vehicles clients are restricted to 4 bags of shopping per household and are encouraged to use home delivery services.

Who is eligible to use the service?

This is a transport service assisting older people who are frail, younger people with disabilities and the carers of these people, living in Camden, Campbelltown, Fairfield, Liverpool and Wollondilly.

How much will it cost?

Cost will depend on the distance of the trip and your ability to pay. The minimum charge is \$5.00 for a local return trip. Please ask for the cost when making your bookings. If you have difficulty paying please contact the office for assistance.

Our Vehicles

We operate mini buses some of which are fitted with wheelchair hoists. All wheelchairs are restrained during transport with a special restraint system. We can provide a wheelchair for use during transport if you require.

Bookings

For bookings please contact our 1300 138 794 telephone number. Callers are only charged for a local call when using this number. We would appreciate you making the booking as early as possible prior to the date it is required.

Post-HSC
^

DAYS IN THE LIFE of Chris Suffield

From the end of the HSC exams in November, everything has settled down a little. HSC results came out on Wednesday 19 December through the Board of Studies website. I was happy with my results, but the real result that I wanted to know was what my UAI would be. The UAI gives you a rank, and this in turn indicates your chances of getting into university. These came out the day after the HSC results. I was really happy with my results, not only because it was better than I expected, but also because it meant that I had nothing to worry about; I was going to get into my course. 4 weeks later I could really stop worrying when I got accepted into my course at Uni.



because although your family will always be there for you, sometimes it's nice to be friends with other people.

It seems no matter how hard I try, I just can't seem to escape from school! My two brothers just recommenced school in the last couple of weeks, Michael into Year 12 and Brendan into Year 8. I'm already being called on to help with schoolwork, such as helping with Mathematics I thought

I would have forgotten by now, or proofreading English work. I guess my brothers are lucky that I've got a little more time on my hands to lend a helping hand every now and then.

You have a lot of time on your hands after you have finished all your formal classes in Year 12. I know I did nothing for the first week after exams, apart from sleeping and being a bit lazy. But hey, everyone deserves a break after 13 years of schooling (right?). One of the things I have done during this break is keep in contact with my school friends. I know I sent a lot of text messages in the couple of months after I finished school. I've gone down to the pub with the guys a few times and had a bit of fun, so it's all good. It's easy to stay in contact with people when you see them at school every day, but when that period is over, staying in contact becomes something you have to want to do. Most of my friends have got into Sydney Uni, whilst I'm going to Macquarie Uni. It's going to be hard for me to keep in touch with my school friends if I don't put in a little bit of effort because I won't see them as often as I used to. I want to keep in contact with them, but initially my parents and brothers were the ones encouraging me to do so (and sometimes it felt like they were forcing me to). But sometimes that's how relationships are with family. They want what's best for you, even if you're reluctant to do what they say.

After school you may not be in contact with school friends as frequently as you were at school. I want to try and go out of my way to make some new friends at uni, talk to people and be a bit more extroverted. I know it's much easier to do this at school because you always have your friends around you, but eventually everyone has to move on. You won't always be able to rely on the same people throughout your life, so it's important to be able to interact with different people also. The more I think about it, the more I realise that friendship is something that requires effort. But it is something you want to put effort into because it can be rewarding in the longer term. Having friendly relationships with different people is important,

Once I received my Uni offer for my course and accepted it over the internet I found out that I had to go to the Uni in order to complete my enrolment into the course. I had to go to Uni for enrolment on the 30th Jan. But even before I did this, I knew the subjects that I wanted or had to get enrolled in. One of my friends who is also going to Macquarie got me the Undergraduate Studies Handbook from the Uni. The Handbook has been very useful for me because it helped me with my subject selection for elective courses. I wasn't really sure what I wanted to do apart from my major and I was more able to scope out potential elective subjects.

I think it is important to be extremely organised before commencing uni. I had already planned out my timetable before the enrolment day, and this helped because that was one of the things required to be done on the day. This is even more important if you have a wheelchair because not all of the classrooms are accessible at every uni. I even have most of my text books already, so I'm starting to get a feel for my subjects already. I heard a lot of things I already knew on the enrolment day, but it always helps to hear some things again. It has to be remembered that Uni is a lot different to school; there's more freedom, but this also means you have to find out some things for yourself.

I also had a meeting with the Disability Support unit at the Uni, and they can help out with note taking and other academic things that some students might need. But the good thing is that everyone seems like they want to help you out. So I start Uni at the end of this month. I'm looking forward to it a lot and I think I'll have a lot of fun. Once I get settled in, maybe after a few weeks, then I'm sure I'll feel comfortable. There is no avoiding the fact that it's still going to be a lot of hard work, but I'm ready for the challenge.

Chris Suffield

WHEN YOU GOTTA GO YOU GOTTA GO

Was this it? The PERFECT Wheelchair Accessible toilet! (Note that I do not say disabled toilet – that would not be of any use to anyone as it would no longer work.)

I thought that I had found it and there it was, right next to the venue. In fact it was so close and so convenient that the guest of honour (who had no disability) had difficulty in finding an ordinary loo and had to use it.

But alas no. The door opened inwards and I had to have someone stand by to let me out. And then to lift the lid on the pan – too heavy – again I needed help. There were some plusses. The flush button was on the wall and I could actually reach and operate it and the washbasin was high enough to get close and the tap had an extended handle. I could wash my hands.

Wheelchair accessible toilets come in all shapes and sizes. Some are so small that you cannot turn round in them. In some you dare not close the door for fear that you will not be able to get out, and I never lock the door in case – it has happened! On one occasion I just could not open the door and had to yell for anyone, anyone passing to let me out.

Then there is the problem of flushing. Sometimes I can reach the button but am not able to press it. In most cases it is just too high.

The washbasin is another problem. The usual basin is so low that you can't get a wheelchair under it and the taps are often out of reach. As for the soap and hand towels you will be lucky to reach and use them.

A common problem is the use of the wheelchair accessible toilet as a storeroom. The cleaning equipment and even the

garden tools have been found to clutter the already tiny room which must also have a couple of bins.

Many wheelchair accessible toilets are locked and a special key is available to open them. I am told that this is to prevent vandalism – understandable if the facility is in a place which may be unfrequented such as a park – but I fail to see why a wheelchair accessible toilet in a shopping centre should be more prone to vandalism than the regular toilets located alongside.

The wheelchair accessible toilets at Olympic Park were well designed by the Olympic Access Committee but they double as baby change rooms. Until I had a couple of long waits during the games I thought that this was a good idea. Good in theory but in practice the wait can be long!

People with disabilities come in many shapes, sizes and degrees of disability. I should note that my requirements in a toilet are, for various reasons, not as great as they may be for some others as I do not have to use rails to transfer across to the seat. I only have to get in and get close. And then to get out!

So the search continues. For a toilet that is large enough, has a lightweight or no pan lid, a door that opens outwards or is on a pivot and can be opened by a person in a wheelchair from the inside, a flush button that can be reached and pressed from a chair, and with a washbasin with taps, soap and towels I can reach. One that I can use independently.

Elizabeth McDonald
MDANSW member

Rural roundup

Hi all,

Carolyn has asked me to contribute to *Talking Point* so that I can share some of my life's experience with you and hopefully over time I can write something that is both encouraging and informative for you all.

Writing this article brings back many memories from my childhood and my first contact with the Muscular Dystrophy Association in South Australia and in particular the Roundabout newsletter which I would wait eagerly for in the mail. There was a colouring-in competition that I would carefully do and recall winning some of them much to my delight.

I was diagnosed as having a Muscular Dystrophy very early in life and in my early twenties after extensive tests done by Dr Graeme Morgan at Prince of Wales hospital I was told that I had Kugelberg-Welander disease –

Elaine Wooden is an outstanding woman from Orange who has come on board to write a regular feature for Talking Point – our "rural correspondent" so to speak. She has much experience in getting things done for people with a disability, is a grandmother and offers a down to earth approach to reflections on life.

a form of Spinal Muscular Atrophy.

I decided very early in life that I was going to live as normal a life as possible and have achieved most of the goals that I set out to accomplish (others I am still working on).

We have advanced so much today with technology and automation that nearly everyone can live in the community and function to the best of their ability despite the level of disability they may have.

I am still actively involved in advocacy issues, protecting the foundation laid down so many years ago, so we can continue to enjoy our rights and privileges that we have today.

Until next time,

Elaine Wooden
MDANSW member

Nicole Lee Giles

10/31/1987 – 10/10/2007

Where to begin?

Nicole would write this story herself so much better than I.

As we faced her 21st birthday in March, we approached it with a certain amount of sorrow that she did not quite make it and she had such big plans to celebrate this significant milestone. For us, we celebrated her birth and gave thanks for every day that we had to get to know her.

Nicole was born a little early and we thought at the time a little low sugar and jaundice were the biggest things we would have to handle with our beautiful baby girl.

As time went on we noticed her difficulty in walking and tightness in her ankles. Life took rather a sharp turn towards physios, OTs and doctors trying to understand what was happening. Long story short, after many attempts to diagnose and misdiagnose we came up with a label of Congenital Myopathy - Muscular Dystrophy (undefined). Investigation is still in progress much to Professor North's frustration.

In brief, weakness, contractures, scoliosis and respiratory failure and finally difficulty in swallowing.

Throughout Nicole's life she fought the labels and to be heard as an individual who knows her body best. Gracefully she accepted her physical limitations but not the limits set by others. She made and redesigned her goals to suit her and her ability for each year that passed and each challenge thrown her way, never losing sight that there was so much more to her than a medical condition.

Nicole attempted dance and Scouts when she was very young and excelled academically and with the piano. She enjoyed her music, her art and scrapbooking but writing was her true passion. Her personality was strong and wilful. She held strong opinions on most things and was always sure that she was right.

This determination, faith and strength would carry her through to the end.

As time passed and the dystrophy took its toll it would find Nicole wheelchair dependent by ten and nocturnally ventilated with a rather dim prognosis. At fourteen Nicole was on full ventilation and yet she continued to charge on, celebrating her 18th birthday in style with all the glitz and glamour she could muster. What



Above: Nicole appeared in Talking Point Issue 63 giving a cheque to Rachel Spencer – a donation of \$974 to MDANSW from the launch and initial sales of *The Unsaid*. See Talking Point Issue 61 (page 11) for more about Nicole and her poetry.

opportunities were taken from her she created herself.

Nicole had excelled at writing throughout high school and had written some short stories. As her hands became more difficult to use and her strength and stamina diminished she turned to poetry. This would prove to be her forte.

Nicole had her first book of poetry published, *The Unsaid*, selling 400 copies, donating her profits to MDANSW and Bear Cottage. Nicole got great pleasure in finally having a voice and feeling like she had made an impact; a difference. She received a lot of positive feedback and was asked to be a guest poet at Poetry in the Park. She proceeded to write a second book of poetry, *I Have Spoken*, which will be released this year.

Her poetry expresses her dreams her hopes, her disappointments, her anger, her faith; with absolute honesty. I hope you have the opportunity to read Nicole's work, as she put in words so profoundly what is was to be her.

All in all, she did not focus on what she could not do; she would focus on what she could do. NO REGRETS.

Take advantage of every opportunity, create your own opportunities, and even against all odds, strive to be and embrace what is to come. Know that we have a purpose and understand life, love and heaven is our reward.

Sharon Robson (proudly Nicole's Mum)

In February I lost my mate Phil Henshaw, or Dr Phil as I affectionately called him. He passed away peacefully at home aged 40. I had only seen him three weeks ago at Revesby Workers for lunch. We had plans for Beatnix and Rocky Horror in the coming weeks. Phil had a great life, despite his SMA, and made the most of his 40 years. I have such fond memories of our 17 year friendship; I reckon there's an awesome wheelchair footy match going on up there now!! A service for Phil was held at Rookwood followed afterwards at his beloved Revesby Workers. His good mate Colin Stubbs spoke at his service and I'd like to share some of Phil's life with you. Our love and thoughts are with Joan and family. – Carolyn Campbell-McLean

Philip Dean Henshaw

19/6/1967 – 7/2/2008

I have been honoured, by the family, in being asked to give the eulogy of Philip Dean Henshaw. Phil was born 40 years ago at Upper Hutt in New Zealand. He came to Australia when he was young and lived in South Australia. The family moved to Sydney and finally settled in Revesby.

Phil attended Broderick School at Lakemba. He was an excellent student with a good academic mind. Upon reaching High School, Frank Henson greeted him with a punch in the mouth. But Phil took a stand, used his wit and won the respect of Steve, (King student of the institution). As the years passed, Frank and Phil became inseparable mates.

After finishing his HSC Phil chose a life of sport & leisure rather than attend Uni. He was a cricket lover, an admirer of Don Bradman, race horse fan, wine connoisseur, chess player, and much more. He may have lived in the West but his heart was always in the Eastern Suburbs (Roosters).

I met Phil, with Frank, George, Kenny, Geoff and others at a dinner at Westmead in the mid '80s. The gang followed me home and stayed the night. Phil quietly entertained himself by reading some of my ... glossy magazines.

Phil was a charming and spirited person. He had a zest to explore & learn, and achieved many feats in his life. I will break these into three things – Travel, Committee Involvement and Sport.

In the '80s a social change was happening. Disabled persons were encouraged to explore individual goals and desires. Phil embraced this with all his heart. Attending many concerts, sporting events, movies, theatre, travel – whatever was going.

I have many memories and stories of our trips. Here's a few: Phil used many forms of transport: plane, train, ship, houseboat, liner, campervan, bus, caravan and in Perth being strapped behind a cage in a hired delivery van.

My first trip with Phil was to Canberra. We stayed at motel with a doctor on call. This was a safety issue for the young inexperienced travellers. We found a pinball machine and Phil with the aid of a ruler played one flipper and I the other. We made a good team and scored well.

Phil visited the Jenolan Caves before they were accessible. He needed to be carried though the cave ... a risky adventure, as the cave floors are slippery and being dropped a real possibility. I often wondered if Phil taking this risk sped up the creation of an accessible cave?



Phil, Hein and me once borrowed a Mazda bus, threw in some mattresses, a gas cooker & made it a campervan. On the NSW North West Trip, we drove out of Moree to see the many stars against a clear dark sky. Phil, Frank, Kerrie and me watched a satellite cross the sky. It was a magical moment and a great trip.

Phil understood that things took time and that steps were needed to move forward. So, on the Tassie trip we left written suggestions for improvements, for following electric wheelchair traveller. At the summit of Mount Wellington, Hobart, we sipped hot tea as we watched people struggle past our campervan in the cold and windy conditions.

Phil always reached for the summit of an idea, belief or ideal. This need to improve opportunities for other wheelies extended into his committee involvements. For roughly 15 years Phil served on the Push & Power Management Committee in many positions. He was President leading the change to incorporation in the year 2000. He was also the delegate, administrator, player and coach for the SweatHogs/St George Club. Phil trained many youngsters to be better sports players and better people.

Phil was a great tenpin bowler. His average was 177 and he was the best wheelchair bowler in Australia for the past decade. He competed in three Australian Disabled Championships. Every Friday night for 25 years Phil played in a mainstream bowling competition. His skill and talent shamed many of his fellow bowlers.

Phil played Wheelchair League, Soccer, Hockey, Volleyball, Cricket, Blow Darts, if there was a sport played in an electric wheelchair he would have a go.

There was another side to Philip ... yes, he was kicked out of class for bad behaviour. Whilst wandering around the schoolyard, Phil found some isolated garbage bins, and with limited body movements – he used his chair to ram the crap out of them. This gave him great relief from his frustrations. Playing sport also helped this release.

There was the famous finger stretch ... but better, was his skill of flicking a plastic spoon with his mouth and fingers. Phil would hit you ... as you turned to see who did it – he would act so innocently – that was another skill ... acting innocently. But his supporter's laughter would give him away.

One New Year Eve, Hein, Phil and I were doing the rounds of hotels – as you do. We met a lady who was very thankful to see us. Her son had recently been diagnosed with MD. By just seeing Phil out and enjoying the night gave this lady hope for her son. It was a great moment, drinking and making someone else happy too – what an achievement.

Phil loved his family and being a son to Joan, a brother to Kim and an uncle to Jarrod & Kyle was very dear to him. He was my mate ... we shared many moments, both sorrowful and joyous. I will miss him ... as you will.

Colin Stubbs

Client Services update

This year has had a flying start with March already upon us and the next edition of *Talking Point* ready to go. The January break came and went as I blinked! Two new **FlexiRest** applications were successful in gaining some additional 'respite' for some carers and members. Unfortunately for MDANSW, the news that our CEO Ian Dear was leaving us came as a surprise, but he seems to have had 'a good innings' and is ready for another challenge!

MDANSW was looking forward to the **NEWS** Fundraising Event in February. **The Black & Bling Ball** was held in the Wentworth Room, at the Parramatta Leagues Club on Saturday 16 February 2008. The 'black & bling' theme was beautifully carried through with the venue creatively and extravagantly filled with lavish black and silver decorations. All this combined with the required 'dress to impress' made for an extremely elegant night! The two young 'DJs' performance encouraged the guests to get out there and dance the night through. My compliments to the organisers and the perfect venue they chose for a most enjoyable night. **NEWS** is revving up and ready to compete through 2008.

Once again I have been able to participate with **The Women's Group Meeting** held at Sandie Simmonds' house at Willoughby. This time three Hunter Region members drove down to join in the day with good discussion on 'Solitude' and the importance of 'taking time out' for your own well-being – make sure you 'multi-task' it in ladies! The day was a gorgeous day of fine weather with great food and good company. I look forward to the next meeting in a few months time.

More exciting news through February was the appointment of our **new Carers Program Co-ordinator** Georgina Christofis, bringing with her an enthusiasm about travelling throughout the NSW region to meet and offer support to MDANSW Carers. Within the next few months, Georgina and I will be travelling south to the Illawara and the Riverina Regions and then up to the North Coast and Hunter Regions to meet and discuss Carers needs.

MDANSW will be having a **Family Picnic Day** in April, 2008 for the **Metropolitan Region** at Waterloo for the MDANSW family members to meet Georgina. The **Hunter Region** has organised a **Fundraising Luncheon** at Merewether on Wednesday 7 May 2008 (see pg 6 of this issue of *Talking Point*). MDANSW Board Member Dr Heather Johnston has kindly agreed to give a talk at the luncheon.

There is a **Myositis Group Meeting** on 3 June 2008 (see pg 18) and MDANSW hope to organise another **Telegroup** in June.

Looks like some busy times ahead and I look forward to meeting more MDANSW members and carers over the next few months.

Viktoría Butler

Client Services Coordinator

INTRODUCING...



Georgina Christofis

new Carers' Program Coordinator

I spent the past two years developing and coordinating a Carer mentoring project and hope to use some of my expertise working with carers in my new role. I'm delighted to be working in the area of muscular dystrophy, and hope to achieve both the goals set out by the organisation and meet the concerns and needs of carers caring for loved ones.

I completed a Bachelor degree in Applied Science Psychology at the University of Western Sydney and also completed two years of a Health Sciences degree at the University of Sydney. In my previous role, I worked on a number of Brain Injury Projects, working in Respite and Recreation, Information and Referral, Carer Mentoring Development and coordinated the Brain Injury Association of NSW Speakers Bureau. I hope to complete my MBA by 2010.

I have one child, Jennifer. My main interests are my family, travel, Australian politics and cooking home-made traditional European dishes.

I hope to develop strong links with carers and service providers working in CALD communities this year, expanding the MDANSW CALD support networks to Italian and Greek communities in 2008/2009.

CONTINENCE AIDS ASSISTANCE SCHEME

The Continence Aids Assistance Scheme (CAAS) is an Australian Government program administered on behalf of the government by 'Intouch', the commercial arm of the Spinal Injuries Association Incorporated.

CAAS clients receive a \$470 per year subsidy on incontinence products ordered through Intouch. An assessment from an appropriate health professional is necessary to support your application for CAAS assistance.

People with incontinence caused by neurological conditions, Muscular Dystrophy, are eligible as stated in Category 6.

For more information please contact the CAAS Helpline on 1300 366 455.

FlexiRest Respite Program

In the previous edition of *Talking Point* I mentioned a little about the **FlexiRest Respite Program** run by a consortium: MDANSW, MS and MND with funding from DADHC, to offer flexible funding opportunities for their members (see opposite).

Since its inception, the FlexiRest Coordinator Julie Becke, has successfully funded members from each organisation with various 'respite funding'. I would like to mention a few of these that MDANSW were successful in gaining for our members.

One of our members and his carer who live on a farm in an isolated area, has been cared for by his mother (now ninety-odd years young) and feeling the strain of copying at the same pace, was able to apply for FlexiRest and granted funding for a 'physiotherapist' to come in for a short period of time to improve his mobility and give a little respite to his mother.

The carers and member in a family with young children were able to go on a short holiday as a 'respite break' for all the family to enjoy together. They previously had not been able to manage a holiday and were really excited to be going away to experience a different environment together.

Another member enjoyed hydrotherapy for a respite break.

Another MDANSW member was feeling he needed a break as his MD had deteriorated. FlexiRest was able to approve him some funding that allowed him to take a short break with a fulltime carer. The funding is flexible enough to enable the member to choose when and where they can go for their respite break.

MDANSW have had two more applications approved and would like to see more members take advantage of such a worthwhile Program (see pg 19 for a FlexiRest success story).

I am awaiting your response!

Please apply to Viktoria at MDANSW on 9697 9111.



MDA CAMPS

As you know, I have been busy gathering information towards the possibility of running camps for MDANSW members to participate in short breaks, through the year. This has been

done successfully by MDAVIC since 1986 and thereby provided an opportunity for children to meet, make friends and have fun!

MDANSW is considering the feasibility of organising camps and will need more time throughout the year before this can happen. In the meantime, with the new FlexiRest Program available and meeting the criteria, I was thinking what an ideal opportunity if members might like to experience a short break at one of the Victorian Camps. You could help my hands-on research!

The cost of the camps varies between \$220-280 per participant (including the carer) and that includes all accommodation, food and activity costs. The majority of the campers are between 7 and 25 years, although there is no age limitation.

On top of this cost you would have the return airfare and perhaps accommodation at a hotel for one night. This would be short term respite meeting the FlexiRest criteria.

Please consider an adventurous short break! I have pamphlets I can send you for further information.

Contact Viktoria at MDANSW on 9697 9111.

FLEXIREST

Supporting people in NSW with progressive neurological disorders

FlexiRest offers support to people with muscular dystrophy, motor neurone disease and multiple sclerosis. **FlexiRest** funds a range of respite related services either in-home or out-of-home for these people, their families and carers.

Respite is a short break for you and your family and/or carer. **FlexiRest** aims to be flexible and responsive to your individual needs.

Examples include but are not limited to:

- in-home respite where the respite is provided in your home for a short or time limited period
- short breaks that you may use your funding to purchase support for the whole family to go on a short holiday together
- peer support/age appropriate respite involving leisure and recreation activities with people of similar age with like interests
- transport support for you to access respite services
- vacation care and before and after school care where schools provide integrated services that employ support staff to help children with disabilities.

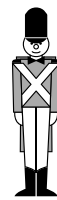
Eligibility:

- You must live in NSW.
- You must be registered with MDANSW, MND NSW or the MS Society of NSW/VIC
- You must have a demonstrated need that cannot be met by ongoing community services.

This new initiative operates with funding from the Department of Ageing, Disability and Home Care (DADHC) and is run by a Consortium consisting of Muscular Dystrophy Association of NSW, Motor Neurone Disease Association of NSW and the MS Society of NSW/VIC.

For more information:

Please contact your organisation:



Muscular Dystrophy Association of NSW

MDANSW

1800 635 109

fight for muscular dystrophy



Motor Neurone Disease Association of NSW

MND NSW

1800 777 175



MS Society of NSW/VIC

1800 042 138



THE MYOSITIS ASSOCIATION - AUSTRALIA INCORPORATED



Keeping in Touch Group
in conjunction with MDANSW

invites you to a

SEMINAR ON MYOSITIS AND EXERCISE

with renowned guest speaker Dr Bev Phillips

AT OUR NEW VENUE

ATRIUM ROOM, 1st Floor, CASTLE HILL RSL CLUB

77 Castle Street, Castle Hill

from 10.30am to 2.00pm

on Tuesday 3 June 2008

.....
A delicious morning tea of jam, cream and scones will be available at 10.30am.

Lunch will consist of mixed sandwiches. Tea and coffee available the whole time. Please let us know if you have any special dietary requirement when you RSVP and we will see what we can arrange for you.

A lift is available in the foyer. The club is wheelchair accessible, has disabled parking and toilet facilities.
.....

programme:

- 10.30am – 11.00am** Welcome, have a cuppa and catch up with friends
11.00am – 12.00pm **Part I of Dr. Bev Phillips talk on Myositis and Exercise:** What, how and when. Questions.
12.00pm – 1.00pm **Lunch**
1.00pm – 2.00pm **Part II:** TMA exercise DVD. Discussion & questions.
.....

cost: \$17.50 per person

Please let us know the names of the persons who will be attending when you contact **either**

Anita Chalmers

tel: 02 4464 2043

email: geoffandanita@ihug.com.au

OR

Viktoria Butler - MDANSW

tel: 02 9697 9111

email: services@mdansw.org

RSVP no later than
30 May 2008

ALL ABOUT OUR GUEST SPEAKER

Associate Professor **Bev Phillips**, PhD, PGDipHlthSci, Dip. Physio.

Associate Professor of Allied Health, La Trobe University
and Ballarat Health Services

Bev Phillips first started working with patients with inflammatory myopathy in 1989 when employed as the physiotherapist in the Neuromuscular Clinic at the Australian Neuromuscular Research Institute in Perth, Western Australia, and she completed her PhD in 1998 in the area of the assessment of muscle performance in patients with inflammatory myopathy. Bev moved to Melbourne in 2000 to work as a Senior Lecturer at the School of Physiotherapy at The University of Melbourne. From 2000 to the end of 2005 she also worked as the consultant physiotherapist at the adult Neuromuscular Clinic at Monash Medical Centre, continuing her work with patients with inflammatory myopathy and other muscle and nerve disorders.

Bev made a 'tree change' in 2006 and started work as the Associate Professor of Allied Health, leading the Grampians Region Allied Health Rural and Regional Recruitment and Retention Strategy project, which is funded by the Department of Human Services Victoria, in partnership with La Trobe University and Ballarat Health Services.

MDANSW – 2008 CALENDAR OF EVENTS

APRIL

FAMILY PICNIC DAY – UNDER 10s

SATURDAY 19 APRIL
11AM – 3.00PM

FAR NORTH COAST REGIONAL CARERS VISIT

22 – 24 APRIL
BALLINA RSL CLUB (TBC)

MAY

HUNTER REGIONAL LUNCHEON

WEDNESDAY 7 MAY
THE BEACH HOTEL
Cnr Fredrick and Ridge Streets
Merewether

GOLF DAY

THURSDAY 15 MAY
CONCORD GOLF COURSE

RIVERINA REGIONAL CARERS VISIT

TUESDAY 27 – 29 MAY
WAGGA WAGGA RSL

JUNE

METROPOLITAN CARE FOR CARERS MEETING

WEDNESDAY 18 JUNE
10AM – 2PM
Venue to be decided

TELEGROUP – 8 WEEK PROGRAMME

1 HOUR A WEEK
ALL LIVING IN NSW
Please call MDANSW
with expressions of interest
02 9697 9111

JULY

MULTICULTURAL LUNCHEON

WEDNESDAY 16 JULY
10AM – 2PM
MDANSW office
49 Hansard Street
Waterloo

CENTRAL WEST REGIONAL CARERS VISIT

15 – 17 JULY
BATHURST/ ORANGE/ PARKES
Venue to be decided

HUNTER REGIONAL CARERS MEETING

24 – 25 JULY
Venue to be decided

Good morning Viktoria,

Just wanted to let you know that we had an amazing holiday at the Gold Coast!! The kids are still raving about it and everything was just perfect, including the weather!!

We went to the theme parks and relaxed in the spa and pool. The cascade gardens were stunning and the kids spent hours playing at the park!

What a wonderful way to spend a week and it's hard to get back into the routine of home again.

A huge thanks to the FLEXIREST RESPITE PROGRAM, to you and to MDANSW for our much needed family vacation!! Could you please pass on my thank yous to Julie Becke from the MS Society for all of her help as well.

Hope to see you soon.

Regards

Lisa Bramble xx

Updates on two potential treatments for Duchenne muscular dystrophy

1. Exon skipping

Approximately 75% of boys with Duchenne muscular dystrophy have a deletion in the dystrophin gene. At the end of 2007 a Dutch group working on exon skipping published the results of their preliminary study. The boys had a deletion at exon 50, resulting in a stop codon being generated in Exon 51 (an antisense oligonucleotide) and dystrophin then unable to be made. A substance called PRO051 was engineered, allowing skipping of exon 51 and dystrophin to be produced. It must be remembered that this would be a different dystrophin to normal, more like what is seen in Becker muscular dystrophy.

Four boys took part in the study. A muscle on the front of the leg was biopsied to confirm there was no dystrophin present in the muscle. There was then a single injection of PRO051 into the muscle and 28 days later a further biopsy. Two questions were important in this study: (1) was it safe and (2) was dystrophin able to be made in the muscle following the injection. The injection seemed to be safe, with side effects noted including pain at the site of the biopsy, blistering after wound closure, flu like symptoms and one case of mild diarrhoea. The post treatment biopsy showed that at the site of injection dystrophin was being produced at about 3% to 12% of what is seen in normal muscle. There was no improvement in muscle strength.

Although promising, there are a number of major hurdles to be overcome. There are many muscles severely affected in Duchenne muscular dystrophy, including the heart muscle. How would this sort of treatment be able to be given to all the places needed? There are many different deletions in Duchenne muscular dystrophy and each of these would need their individual exon skipping substance. Another problem is that the treatment is not permanent, in that the substance breaks down over time.

A study using this same technique of exon skipping is underway in the United Kingdom. This is also primarily a safety study and the muscle being studied is a small muscle in the foot in boys with Duchenne muscular dystrophy who are no longer able to walk.

2. Reading through a nonsense mutation (PTC124)

In about 15% of boys with Duchenne muscular dystrophy there is not a deletion but there is what is

called a 'nonsense' mutation, leading to a premature "stop" and dystrophin can no longer be made.

A substance, PTC124, has been developed to attempt to read through this "stop" codon and allow dystrophin to be made. Preliminary results of trials of this substance were reported in 2007. Studies were done in boys who were able to walk and a small foot muscle was biopsied before and after treatment for 28 days. PTC has the great advantage that it can be given by mouth.

After treatment some dystrophin was seen in the muscle biopsy in about half the boys treated. There was no improvement in timed tests of strength. Side effects were rare and included abdominal pain and diarrhoea. They were more common when higher doses were used.

Further studies of this promising substance are underway. To be eligible for the study boys of course have to have a nonsense mutation in the dystrophin gene. They need to be able to walk 75 metres (without assistance) within six minutes. They need to undergo a muscle biopsy before and after the 12 month treatment period and attend for monthly detailed checks during treatment. There are three possible treatments that the boy may have and it is not known until after the study which type of treatment they have had. Two are of different doses of PTC 124 and one is a placebo, which means there is no active substance in the treatment. It is estimated that 165 boys will need to be enrolled to give meaningful results from the study.

CONCLUSION

Although exon skipping research has occurred for some years, studies in humans are finally happening. However, delivery of the exon skipping oligonucleotides to affected muscles remains a major challenge.

PTC 124 is a promising treatment for the small number of boys with nonsense mutations, however, it will probably be two to three years before it is known whether it is effective as well as truly safe.

Obviously it has become very important to know what type of mutation a boy with Duchenne muscular dystrophy has. Fortunately, the molecular genetics reference laboratory for dystrophin testing in NSW (SEALS, Randwick Campus) has been at the forefront of this work, supported in part by MDANSW.

Heather M. Johnston MB ChB FRACP
Medical Director MDANSW

ANSWERS

to Bruce's Brainteaser on pg 7.



- | | | | |
|----|-----------------------------|----|-----------------------|
| 11 | North by Northwest | 11 | The Ten Commandments |
| 12 | South Pacific | 2 | When Eight Bells Toll |
| 13 | Two Women | 3 | East of Eden |
| 14 | Three Coins in the Fountain | 4 | Diamonds are Forever |
| 15 | Four Weddings and a Funeral | 5 | A Double Life |
| 16 | West Side Story | 6 | The King and I |
| 17 | The Queen of Spades | 7 | The African Queen |
| 18 | The Joy Luck Club | 8 | Ace Up My Sleeve |
| 19 | Cool Hand Luke | 9 | Braveheart |
| 20 | Separate Tables | 10 | Jumpin' Jack Flash |

A small group experience for any mother of child/ren from birth through school age who is constantly trying to meet the physical and emotional challenges they face every day.

If you would like an opportunity to think about balancing your needs with your family's, and some time to reflect and "be" with other mums ... then maybe you should join us!

MOTHERING IN THE F-A-S-T LANE



when: Mondays, 10am to 12noon beginning May 5 & concluding June 30, 2008
May 5, 12, 19, 26 & June 2, 16, 23 & 30 (a total of 8 sessions)

where: Learning Links
12-14 Pindari Road
Peakhurst

cost: \$10 for members
\$30 for non-members

Free child care available on site.

enquiries: Mary Morgan 9534 1710

To register your interest call Dana on 9534 1710 or email reception@learninglinks.org.au

MACNICOL COTTAGE AT BALLINA NSW

I have received a fabulous recommendation for a great respite stay up in Ballina! Apparently, the cottage is owned by a lovely couple, Robyn and Bruce Horden.

The cottage is fully set-up for wheelchair users with any further equipment requirements available for hire from Northcoast Equipment Hire in Ballina.

The website to check this wonderful retreat out is:

www.ballinamacnicolcottage.com.au

Viktoria Butler
Client Services Coordinator



Helping Kids Learn
Funded by DoCS and Club Rivers

TRANSPORT FOR HEALTH Isolated Patients Travel and Accommodation Assistance Scheme (IPTAAS)



Transport for Health – IPTAAS is a transport and accommodation subsidy scheme that assists people in isolated and rural communities to gain access to specialist medical treatment not available in their own area.

For more information, or to be emailed a PDF of the application form, please call Viktoria Butler at the MDANSW office on 9697 9111.



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Letters to the Editor (Carolyn Campbell-McLean), can be addressed to:

The Editor, *Talking Point*
Locked Bag 1005,
Rosebery, NSW, 1445

TALKING POINT

THE NEUROMUSCULAR CLINICS

Children's clinics

Sydney Children's Hospital, Randwick
Neuromuscular Clinic 9382 1700

Sydney Children's Hospital
Outreach clinics at Canberra Hospital, Canberra
and John Hunter Hospital, Newcastle
Contact through Sydney on 9382 1700

The Children's Hospital at Westmead
Neuromuscular Management Clinic 9845 1904

Adult Clinics

Concord Hospital Neuromuscular Clinic 9767 6864

Prince of Wales Hospital, Randwick
Nerve and Muscle Clinic 9382 0722



or services@mdansw.org

Send your letters to The Editor, MDANSW,
Locked Bag 1005, Rosebery NSW 1445
or email cazza74@bigpond.net.au

6 February 2008

Dear Ian,

I am writing in response to the article written by John Little in *Talking Point* Vol 66 (pg 12).

I take issue with John's statements "Aussie chairs are designed by business people purely to make unreasonably huge profits out of vulnerable people with a disability" and "we are taken advantage of over and over again by greedy uncaring people".

I have worked in this industry for 24 years and find his comments highly offensive. The majority of the companies I work with also do not fit his description. The disability sector is a hard industry to make "huge profits". To be a supplier in this industry you have to be prepared to invest hundreds of thousands of dollars into demonstration equipment, carry a large inventory of spare parts to service the equipment you sell, be prepared to work very long hours, provide loan equipment for Government departments and be prepared to carry outstanding debts for 90-150 days. All this has to be done on a margin which is poor compared to many other industries.

If you were just after large profits you would not work in this industry. The majority of companies I associate with in this industry strive to achieve the best outcome for their clients. Do we make money out of this – yes we do. If any company does not make a profit you close down.

Over many years GTK Rehab and other suppliers have supported many groups including MDA. The description of greedy uncaring people does not apply to the majority of suppliers in this industry.

Yours faithfully,

Greg Kline

Managing Director

GTK Rehab

Want to buy, sell or donate equipment, products or vehicles that other members may be interested in?

FOR SALE

5/2003 Toyota Tarago GLi White Automatic

with rear floor modification by Freedom Motors (Passenger design - 5 Passengers + 1 wheelchair) with auto docking system.

(The wheelchair operator drives into vehicle via ramp in rear and is locked into position, when they wish to exit the vehicle they just reverse their wheelchair out).

Rego till 7/2008

81,500km

Tinted windows, Immobiliser.

POA

FOR SALE

1 M1 Roller Powerchair (blue)

(Can be fully adjusted to suit person's size)

Brand New September 2006, only used for 12 months.

\$2,500 ono

FOR SALE

Pressure Mattress – \$550 ono

FREE - to a good home - 1 adjustable power-operated bed

If you are interested in any of the above items please do not hesitate to phone **Rob** or **Donna Riley** on (02) **9774 3870** or **0417 249 025**.

TP SUCCESSFUL DEAL!

Just to let you know of a great all round win-win situation.

Carlos advertised a chair in *Talking Point* Vol 66.

This was just what Ann had been wanting. With great initiative from both Ann and Carlos they were able to arrange the pick-up and delivery at a reasonable price, of the chair between their abodes.

Carlos was very generous in donating the proceeds to MDANSW and found a good home for his chair with a fellow member!

Thank you Carlos and Ann from MDANSW.

STOP PRESS!

The new CEO of MDANSW, David Jack, will take up his role on 19 May. Further information on David will be provided in the next edition of *Talking Point*.

Pieces Of Me



works on paper

by *Monica Ellis*

Opening Night: 6 - 8pm Thursday 5th of June

Art At Home Gallery
467 Darling Street, Balmain

Gallery Hours: Monday to Wednesday - Appointment only

Thursday - Sunday: 11am - 5pm

Exhibition closes June 18th

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GALLERY

www.artathome.com.au

phone: 02 9555 5073

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, Reply Paid 78684, Rosebery NSW 1445.

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.

