muscular dystrophy
new south wales

Building Strength

ANNUAL REPORT 2007/2008

The Kirby Family (L-R):
Flynn, Peter, Blake, Brittany, Connor, Julianne

My daughter was just a few months old when I was tested for MD ... It took me a long time to admit to myself that I had a problem and no one I know had even heard of muscular dystrophy before.

I live my life quite normally and have a lot of support ... I have good days and bad days just like everybody else but I think that my peace of mind comes from my acceptance of my disability ... My husband and children are wonderful helpers around the house...

I have met some amazing women and men who live with disabilities over the years in which I have been involved with MDNSW and these people inspire me in so many ways. Joining the women's group and attending various support groups and activities has been a great way for me and my family to gain knowledge and friendships from others in a similar situation.

I don't fight the things that I cannot do any more and although I will never give into the impossible tasks, I am able to comfortably ask for help from my family.

I look at my MD as the next challenge in my life and although it is one of the biggest challenges yet I am ready to embrace it with a positive attitude and an open mind. You just never know what cure is waiting just around the corner...

Lisa Bramble

Chris Suffield successfully completed his Higher School Certificate at St Aloysius College. He is now at Macquarie University undertaking a Bachelor of Commerce degree. Chris has Duchenne muscular dystrophy and is a stalwart member of National Electric Wheelchair Sports (NEWS).

"I started University earlier this year ... It's been an interesting experience so far, and I have to say I'm enjoying it. The first thing I noticed on my first day was the amount of people staring. Back in high school, everyone knew why I was in a wheelchair. University is a whole new environment. It made me realise just how little exposure most people have to people with disabilities. You sometimes almost feel sheltered from it when around friends and family, but when you're on your own you come to see it more ... the point I am trying to make here is that you need to make a positive out of the situation you're in, and then things work out ..."

Chris Suffield

John Little has FSH MD which was diagnosed at the age of 16 and has been in a wheelchair for the past 10 years. He and his partner Suzanne travelled extensively in the UK and Europe.

"... sitting back and waiting for somebody else to do stuff is not what we are. MD is not easy to deal with ... but it doesn't mean that an interesting life isn't possible. At 62 this year I have not done everything that I want to, by a long shot. And while there is still breath in this old body I will keep taking the next step, well sort of, if you get my meaning! ..."

John Little

"I am writing to express my gratitude for the financial assistance that I have recently received from MDNSW ... I would also like to comment on the regional meetings that have taken place in Wagga over the past 18 months, under the banner of your carer's initiative.

Until these gatherings began, my partner and I had never met another person with problems similar to my own, or for that matter, anyone caring for anyone with such problems. As we live in a regional area we had also had little contact with medical specialists. Through your carer's initiative we have met other people from our district who are facing similar challenges.

This has provided us with a network of people who under normal circumstances, we would probably never have met. Until these meetings commenced, I felt that I had no one to talk to about the types of problems my partner and I face. Besides the beneficial social interactions, your visits have provided valuable information about the services provided by MDNSW, and also provided information about services available in our region, as well as giving members the opportunity to share knowledge and general experience about local services.

Most importantly it allowed us to meet face to face with Staff from MDNSW. For me, it provided a very "personal face" to the organisation."

Cheryl O'Brien

Pictured on front cover – Chris Suffield

CEO Report

We live in a world where change is now common place. This is both a challenge as change can be stressful, and comforting as change also presents opportunities to those experiencing new things in their lives.

Since joining MDNSW in May 2008 I have come to learn that many of our clients living with a neuromuscular disorder experience significant change in their lives. This often requires new items of equipment, adjustments to daily schedules and restrictions placed on their abilities and capacity.

It is during these periods of change and transition MDNSW desires to be a supportive presence in the lives of our clients as well as available during the everyday of life.

Acknowledging these change cycles MDNSW has undergone a significant period of consultation and planning during the final six weeks of the 2007/08 year and beyond. A survey of all MDNSW members and personal discussion with many clients as well as Board members, staff and colleague service providers laid a foundation for a strategic plan which will enhance and extend the services of MDNSW.

This strategic plan includes a new vision statement and articulates the purpose, ambition and values by which the organisation wishes to be characterised.

A renewed focus on client well-being is the centrepiece of this new vision and a strategic plan has now been developed defining how MDNSW desires to contribute to an improved quality of life for its clients and their families.

OUR VISION

Improved quality of life for our clients

OUR AMBITION

Deliver diverse, quality services and support innovative research engendering client well-being and confidence

OUR PURPOSE

Cultivate a community of support which empowers clients

OUR VALUES

Compassion and responsiveness
Integrity and respect
Partnerships and teamwork

This vision will build on past achievements, some of which are outlined in this Annual Report, including the carer support program and the multifaceted client services program. The successful FlexiRest program operated in partnership with MND and MS, is an example of a program with clear benefits to clients also representing the opportunities available when we work together with others.

To enable the vision to succeed, a number of organisational changes have been made, including adoption of a new branding to enhance the profile and image of MDNSW, a new website and promotional materials, relocation to a new office more central to our client group also providing more appropriate facilities and increasing human resources in client services and fundraising.

During this period of transition a new team has been recruited and is enthusiastically embracing the challenge of achieving the vision and strategic plan.

Plans for 2009 and beyond include development of a weekend retreat program for young adults and adults, home support program, a camping program with the first planned for October 2009, enhanced regional support and increased funding for equipment and research.

Fundraising for these initiatives is critical and is driven by a comprehensive plan including support from national fundraising activities operated under the umbrella of the Muscular Dystrophy Foundation Australia (MDF Australia).

I would like to pay tribute to former CEO, Ian Dear, whose achievements included successfully attracting a government grant to fund the carers support program. He left a stable organisation and remains a valued friend of MDNSW. I would also like to express appreciation to Rob Ferguson, President of MDNSW, for his leadership and to members of the Board who have given significant support to the new vision and are contributing expertise, time and wisdom to the organisation during this important period of growth.

David Jack
CHIEF EXECUTIVE OFFICER

President's Report

'BUILDING STRENGTH'

FINANCIAL RESULT

This financial year we recorded a deficit of $96,372 against last year's surplus of $53,480. Our income was $48,368 higher than last year's, with increases in donations and special events of $23,433 , and other income of $24,935. Expenses increased about $20,000. The main difference this year was that income from our managed funds fell about $59,000, and the value of the funds fell $128,037. As a result net assets at the end of the year were $875,431 (last year $971,803)

PLANNING

There has been a great deal of thorough planning and resultant change since December 2007. I will outline these changes from a board level.

Two directors retired in October, before last year's AGM. We were sad to lose both Ellie Carew who joined us in December 2002 and Vaughan Woods who joined in September 2004. Both contributed a great deal to the Association, in their particular skill areas, and in a general sense.

The Board of Directors had two new additions this year:

- Graham Troy joined the board as treasurer in December, to replace Vaughan Woods. Graham is a CPA (Certified Practicing Accountant), and continues the higher level of financial control which Vaughan had set in place.
- Ross Parker joined us after retiring as the Human Resources Director of the publicly listed Crane Group. I believe we are most fortunate to have someone with Ross' level of commercial and particularly HR experience on the Board. This addition has been particularly fortuitous at a time when we were required to recruit key staff, and Ross' role in the recruitment process was substantial

Both Graham and Ross have played key roles in the restructuring that has occurred since they joined us, which began with a successful strategic planning meeting in February.

In January this year Ian Dear advised us that he planned to retire as CEO, having made a huge effort for over 3 years, a time of consolidation.

Some of Ian's achievements include:

- Bedding down of the State Government funded Carers Program
- Procurement of the recently introduced State Government funded FlexiRest respite program jointly with MS Australia and MND New South Wales
- Introducing our services co-ordinator's visiting program to the major Sydney clinics
- Establishing a workable bequest program
- Overseeing major facelifts and making major contributions to our major communications media including 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. Pathways to a Cure conference and hypothetical, and the Government House reception for our 50th anniversary
- Improving our relationships with corporate supporters such as Red Rooster, Randwick Labor Club, Turramurra High, Best & Less, and major donors

Above: Staff at Miranda Red Rooster

- 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)

Ian made a major contribution to the one day Strategic Planning meeting and organized a professional facilitator who came from Melbourne at no cost to MDNSW. The major outcome of the meeting was a well considered blueprint for our changing future which the meeting appropriately named 'Building Strength', and which was subsequently adopted by the Board.

Our major recruitment campaign produced over 60 applications and after interviewing about 5 applicants, the Board chose David Jack, who commenced on May 19, on a 5 year contract.

David will report on the staff changes which took place subsequent to his joining us. These were very much in line with our building strength decision to free up the CEO by providing him with an assistant, who could also manage the account requirements.

'Building Strength' essentially encapsulated the decisions we made about:

- The improved services we wanted to provide to our members
- The people we needed to deliver them, and
- How we could provide the funds that would be required

The timing of the Strategic Planning was critical in that we were able to focus on the important characteristics required in a new CEO to drive the changes we wanted.

NEW OFFICE

One significant decision in 'Building Strength' was to move from our previous office. A careful study was done in late 2007, looking at the location of our key people, being members, staff, and others we deal with.

We decided to move to a more central Sydney location to be more accessible. We were fortunate to find somewhere which was not only central, but very accessible, with an adjacent new shopping centre, post office, and very pleasant surroundings.

I believe that this new office has made a big difference to the state of mind of all of those working there.

We were fortunate that all fit-out, security and almost all the furniture was included in the rent at no extra cost, and we were able to negotiate a 6 month rent free period in a lease with predetermined rents over the term of the lease.

The Shepherd's Bay community centre which is accessible, fully fitted out with modern sound and video equipment , and only 150 metres away, is ideally suited for seminars, conferences, meetings, and most importantly, future activities we are planning for our members. This is such an improvement and saves us seeking out premises off site for these purposes.

NATIONAL COLLABORATION

Another important decision the Board made at the 'Building Strength' conference was to endeavour to work together with our sister associations in other states, and specifically 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 neuromuscular disorders at a national level, and thus
- increase the potential for greater funding from government, corporations and philanthropic bodies at a national level.

A very positive dialogue has taken place, followed by constructive collaboration between NSW, Queensland, South Australia and Tasmania, and to some degree in Victoria, and Western Australia

Muscular Dystrophy Foundation (MDF), set up by MDNSW in 2003 is the entity through which this has occurred. The Board of MDF now has a director from each of these states, with the chairman, Brian O'Sullivan from Melbourne, being independent.

CEOS DUAL ROLE

Our new CEO David Jack has been instrumental in bringing this about, gaining the support of other state CEO's, working on an executive, rather than board level.

A national fundraising appeal was conducted in November 2008 in NSW, Queensland, South Australia and Tasmania, with other plans under way, along with sharing similar naming protocol, and logos.

The CEO's employment contract provides for him to spend a maximum of 20% of his time on MDF matters for which he is reimbursed by MDF. While employed by MDNSW, he also carries the title of CEO of MDF. I was elected Secretary of MDF in May this year, which enables a large degree of input into the direction of MDF from NSW.

CLIENT AND CARER SERVICES

We had limited success with our client services provision during the last year, however, highlights include the Carers Program enthusiastically developed by Georgina Christofis, and the successful FlexiRest program, which Ian Dear launched along with MS Australia and MND NSW. The FlexiRest program for respite provision has gradually taken on and has been very well received by members. I believe the structures are now in place to make some very positive changes to the services we provide in NSW.

RESEARCH

Of the $70,000 that was committed to research from the 2006/2007 budget, MDNSW approved and paid for 2 grant applications, for amounts of $15,647.25, and $32,292 , totalling $47,939.25.

In the 2007/2008 budget we envisaged two grants to be made, and after advertising, one grant for $60,000 was recently approved by the Board.

50TH ANNIVERSARY

The year 2007 marked the major achievement of our 50th Anniversary, with several very successful events, with 2 member events in particular being highlights. These were:

- The Pathways To a Cure medical seminar, and hypothetical at Homebush Bay, facilitated by Robyn Williams from the ABC, and largely planned by Ian Dear and Bruce Ellison. This event attracted over 150 people, and was hailed a great success.
- The Reception at Government House, hosted by our Patron, the Governor of NSW, Marie Bashir, which all attendees seemed to enjoy.

THE FINANCIAL CHALLENGE

The difficulty we will and are already facing is the as yet unknown effect of the economic downturn on our ability to raise the funds we need to achieve the plans that we are making. I believe that this is our biggest challenge. We are considering a variety of fundraising plans with the assistance of a not for profit fundraising consultancy.

I believe that there is an increased chance of gaining State Government and private funding support if we can put a good case for specific projects that we want to introduce, just as we have with our carers and respite programs. Both the state and private sectors are however experiencing their own financial strains, for different reasons.

Thank you.

Rob Ferguson

PRESIDENT

MDNSW Directors and Staff

PRESIDENT AND BOARD CHAIR

Mr Robert Ferguson BA
Property Consultant
Director since: May 2001
Vice President 2004 - October 2007
President since November 2007

VICE PRESIDENT

Mr Colin Gunn BA (Hons)
Retired
Director since 2006
Vice President since November 2007

MEDICAL DIRECTOR

Dr Heather M Johnston
BSc MB ChB, DObst RCOG DCH FRACP
Head, Department of Neurology
Sydney Children's Hospital
Director since: 1993

HONORARY TREASURER

Mr Vaughan Woods M.AppFin B.Bus CA
Chartered Accountant
Director since: 2004, Resigned October 2007

Mr Graeme Troy BComm CPA
Appointed November 2007

BOARD MEMBERS

Mr Percival Alwyn Baptiste JP
Retired
Director since: November 2001

Ms Eleonora Anna Carew BA Dip Ed
Public Relations Consultant
Director since: December 2002
Resigned October 2007

Dr Alastair Corbett MB ChB, MD FRACP
Head of Department of Neurology
Concord Hospital
Director since: December 2002

Mr Bruce Ellison
Director since: 1992
Resigned as President November 2007

Dr Kristi Jones MB BS Ph.D FRACP DCH CG(HGSA)
Clinical Genetics Specialist
Director since April 2006

Mr Ross Parker BA
Human Resources Director
Director since 2007

Mr Ian Williams BEc MBA
Banking Executive
Director since October 2005

STAFF

CHIEF EXECUTIVE OFFICER AND COMPANY SECRETARY

Mr Ian Dear BA LLB
Commenced July 2007, Resigned May 2008

Mr David Jack BA Grad Dip Public Sector Mgmt
Commenced May 2008

OFFICE MANAGER

Mr Bob Horan

CLIENT SERVICES COORDINATOR

Ms Viktoria Butler BSW
Resigned June 2008

CARERS PROGRAM DEVELOPMENT COORDINATOR

Ms Georgina Christofis B AppSc (Psych)

AUDITORS

KPMG

HONORARY SOLICITOR

Mr Simon Gate

MDNSW Board

Standing: Graeme Troy, Colin Gunn, Ross Parker, Rob Ferguson, Kristi Jones, Ian Williams, Percy Baptiste, David Jack

Seated: Bruce Ellison, Heather Johnston   Missing: Alastair Corbett

Life member honoured

Dr Jacqueline April Morgan was awarded an AM in the General Division of the Order of Australia, for her "service to medicine, particularly in the field of neuromuscular disorders, and to the community through a range of organisations involved in research and support for people with muscular dystrophy."

Jacqueline was Honorary President of MDNSW from 1986 to 1998.

A great deal of Jacqueline's life has been spent involved with neuromuscular disorders. She supported her husband, Professor Graeme Morgan in the 1960s in visiting every family in NSW known to be affected by muscular dystrophy. This experience very much determined her decision to devote her energies to helping people with neuromuscular disorders. She did two stints as Medical Research Officer in 1965-67 and 1970-72 focusing on children with muscular dystrophy and then on inherited ataxias and other neuromuscular disorders.

During the early 1980s Jacqueline went back to university and by 1983 graduated with a law degree. She worked in the NSW Attorney-General's Department from 1987 to 1993 as Research Officer and later Executive Member of the Privacy Committee of NSW. Our Association was fortunate that Jacqueline was able to find the time to volunteer to be the President, work in Government and raise her family during this period.

We are proud that Dr Jacqueline Morgan has been honoured in this way.

Graeme McMartin (Principal, Turramurra High School) and students receive recognition for Turramurra High School support for MDNSW from Ian Dear (former CEO, MDNSW)

An overview of client services

Viktoria Butler joined us as Client Services Co-ordinator in August 2007, and departed in June 2008.

EVENTS

A variety of events were organised during the year, including:

- Members Advisory Committee meetings
- Telegroup conferences with members in outlying regions
- Women's Group meetings at Sandy Simmonds' Willoughby home
- The very successful Pathways to a Cure medical conference and Hypothetical at the Novotel Hotel, Homebush Bay
- A family picnic day
- A Myositis Group meeting
- Harley Owner's Group (HOG) day at Waragamba Dam
- The children's Christmas party
- A day out with Sailors with DisAbilities

CLINICS

Viktoria attended Neuromuscular Clinics at Sydney Children's Hospital, The Children's Hospital Westmead, and Concord.

PATHWAYS TO A CURE MEDICAL SEMINAR

The Pathways to a Cure Conference was by all accounts, one of the best events we have organised. It, along with the Reception at Government House, was a highlight of our 50th Anniversary celebrations. It required a huge organisational effort, and considerable logistical planning. It was a great testimonial to several organisers, including Ian Dear and Bruce Ellison.

To secure the support of Professors Kathryn North, Anne Cunningham, and ethicist Dr Bernadette Tobin was quite an achievement, along with Robym Williams, host of ABC radio's Science Show and Sophie Scott, ABC health reporter.

Professor Graeme Morgan and Louise Suffield, members who have had a long association with us added to the afternoon, Professor Morgan in describing our first 50 years, and Louise Suffield in being on the panel for the hypothetical, from the perspective of a mother of a boy (Chris), with Duchenne Muscular Dystrophy (DMD).

The Conference opened with a retrospective on Muscular Dystrophy over the past 50 years followed by the outcomes of research over only the past decade. Topics discussed by the speakers focussed on trials and therapies for MD, studies of stem cell transplantation with possible restoration/cell growth and the ethics involved in such research. The focus was on the 'lack of the protein Dystrophin' in DMD, with great detailed diagrams (most informative) and discussion on the various therapies that will hopefully enhance the muscle regrowth for future clinical application. Stem cell research with therapeutic cloning was explained with the hope of future application resulting in cell regrowth.

The hypothetical panel addressed a fascinating scenario of a wealthy philanthropist wishing to donate a large sum of money to a researcher who was claiming success in the treatment of muscular dystrophy in mice. The philanthropist's five year old son had recently been diagnosed with Duchenne MD.

The hypothetical panel addressed a fascinating scenario.
L-R: Bernadette Tobin, Kathryn North, Louise Suffield, Robin Williams, Sophie Scott, Anne Cunningham

A variety of interesting hypothetical scenarios were addressed by the panel, and interchange with the audience.

FLEXIREST

The very successful NSW Government funded FlexiRest program was introduced during the year, and several successful applications were made by our members.

FlexiRest provides much needed funding to our members either in or out of their home for various forms of respite.

FlexiRest funds various forms of respite such as:

- In - home respite within the members home for an agreed period of time
- Short breaks for the family
- Leisure and recreational activities with people of similar ages, with similar interests.
- Vacation care and before/after school care where schools employ staff to help those with disabilities
- Transport support to enable these activities
- Where the need cannot be met by existing community services

FlexiRest funding is provided through DADHC by the NSW State Government to MDNSW along with MND New South Wales and MS Australia.

MULTILINGUAL FACT SHEETS

During the year fact sheets on the numerous forms of Muscular Dystrophy and other neuromuscular disorders were translated into Arabic, Chinese (Mandarin, and simplified) and Vietnamese. We are now able to offer this important information in English, Greek and these new translations.

HOGS Activity Day

Fox Hills Golf Club Ladies Committee awarded by MDNSW for its support

Care for carers program

Carers have varied and changing needs. MDNSW's aim is to address these needs and support all carers across NSW in particular those in regional/rural areas and those from culturally and linguistically diverse backgrounds.

The Care for Carers Program has proved a worthwhile and much needed program during its inception and development from 2005-2007 and can continue to grow and support carers of people with neuromuscular disorders throughout NSW. Diversity and flexibility of carer support programs are vital factors in being able to provide service and support carers; particularly those who may be isolated due to geographic, social or cultural factors.

The proposed performance indicators and activities for Care for Carers Program 2007/08 aim to address these needs and support all carers across NSW in particular those in regional/rural areas and those from culturally and linguistically diverse backgrounds.

METROPOLITAN SUPPORT NETWORKS

Feedback from initial carers' survey, member survey 2008 and response to activities within the Sydney metropolitan area show the demand for carer-focussed events is broad and varied. Providing a range of activities to carers is an effective way of providing support. Activities include social events for carers, family activities eg. picnic days and specific support groups eg. Women's group, information sessions/workshops.

A range of information sessions/workshops will be developed or adapted for carers and include topics such as communication skills, self-advocacy, caring for yourself , manual handling and back care.

Carers Program Managers have held:

- 5 Women's Groups
- 2 carers' seminars
- Multicultural luncheon
- Christmas picnic
- Under 8's family picnic
- Family day out at Lake Macquarie

REGIONAL/RURAL SUPPORT NETWORKS

The regional and rural support networks are proving to be a successful element of Care for Carers. MDNSW sees room for further development of the networks; providing a broader range of activities similar to those mentioned above in Metropolitan Support Networks and broadening the number of regions with the inclusion of New-England and Far South Coast.

During the year Carers Program Managers have organised and attended gatherings at regional centres in:

- Illawarra - 3 carers' meetings, 1 carer seminar and 1 carer luncheon
- Hunter – 1 carers' meeting, 2 carers' luncheons, 1 family social picnic. There was also a very successful Hunter fundraising event organised by MDNSW carers which was attended by 105 people.
- Mid-North Coast – 1 carers' forum at Coffs Harbour, 1 carers' advocacy seminar at Ballina, 1 carers information seminar at Grafton.
- Central West – 1 Carers' Expo, 1 Carers' Seminar
- Riverina – 1 carers' lunch at Wagga, individual visits at Narrandera and Coolaman, presentation to regional Community Health and Interagency staff, 1 carers' seminar

Above: Georgina Christofis

Above: Family Day

CALD SUPPORT NETWORKS

As with many projects, reaching CALD carers is a challenging task. MDNSW believes accessing and supporting CALD carers is an important part of the Care for Carers program.

Suggested changes and additions to the CALD Support Networks aim to broaden the organisation's ability to support CALD carers by expanding the CALD target groups; one per year for 3 years. This will provide individual support for families, translating specific information, increasing awareness of neuromuscular disorders among the CALD communities and improving general access for CALD carers and families to MDNSW and Care for Carers program eg. providing interpreters at Metro Support workshops.

Activities during the year have included:

- Initial meetings/information sessions for carers and services providers
- Arabic Carers and Services meeting
- Chinese Carers Support Group presentation
- MDNSW Multicultural luncheon
- Individual support given to 2 Greek and 1 Vietnamese families

General community awareness information on Care for Carers program, MDNSW and muscular dystrophy has been published in ethnic specific papers, Arabic, Australian Chinese News and Vietnamese Herald Newspapers. General MDNSW information sheets have been translated in Greek. Myotonic Dystrophy Fact Sheets have been translated in Arabic, Chinese and Vietnamese.

TELEGROUP COUNSELLING

Telegroup Counselling is an effective way of reaching and supporting isolated carers. MDNSW ran an inaugural TGC program in 2006 which proved to be successful in supporting the carers involved. MDNSW is confident that similar programs can be run for other carers such as grandparents of children with muscular dystrophy or partners of people with muscular dystrophy in October 08.

Monash Golf Club Ladies Committee who worked hard to raise funds for MDNSW.

National Electric Wheelchair Sports Report

NEWS is the only competition available for people with neuromuscular disorders to compete on an "equal playing field" throughout Australia and New Zealand.

The 23rd Annual National Electric Wheelchair Sports (NEWS) was held at the Sydney Academy of Sport, Narrabeen in April 2008.

NEWS, was the brainchild of Roger Melnyk, who had Muscular Dystrophy and was the Executive Officer of the Muscular Dystrophy Association of Victoria. NEWS was first held in Melbourne in 1986 and has been held annually since. The sports played are designed specifically for people with muscular dystrophy and allied neuromuscular disorders who use a powered wheelchair for normal mobility and include the sports of Hockey, Soccer and Rugby League. NEWS is the only competition available for people with neuromuscular disorders to compete on an "equal playing field" throughout Australia and New Zealand.

Each sport is specifically designed for athletes who use an electric wheelchair and are played on a basketball court and each sport is played with 5 players per side and one substitute player. Hockey is played with a plastic or graphite hockey stick and a plastic ball. Soccer is played with a rubber "doubled dipped monster balloon" which is 60cm in diameter. In Rugby League players pass the ball by calling the number of the player they wish to pass to and tackles are made by contact of wheelchairs, and a tennis ball is used to throw instead of kicking the ball.

The tournament involves three days of round robin competition, with a day dedicated to each sport. The fourth day is a free day for athletes to do some sightseeing and the fifth day is set aside for finals for each sport and a presentation dinner. NEWS 2008 had competing teams from New South Wales, Queensland, South Australia, Victoria and Western Australia.

The NSW Colts, for 2008, were Stephen Webb (Captain), Chris Suffield (Vice Captain), Peter Dalrymple, John Shepherd, Hamish Armitage and Jordan Crane. The team was again coached by Michael Baptiste.

The Opening Ceremony was held on Tuesday, 15th April, followed by the round robin competition in Rugby League. The games were officially opened by the Hon Mr Graham West, MP, Minister for Sport and Recreation, Minister for Gaming and Racing, State Member for Campbelltown.

The Rugby League title was won by Queensland who beat New South Wales 14 – 8; Hockey was won by Victoria 4 – 3 over Queensland and New South Wales defeated Queensland 1 – 0. By virtue of their performance in the Round Robin competition, Queensland won the Roger Melnyk Trophy. Stephen Webb was Overall Best and Fairest for the 3rd consecutive year, although, this year he had to share it with Andrew Brandredth from Victoria. Stephen also won NSW Best and Fairest.

The 2008 tournament was supported by a substantial donation by Macquarie Bank. The New South Wales squad members and their families all worked together to fundraise for their team's expenses. Fundraising activities included a Dinner Dance, Golf Day and Trivia Night, as well as donations from supporters.

I wish to thank the Muscular Dystrophy Association of NSW for all their assistance in hosting NEWS 2008.

Michael Baptiste

NATIONAL DIRECTOR, N.E.W.S. AND NSW COACH

Back row: *Margaret Dalrymple, Bruce Armitage, Rick Suffield, David Webb, Kelly Crane, Martin Dalrymple, Eileen & Percy Baptise*
Front row: *Peter Dalrymple, Hamish Armitage, Chris Suffield, Stephen Webb, Jordan Crane, Donny Shepherd, Michael Baptitse*

Financials

MUSCULAR DYSTROPHY ASSOCIATION OF NEW SOUTH WALES

Income statement

For year ended 30 June 2008

	2008 $	2007 $
Revenue from donations and special events	462,323	438,890
Other income	115,212	90,277
Appeal/special event expenses	(68,231)	(39,249)
Client service provision expenses	(355,630)	(355,421)
Administration expenses	(115,147)	(98,693)
Depreciation expenses	(6,961)	(6,265)
Other expenses	(58,269)	(78,009)
Loss before financing (cost)/income	**(26,703)**	**(48,470)**
Financial income	58,368	117,111
Financial costs – Change in fair value of managed funds	(128,037)	(15,161)
Net financing (cost)/income	(69,669)	101,950
Surplus/(loss) for the period	**(96,372)**	**53,480**

INDEPENDENT AUDIT REPORT TO THE MEMBERS OF THE MUSCULAR DYSTROPHY ASSOCIATION OF NEW SOUTH WALES

SCOPE AND QUALIFIED AUDIT OPINION

We have audited the summarised financial report of the Muscular Dystrophy Association of NSW for the year ended 30 June 2008 comprising the income statement and balance sheet as set out on this and the following page.

In our opinion, the information reported in the summarised financial report is consistent with the annual statutory financial report from which it is derived and upon which we expressed a qualified audit opinion in our report to the members dated 9 October 2008. The qualification was in respect to completeness of revenue from donations and fundraising activities. The Association determined that it was impracticable to establish controls over the collection of these sources of revenue prior to entry into its financial records. Accordingly, as the evidence available to us regarding revenues from these sources is limited, our audit procedures with respect to these items of revenue had to be restricted to the amounts recorded in the financial records. We are therefore unable to express an opinion whether the revenues from these sources is complete.

In respect of the qualification however, based on our understanding of the internal controls, nothing has come to our attention which would cause us to believe that the internal controls over revenue from fundraising appeal activities by the Association are not appropriate given the size and nature of the Association.

For a better understanding of the scope of our audit, this report should be read in conjunction with our qualified audit report on the annual statutory financial report for the year ended 30 June 2008.

KPMG
Carlo Pasqualini
PARTNER
15 December 2008

Balance sheet

As at 30 June 2008

	2008 $	2007 $
Assets		
Cash and cash equivalents	306,247	341,919
Trade and other receivables	21,659	61,714
Inventories	-	9,689
Investments	579,795	631,191
Total current assets	907,701	1,044,513
Plant and equipment	14,086	3,634
Total non-current assets	14,086	3,634
Total assets	921,787	1,048,147
Liabilities		
Trade and other payables	24,898	59,599
Employee benefits	21,458	16,745
Total current liabilities	46,356	76,344
Total liabilities	46,356	76,344
Net assets	875,431	971,803
Equity		
Allocated capital funds	123,389	325,218
Retained earnings	752,042	646,585
Total equity	875,431	971,803

COMPLETE 2008 ANNUAL FINANCIAL REPORT

The summarised financial report and other specific disclosures have been derived from the Muscular Dystrophy Association of NSW full financial report for the financial year. Other information included in the summarised financial report is consistent with the full financial report.

The summarised financial report does not, and cannot be expected to provide as full an understanding of the financial performance, financial position and financing and investing activities of the Muscular Dystrophy Association of NSW as the full financial report.

A copy of the 2008 Annual Financial Report, including the independent audit report, is available to all members, and will be sent to members without charge upon request. The 2008 Annual Financial Report can be requested by telephone (02) 9809 2111 and by email at info@mdnsw.org.au.

Thank you to our donors

WE WOULD LIKE TO THANK ALL OUR DONORS BUT WISH TO ACKNOWLEDGE THE FOLLOWING GIFTS AND CONTRIBUTION FROM 1/7/07 TO 30/06/08

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