ANNUAL REPORT 2008/2009

md
muscular dystrophy
new south wales










Building Strength Through Change

www.mdnsw.org.au

Contents

Morgan is a vibrant, fun loving 4 year old who has Ullrich Congenital Muscular Dystrophy. Whilst Morgan approaches life with a positive attitude, it is not an easy ride, as dad Anthony explains...

"It is hard having a child that is totally dependant on you and seeing him constantly struggle to do things that you and I take for granted – like standing up. Everyday is a new hurdle and challenge with Morgan's condition, you never know what is going to happen next and you basically live moment to moment, day to day because you never know how much time you have left. Morgan is an extremely bright little boy, with an active mind and imagination. He wants to get in to everything and it is only his body that lets him down. It is hard to always see people staring at him and pitying him."

"Whenever we need help we know that we can turn to MDNSW for help. No matter what it is whether it is support, opportunities to socialise, interact and learn from other families or advocacy and support with equipment, respite etc MD is there to help. It is nice to not feel alone".

CEO Report

A Muscular Dystrophy NSW (MDNSW) Member Survey conducted in June 2008 highlighted the need for an increase in relevant and practical services. This research along with a MDNSW Board workshop conducted in February 2008 underpinned the development of a strategic plan adopted by the MDNSW Board in August 2008 which included introducing new services and increased emphasis on establishing and maintaining relationships with members.

This new Strategic Plan also focused on partnerships and essential MDNSW organisational developments to ensure MDNSW capacity to deliver vital new services to those members who live with a neuromuscular condition. An encouraging outcome has been the significant increase in families joining MDNSW and being advantaged by the services available.

This Annual Report reports on achievements and shares personal stories of clients who benefit from our work. Whilst this Report is a celebration of a year of significant positive change it is also a restating of our commitment to our vision, “an improved quality of life for people who live with a neuromuscular condition and their families and carers.”

ACHIEVEMENTS – ORGANISATIONAL

Acknowledging that organisational profile, expression of vision and values, promotional opportunities and accessibility are fundamental to success, MDNSW has undertaken a range of changes. These have been pursued with the intention of building organisational capacity to ensure clients are provided with increased support and service.

Changes include:

- New vision, mission and strategy giving a sharper and enlarged focus to our activity
- New branding giving greater prominence to our organisation both in NSW and nationally
- New website giving a better profile and increased accessibility to information and resources
- New office offering improved parking, public transport, accessibility for clients and facilities for events
- New database enabling improved contact with supporters and clients and recording of information

ACHIEVEMENTS – SERVICES AND SUPPORT

This past year has seen the introduction of new and expanding of existing member services and activities, including running the first MD Camp in NSW. It has been encouraging to hear from members enthusiastic about this and other initiatives and contributing new ideas and insights.

New initiatives implemented by MDNSW Client and Carer Services, include:

- Home Support Program
- Weekend Retreat for young adults and adults
- Camps for children, young people and the young at heart
- Increased regional focus through workshops and home support
- Livewire net community for children and teenagers
- New client focused events including Melbourne Cup Lunch and Pamper Days
- Enhanced events including HOGS Picnic Day and Christmas Parties

These and other activities have been welcomed by our clients and their families and are detailed in this Report.

RESEARCH

During the past 10 years MDNSW has invested nearly $600,000 in important research. Currently MDNSW is funding an important research project by Dr Erika Becker at The University of Sydney into Friedrichs Ataxia. Thank you to volunteer members of the Scientific Advisory Committee who do an enormous amount of work evaluating submissions under the guidance of the MDNSW Medical Director, Dr Heather Johnston.

ADVOCACY

MDNSW has taken an active role in advocating for its clients. A written submission to the Parliamentary Inquiry into Program of Appliances for Disabled People (PADP) resulted in MDNSW being invited to make a personal presentation to the inquiry. This inquiry has resulted in a range of welcome recommendations.

Joining the national push for a National Disability Insurance Scheme, MDNSW has formally expressed its support for such a scheme. It is hoped that a feasibility study will be agreed to ensuring that our clients and their families and carers will have the support and resources they need to become full participants in all aspects of community.

NEWS

MDNSW is proud to be associated with the National Electric Wheelchair Sports (NEWS) and committed to continuing to provide support to this important program. Congratulations to NEWS NSW on their success at the Annual NEWS Tournament held in April. All the teams competed strongly with NSW deserved winners overall.

PARTNERSHIPS AND FUNDING

It is becoming increasingly difficult to successfully apply for government funds to supplement our income. Government departments desire to place funds with disability service providers who work across the disability sector or those who support large numbers of people. Small disorder specific organisations such as Muscular Dystrophy NSW typically do not meet funding criteria. Despite these challenges, MDNSW is in a partnership with NSW Health to deliver a carers support program with a special focus on regional NSW and people from a CALD background. This is now in its third year and you will read of its success in this report.

More recently a partnership has been developed with Ageing, Disability and Home Care (ADHC). Funding was given on 30 June 2009 to subsidise MDNSW to run a Camp and a Retreat annually for three years. This is a most welcome opportunity with MP Paul Lynch, Minister for Disability Ageing and Home Care taking time out of his busy schedule to attend the first Camp held at the Sydney Academy of Sports in October 2009.

MDNSW also continues to offer the Flexirest Program in partnership with Multiple Sclerosis Australia – NSW (MS NSW) and Motor Neurone Disease Association of NSW. We value this partnership and have seen growth in this program during the past year. I am especially appreciative of MS NSW for their excellent administration of the Flexirest Program.

FUTURE CHALLENGES

With these achievements and opportunities come challenges. These include:

- Increasing our support to families who live in regional NSW?
- Increasing our services to young people and young adults
- Increasing our contribution to the equipment needs of our members?
- Increasing our financial capacity to support new and proposed initiatives?

Fundraising has been more difficult this past 12 months and MDNSW has not been immune from the impact of the Global Financial Crisis. However, a substantial bequest taken up in the 2009/10 financial year will provide future financial security in the medium term and a platform for financial growth through new fundraising initiatives.

OUR SUPPORTERS

Investment in the work of MDNSW and the individuals and families it supports is made in many ways. Hundreds of people have made a financial contribution to MDNSW, ranging from the $22 membership to large corporate donations. Every cent is valued and put to good work.

Volunteers are greatly appreciated and contribute in numerous ways. Many empty our Red Rooster and Spotless (Domestic and International Food Outlets) collection boxes faithfully; others contribute to the administrative functions of our office assisting with mailouts, preparing for events or coordinating teams of volunteers; and volunteers also attend events including camps providing invaluable support.

In-kind support is also generously given. This includes people who offer prizes, gifts and goods for events, pro bono legal support, audit services and other necessary professional services.

Thank you to all who have given so generously.

OUR TEAM

These achievements reflect the work of a capable Board with vision, enthusiasm and ambition. I want to especially acknowledge and appreciate MDNSW President, Rob Ferguson for his tireless support, proactive leadership and personal involvement not only in the work of the Board but in the implementation of the plan.

I would also like to acknowledge other members of the Board who also regularly contribute significant personal time to MDNSW. This includes running golf days, managing our new website, offering medical advice and guidance for events, working through various financial matters and negotiations, advising on equipment requests, overseeing the updating of our constitution and offering personal encouragement and support to myself and our team.

Achievements described in this report also acknowledge and reflect the hard work and dedication of MDNSW staff committed to implementing this vision. MDNSW is fortunate to have a stable and harmonious team of professionals who bring initiative, creativity, skills and experience and passion to our organisation and the lives of our clients and their families.

Our Client Services Manager, Renee McBryde joined MDNSW in September 2008, Carer Services Coordinator Georgina Christofis has been with us since April 2008, Bookeeper, Hulya Ucan joined in February 2008 and Office Manager, Maralyn McCann joined in July 2009. They are a pleasure to work with and I value each for their positive and unique contribution.

Thank you to our Board members, staff and supporters who together make such a difference!

Most important of all, thank you to our clients and their carers and families for continuing to express confidence in MDNSW by attending events, allowing us to work with you, and for offering feedback enabling improvement. Our team values the friendships and professional relationships we enjoy with our clients and their families and look forward to continuing to journey with you.

David Jack

CHIEF EXECUTIVE OFFICER

President's Report 2008/2009

'BUILDING STRENGTH THROUGH CHANGE'

Phasellus interdum mi in mi. Maecenas posuere aliquam est. Pellentesque porttitor, eros in pulvinar congue, odio urna dictum nisl, id porttitor urna massa eu arcu. Nunc vehicula luctus arcu. Nulla sapien. Maecenas justo dui, tristique id, commodo nec, suscipit eu, ligula. Suspendisse potenti. Nam et arcu quis nisi vehicula suscipit.

Here is my report for 2009

FINANCIAL RESULT

This financial year we recorded a disappointing operating loss of $213,964. This did not include a loss in our invested funds at AMP of $80,455 due to the considerable fall in the value of these investments during the year. While donations, other fundraising, and return on invested funds was substantially less than last year, we commenced accounting for the first of three equal annual grants from DADHC totalling $300,000 to run annual camps and weekend retreats. Combined with our Flexi-Rest Respite Grant, the Carer's grant for regional areas and those with cultural and linguistically different backgrounds, the State Government funding is taking a greater share of our funding burden. I believe this is an inevitable trend which will continue as Governments accept their responsibility for disability funding, and free up charitable agencies to provide specialised services which Government cannot provide.

PLANNING

A great deal of very focussed strategic planning took place last year, following the appointment of David Jack as CEO in April, 2008 which included:-

- A review of existing services, and recommendatons for future services in a Strategic Plan. Presented by the CEO it was adopted by the board in November, 2008 and incorporated many of the proposals in the original 'Building Strength' document
- A review of our existing fundraising and future options and recommendations was made in the same Strategic Plan.

The Strategic Plan incorporated the following:-

- A resource and information program.
- A volunteer carer recruitment and training program.
- A weekend retreat program.
- A camping program.
- Other programs subject to raising of required funding.

At the board level, this was only made possible by a lot of

At the board level, this was only made possible by a lot of

dedicated hard work following the decision to introduce a number of smaller committees which could properly focus on our needs and options, and recommend outcomes to the full board.

These committees are:-

1. **The Vision and Strategic Planning Committee** which addresses our overall vision and strategy, and which consists of:- Colin Gunn(chair), Ian Williams, Kristi Jones, Rob Ferguson and David Jack.
2. **The Fundraising Committee** which provides input and manpower into our fundraising activities, and which consists of:- Rob Ferguson(chair), Ross Parker, Colin Gunn, and David Jack
3. **The Finance & Remuneration Committee**, which adresses budgeting, monthly performance, audit and any other financial issue. It consists of Graeme Troy – hon treasurer(chair), Ian Williams, Rob Ferguson, Colin Gunn & David Jack.
4. **The Equipment committee** which makes recommendations to the board regarding policy and equipment funding applications, and which consists of:- Dr Heather Johnston, Bruce Ellison, Colin Gunn, Ross Parker, David Jack, and Renee McBryde(chair). This committee meets monthly at present.
5. **The Research working group,** which formulates policy decisions regarding allocation of research spending, and which consists of:- Dr Heather Johnston, Dr Alastair Corbett, Dr Kristi Jones, Colin Gunn, Rob Ferguson and David Jack.

The first 3 committees meet triannually, or for any special purpose for which they are required, the others meet as and when required.

This committee structure has allowed the board to be much more creative, dilligent, precise, and provide a much clearer direction to the CEO and his executives.

SOME OF THE IMPORTANT INIATIVES RESULTING FROM THE STRATEGIC PLANNING REVIEW EMANATING FROM BUILDING STRENGTH PROPOSALS WERE:-

- **New office.** We settled into our new office at Meadowbank on September 1, and have had an overwhelmingly positive response to its more accessible central location, access to public transport (train, rivercat and bus), good parking and functionality - particularly the adjacent community centre which we can use for seminars, conferences and meetings.

- **New logo, letterhead and brochures.** Following adoption of a new logo, using similar graphics with Muscular Dystrophy Foundation (MDF) nationally, we took on a new, modern appearance, including the name Muscular Dystrophy NSW (MDNSW). Our formal corporation name of Muscular Dystrophy Association of NSW has however been retained.
- **New Look Talking Point magazine.** Our quarterly magazine was printed in full colour, and took on a more up to date appearance.
- **New look web site.** Our new livery was adopted, along with a complete redesign of the web site, which has a uniform appearance with the MDF, and links to MDF and other states where appropriate.
- **New data base.** It was very difficult to operate efficiently or ever really attain our goals with such a fundamental platform missing. During the year we procured a pro bono cutting edge, very powerful data base, which is now a foundation of our daily activity and operation.
- **New constitution.** It was decided to seek out pro bono support for the preparation of a more appropriately up to date constitution for MDNSW than the original, which had been in place for many years .

NATIONAL ISSUES - MDF

As you know David Jack is employed by MDNSW, and is “seconded” to Muscular Dystrophy Foundation (MDF) for approximately 20% of his working time. MDF re-imburses MDNSW for David’s time and other costs expended on its behalf.

The MDNSW board is committed to achieving the best possible outcome for those with neuromuscular disorders in NSW and along with the boards of South Australia, Queensland, and Tasmania have a view that MDF’s success must be beneficial to their states.

The structure that the MDF board put in place to achieve this outcome has been most effective. Initiatives and programs are being created and implemented at a state executive level, with direction provided by the MDF CEO David Jack. The board, which presently consists of nominees from all participating states, has more a steering and oversight role.

Muscular Dystrophy Foundation was established to raise the profile of neuromuscular disorders at a national level, and raise funds nationally. It is now beginning to achieve this end and oversaw a successful national Best and Less and other retail outlet merchandising campaigns during the year. It will achieve substantially more in time, with plans underway for a Jerry Lewis telethon in Australia and a national bicycle ride in the 2010/11 year. Collaboration is also occurring with service delivery, particularly in terms of camps being attended by members from other states.

MDF was set up to benefit all of those with neuromuscular disorders in Australia, and with this in mind, the MDF board and executive have kept in touch wherever possible, with the non participating states of Western Australia, Victoria and the ACT.

THE FINANCIAL CHALLENGE

The service provision plans have been clearly identified and are now in place and working well. Our first camp took place in October this year, attended by 39 children, and was an unqualified success. This was a wonderful outcome and fulfilled a dream that many on the board have had for some years now.

The economic downturn did however have a major impact on our ability to raise the funds we need to achieve the plans that we have put in place. The implementation of our new and very relevant services has fortunately given us a clear and easily enunciated case to seek funds from donors.

Fundraising must now be our major focus over the next year, and we have considered a number of fundraising plans with the assistance of a not for profit fundraising consultancy.

We appear to be fortunate in that a major bequest should be received during this financial year, of an amount in excess of $1million.

But we can’t rely on such serendipitous funding, and must find ways of finding more predicatble income streams. We need to continue to increase our profile and public awareness, and become less reliant on a handful of members for such a large financial input.

THANKS WHERE ITS DUE.

I wish to thank my board colleagues for their insightful and very capable contribution during the year. Considering their work is purely voluntary, I believe we are very fortunate to have the capacity, skills and application within the board to provide such a major and wide ranging contribution to MDNSW.

I would like to complement David Jack our CEO for achieving so much since joining us just over a year ago. David’s first 6-9 months were more focussed on strategic planning, and the benefits of that are now clearly visible across the spectrum of a new look MDNSW.

I also thank our small team of dedicated employees supported by a growing team of volunteers, who are gallantly providing ever improving services to our growing list of members.

Thanks to you all.

Rob Ferguson

PRESIDENT

MDNSW
Directors and Staff

Phasellus interdum mi in mi. Maecenas posuere aliquam est. Pellentesque porttitor, eros in pulvinar congue, odio urna dictum nisl, id porttitor urna massa eu arcu. Nunc vehicula luctus arcu. Nulla sapien. Maecenas justo dui, tristique id, commodo nec, suscipit eu, ligula. Suspendisse potenti. Nam et arcu quis nisi vehicula suscipit.

STAFF

David Jack
CEO

Renee McBryde
MANAGER CLIENT SERVICES

Georgina Christofis
MANAGER CARER SERVICES

Maralyn McCann
OFFICE MANAGER

Hulya Ucan
BOOKKEEPER

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

MDNSW Board

BOARD MEMBERS

Mr Percival Alwyn Baptiste JP

Retired
Director since: November 2001

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

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

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

Client Services Report

The MDNSW Client Services Program aims to provide support, advocacy and memorable life experiences to people with neuromuscular disorders and their families. The 2008-2009 financial year was one of great achievement for the Client Services team with record numbers of members turning out to events throughout the year.

A number of new events and programs were added to the already flourishing Client Services Program with 08/09 seeing the implementation of two major client service areas. This included the ground work and funding being achieved for the new MDNSW Camp and Weekend Retreats Programs – MD'S first ever DADHC funding! And the implementation of the Home Support Program.

HOME SUPPORT PROGRAM

The Home Support Program was initiated for clients of MDNSW in response to the need for extra client contact and support.

Talking with members regularly about any issues they might be facing, reinforcing the services and programs available to the members, and having the individual contact, is a beneficial service providing a closer connection to our members. This has been a program that we have received tremendous feedback about to date and one that we are strategically committed to expanding in the coming financial years.

ADVOCACY

The Client Services Program also has an Advocacy Program which aims to protect and advance the legal, human and service provision rights of people with Neuromuscular Disorders. MDNSW staff work to assist clients with achieving positive outcomes. Where necessary MDNSW provides referrals to other organizations that may be able to further assist our clients in a myriad of life areas.

EQUIPMENT

MDNSW accepts applications for essential equipment funding required by MDNSW members, funds permitting.

Applications are considered where the equipment is not eligible for funding through PADP or the timeline for provision by PADP is not realistic for the members quality of life. Equipment must always be prescribed by an occupational therapist.

Member applications are considered by the Equipment Sub-Committee on a quarterly basis. This committee is resourced by Client Services and the program aims to assist as many clients as financially possible each year.

TALKING POINT

Talking Point keeps members of MDNSW up to date with everything that is happening in the MDNSW office, both up and coming and recently celebrated events, research, opportunities for members and carers and lots of other programs and articles of interest.

Every edition of **Talking Point** has a different theme, which is relevant to members and carers. The 2008-2009 TP editions have been some of our best yet – this is largely thanks to Carolyn Campbell Maclean and until recently Louise West.

EVENTS

What a year 08/09 has been! Every month has seen our members turn out in record numbers for events such as the Medical Seminar – "Just Breathe", HOG's 2008, Christmas parties – state-wide, Ladies Pamper days, Winery Luncheons and other excursions, not to mention some very popular Family Days! Not all our events were strictly social with a number of support seminars and of course our regular Members Advisory Committee meetings and Women's Group meetings.

IN THE OFFICE

This year the MDNSW office has been abuzz with change and growth. Celebrating a new team and premises, the 08/09 financial year was a year of collaboration and planning and fundamentally improving the level of service provision to our members. This commitment has and will no doubt continue to pay off with levels of member and partner support, participation and enthusiasm constantly growing.

The year also has seen an increased level of participation between the state organisations particularly around preparing for the first ever NSW camp. Both Suth Australia and Victoria were kind enough to host us at their respective camps to enable us to see the process in action. Additionally much was learnt from being apart of the Window on Tomorrow conference hosted by Muscular Dystrophy New Zealand in May 2009.

THE FUTURE

The 2009/2010 financial year will see the fruition of the first ever MDNSW Camp, weekend retreats and as previously mentioned an increased level of home support. There will also be many new and exciting opportunities for members to take part in – along with a lot of the old favourites – revamped of course! It is a very exciting time for the Client Services Program and indeed MDNSW as a whole and we look forward to reporting again on all the events of the coming year – we are certainly moving in leaps and bounds!

Renee McBryde

MANAGER CLIENT SERVICES

Care for carers program

The Care for Carers program was established to offer support to carers of people living with Muscle dystrophy and other neuromuscular conditions, in particular those from Regional/ Rural NSW and those from culturally and linguistically diverse backgrounds (CALD). The program is in it's second round of funding since it's inception in 2005, and is funded By NSW Health under the State- Wide Carers Program and Muscular Dystrophy of NSW (MDNSW) and coordinated and managed by MDNSW.

The program continues to support carers living in Sydney Metropolitan, Regional and Rural NSW and those from CALD background through its support networks, social support opportunities, information, advocacy and referral, home visit program and culturally appropriate resources.

The Objectives of the program are;

- Increase carer's knowledge and skills in caring for a person with a neuromuscular disorder.
- Enhance social support opportunities for Carers
- Provide carers with relevant, up to date and timely information
- Improve access to existing health and community services

CARERS PROGRAM ADVISORY COMMITTEE

The Carers Program Advisory Committee previously known as the project management committee was established at the start of the program to discuss, evaluate and comment on the Care for Carers program. The group have met on a Quarterly basis throughout 2008/09; 11 December 08, March 26th and June 25th 09.

Members of the Committee during 2008/09 are mentioned below,

David Jack - CEO MDNSW

Renee Mc Bryde - Manager, Client Services MDNSW

Georgina Christofis - Manager, Carer Services MDNSW

Maria Antonio - Carers NSW

Rhonda Murray - Carer Representative MDNSW

Sandra Holland - Sydney Children Hospital Genetic Counsellor (December- June 09)

Robyn Pederson - Sydney Children Hospital Genetic Counsellor

NETWORKING

Establishing and maintaining networks and relationships with other Non- Government, Disability, Health and Government Services continues to be one of the main priorities of Care for Carers. During 2008/2009 the manager focussed on maintaining pre-existing relationships and developing new ones with agencies like the Department of Housing, Respite providers, Disability Support Agencies throughout NSW and Commonwealth Care link services. This was achieved by attending interagency meetings, presenting at a variety of forums, meeting with other services to share ideas and resources, distribution of relevant information and material, supporting other carer events and working in partnership with other organisations on carer activities.

REGIONAL NETWORKS

MDNSW is committed to ensuring people with neuromuscular disorders have equitable access to services irrespective of their location.

People living in rural remote areas are often disadvantaged in accessing services. As a result, MDNSW continues to proactively seek to identify carers/ persons with neuromuscular disorders living in rural and remote areas and assists them in accessing the services they need.

MDNSW has continued it's networking with other services such as non- government, government and health services in rural and remote areas to:

- Identify clients
- Communicate about available services
- Jointly deliver services
- Help them understand the needs of people with neuromuscular disorders and provide appropriate services

We continue to facilitate or provide support to clients and carers directly and through our networks by providing:

- Regular networks
- Home visits
- Telephone and e-mail contact
- Information about neuromuscular disorders and available support services
- Information about providing support to people with neuromuscular disorders
- Seminars
- Carer support groups and regional networks
- Respite services through the Flexi rest Program (DADHC)
- Other client-centred activities that help provide direct support and form social support networks.
- Availability of a carer coordinator to discuss client and carer circumstances and needs and help arrange practical and emotional support.

Examples of the success of the regional networks and the impact the networks have on individual's lives include:

The significant increase of carers from regional areas of NSW accessing the Flexible respite funded by DADHC.

The increased amount of carers e-mailing, calling for information, support and advocacy.

The increased amount events and fundraisers to help support MD generic services for example Black and White Fundraiser (Ken vale college, NSW University as a result of Attendance at the Greek festival of Sydney.
The increase in the meeting and sustainability of carers outside of formal carer meetings

CALD NETWORKS

MDNSW is committed to inclusiveness and actively seeks to ensure that its services are accessible for people from a culturally and linguistically diverse background.

Areas that were focused on in 2008/2009 include:

Increasing community awareness among CALD communities by attending events like Greek Festival of Sydney and Carers Expo in Dubbo.

Providing individual support to CALD carers and families through the Home Visit Support program

Having appropriate information translated and made available on the MDNSW website

Continue to develop relationships with CALD specific workers in the neuromuscular clinics, Carers NSW and ethno specific organisations like the Greek Welfare Centre, Multicultural Disability Advocacy Association and CASS.

METRO ACTIVITIES

MDNSW runs a number of events and activities within the Sydney metropolitan region. The manager of carer services works closely with MDNSW client services manager in planning, promoting and running interesting and varied events to suit specific groups; The cald community, women groups, members living with neuromuscular disorders, Carers living in different areas of Sydney and family members interested in being part of the MD community.

HOME SUPPORT PROGRAM

The Home Support program was initiated for clients and their carers of MDNSW in response to the need for extra contact and support. Talking with members regularly about any issues they might be facing, reinforcing the services and programs available to members, and having the individual contact, is a beneficial service providing a closer connection to our members.

The home support program is aimed to identify the more complex needs faced by clients and carers on issues regarding equipment needs, member's access to services like PADP and others, Home Modifications and the emotional needs brought about by the caring role. Requests and follow up is made with the Client/ carer to ensure outcomes and the needs of carer/ client are met during each visit.

CONCLUSION

The Care for Carers Program is proving a success as it provides much needed support to carers of people with Muscular Dystrophy and other neuromuscular disorders throughout NSW.

Georgina Christofis

MANAGER CARER SERVICES

Financials

Praesent dictum laoreet lacus. Cras mattis nisl at lacus. Maecenas augue velit, venenatis in, ultricies sed, mollis sit amet, purus. Phasellus interdum mi in mi. Maecenas posuere aliquam est. Pellentesque porttitor, eros in pulvinar congue, odio urna dictum nisl, id porttitor urna massa eu arcu. Nunc vehicula luctus arcu. Nulla sapien. Maecenas justo dui, tristique id, commodo nec, suscipit eu, ligula. Suspendisse potenti. Nam et arcu quis nisi vehicula suscipit.

MUSCULAR DYSTROPHY ASSOCIATION OF NEW SOUTH WALES

Income statement

For year ended 30 June 2009

	2009 **$**	**2008** **$**
Revenue from donations and special events	436,106	462,323
Other income	89,092	115,212
Appeal and special event expenses	(33,400)	(68,231)
Client service provision expenses	(524,522)	(355,630)
Administration expenses	(106,072)	(115,147)
Depreciation expenses	(10,503)	(6,961)
Other expenses	(64,665)	(58,269)
Profit (loss) before financing income (cost) and income tax	**(213,964)**	**(26,703)**
Financial income	19,318	58,368
Financial costs	(99,773)	(128,037)
Net financing income (cost)	(80,455)	(69,669)
Income tax expense	–	–
Profit (loss) for the period	**(294,419)**	**(96,372)**

MUSCULAR DYSTROPHY ASSOCIATION OF NEW SOUTH WALES

Balance sheet

As at 30 June 2009

	2009 $	2008 $
Current assets		
Cash and cash equivalents	427,341	306,247
Trade and other receivables	33,267	21,659
Financial assets	480,022	579,795
Other assets	11,500	–
Total current assets	952,130	907,701
Non-current assets		
Property, plant and equipment	18,771	14,086
Total non-current assets	18,771	14,086
Total assets	970,901	921,787
Current liabilities		
Trade and other payables	59,196	24,898
Short-term provisions	41,643	21,458
Other liabilities	289,050	–
Total current liabilities	389,889	46,356
Total liabilities	389,889	46,356
Net assets	581,012	875,431
Equity		
Retained earnings	481,002	752,042
Reserves	100,010	123,389
Total equity	581,012	875,431

Financials

Praesent dictum laoreet lacus. Cras mattis nisl at lacus. Maecenas augue velit, venenatis in, ultricies sed, mollis sit amet, purus. Phasellus interdum mi in mi. Maecenas posuere aliquam est. Pellentesque porttitor, eros in pulvinar congue, odio urna dictum nisl, id porttitor urna massa eu arcu. Nunc vehicula luctus arcu. Nulla sapien. Maecenas justo dui, tristique id, commodo nec, suscipit eu, ligula. Suspendisse potenti. Nam et arcu quis nisi vehicula suscipit.

MUSCULAR DYSTROPHY ASSOCIATION
OF NEW SOUTH WALES

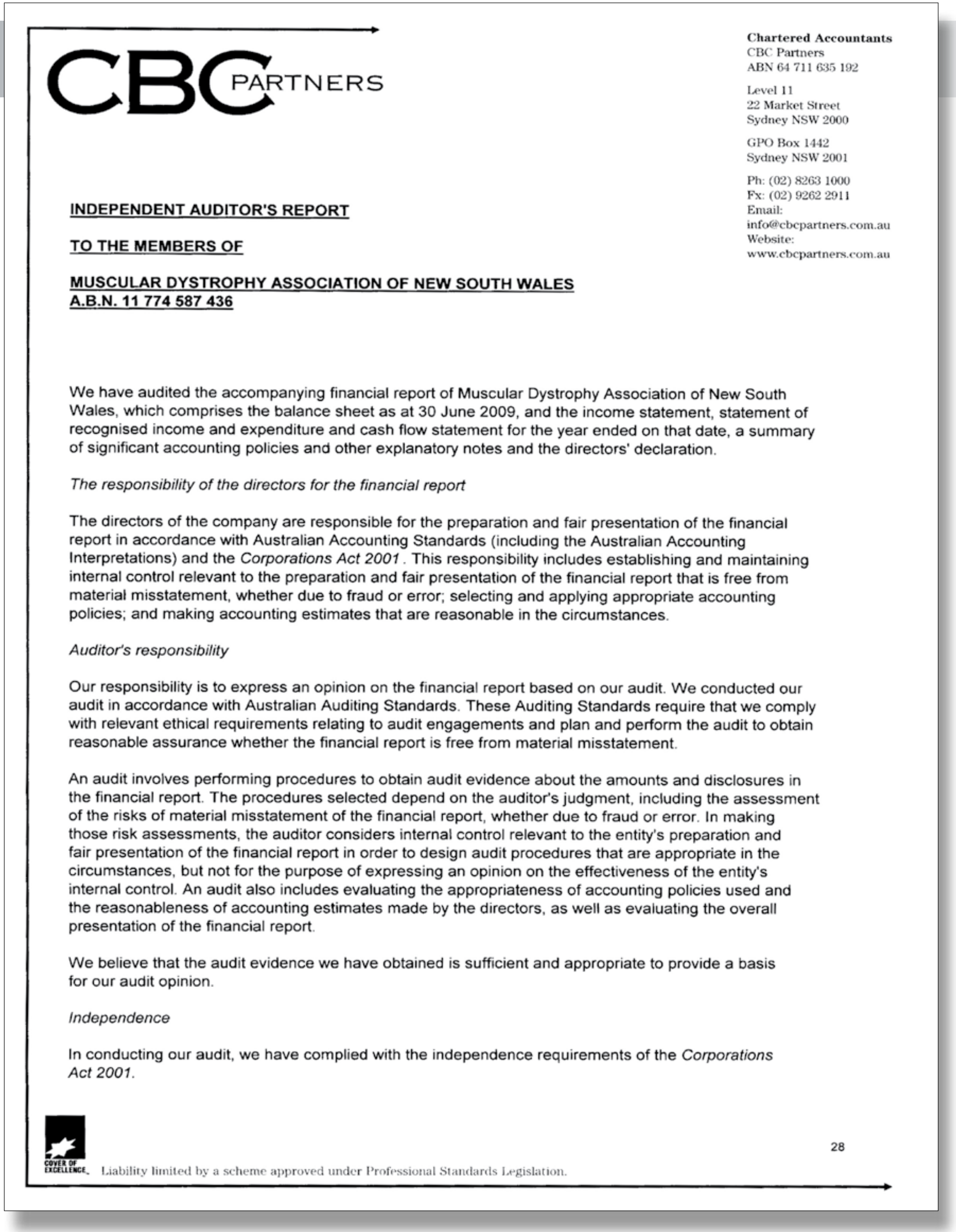
Statement of Recognised Income & Expenditure

For the year ended 30 June 2009

	Capital Funds Reserve	Retained Earnings $	Total $
Balance as at 1 July 2007	325,218	646,585	971,803
Profit attributable to members of the company	–	(96,372)	(96,372)
Transfer of allocated capital funds	(201,829)	(201,829)	–
Balance as at 30 June 2008	123,389	752,042	875,431
Profit attributable to members of the company	–	(294,419)	(294,419)
Transfer of allocated capital funds	(23,379)	23,379	–
Balance as at 30 June 2009	100,010	481,002	581,012

a. Capital funds reserve

The capital funds reserve represents funds allocated for specific expenditure in future years.



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INDEPENDENT AUDITOR'S REPORT

TO THE MEMBERS OF

MUSCULAR DYSTROPHY ASSOCIATION OF NEW SOUTH WALES
A.B.N. 11 774 587 436

We have audited the accompanying financial report of Muscular Dystrophy Association of New South Wales, which comprises the balance sheet as at 30 June 2009, and the income statement, statement of recognised income and expenditure and cash flow statement for the year ended on that date, a summary of significant accounting policies and other explanatory notes and the directors' declaration.

The responsibility of the directors for the financial report

The directors of the company are responsible for the preparation and fair presentation of the financial report in accordance with Australian Accounting Standards (including the Australian Accounting Interpretations) and the *Corporations Act 2001* . This responsibility includes establishing and maintaining internal control relevant to the preparation and fair presentation of the financial report that is free from material misstatement, whether due to fraud or error; selecting and applying appropriate accounting policies; and making accounting estimates that are reasonable in the circumstances.

Auditor's responsibility

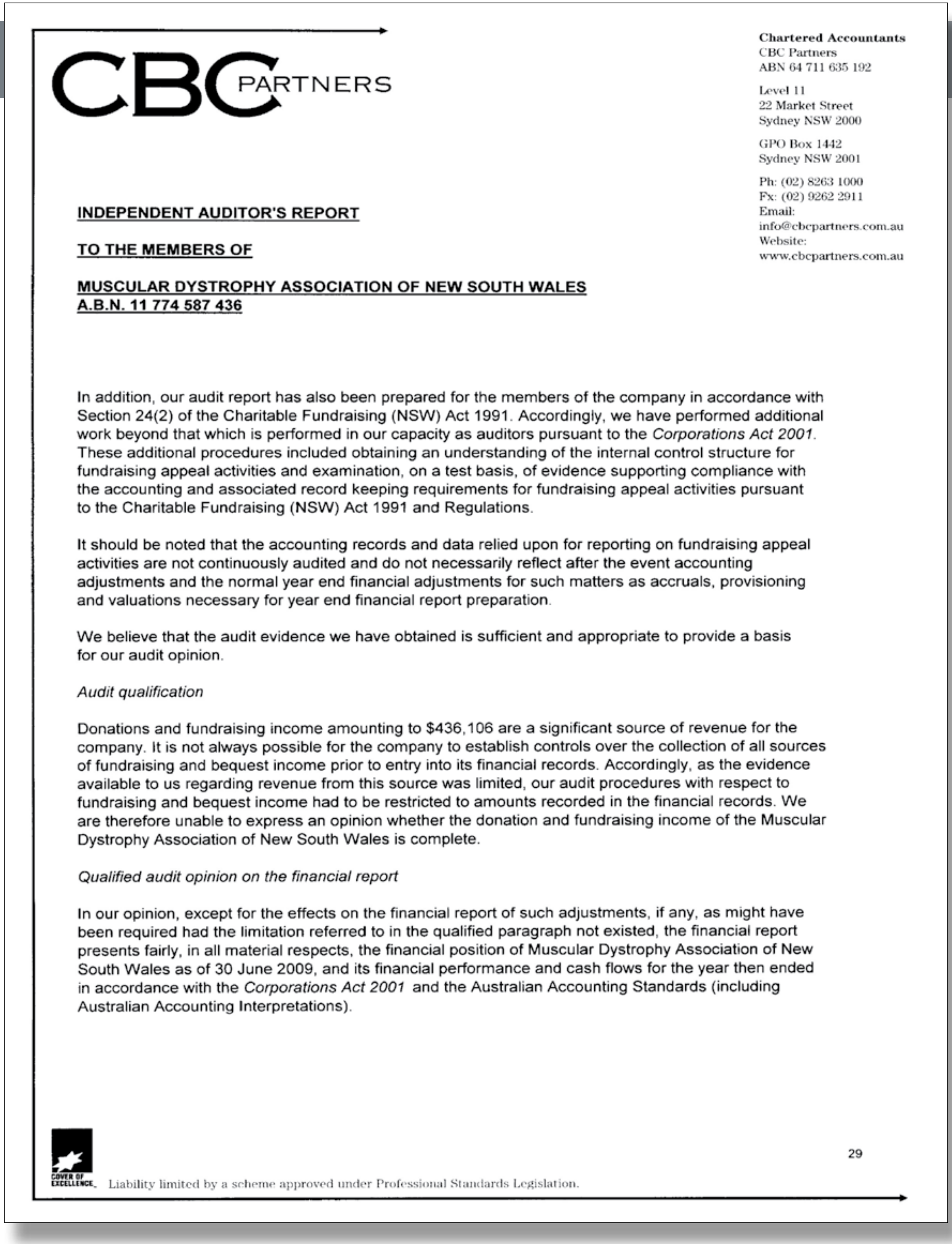
Our responsibility is to express an opinion on the financial report based on our audit. We conducted our audit in accordance with Australian Auditing Standards. These Auditing Standards require that we comply with relevant ethical requirements relating to audit engagements and plan and perform the audit to obtain reasonable assurance whether the financial report is free from material misstatement.

An audit involves performing procedures to obtain audit evidence about the amounts and disclosures in the financial report. The procedures selected depend on the auditor's judgment, including the assessment of the risks of material misstatement of the financial report, whether due to fraud or error. In making those risk assessments, the auditor considers internal control relevant to the entity's preparation and fair presentation of the financial report in order to design audit procedures that are appropriate in the circumstances, but not for the purpose of expressing an opinion on the effectiveness of the entity's internal control. An audit also includes evaluating the appropriateness of accounting policies used and the reasonableness of accounting estimates made by the directors, as well as evaluating the overall presentation of the financial report.

We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our audit opinion.

Independence

In conducting our audit, we have complied with the independence requirements of the *Corporations Act 2001*.



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In addition, our audit report has also been prepared for the members of the company in accordance with Section 24(2) of the Charitable Fundraising (NSW) Act 1991. Accordingly, we have performed additional work beyond that which is performed in our capacity as auditors pursuant to the *Corporations Act 2001*. These additional procedures included obtaining an understanding of the internal control structure for fundraising appeal activities and examination, on a test basis, of evidence supporting compliance with the accounting and associated record keeping requirements for fundraising appeal activities pursuant to the Charitable Fundraising (NSW) Act 1991 and Regulations.

It should be noted that the accounting records and data relied upon for reporting on fundraising appeal activities are not continuously audited and do not necessarily reflect after the event accounting adjustments and the normal year end financial adjustments for such matters as accruals, provisioning and valuations necessary for year end financial report preparation.

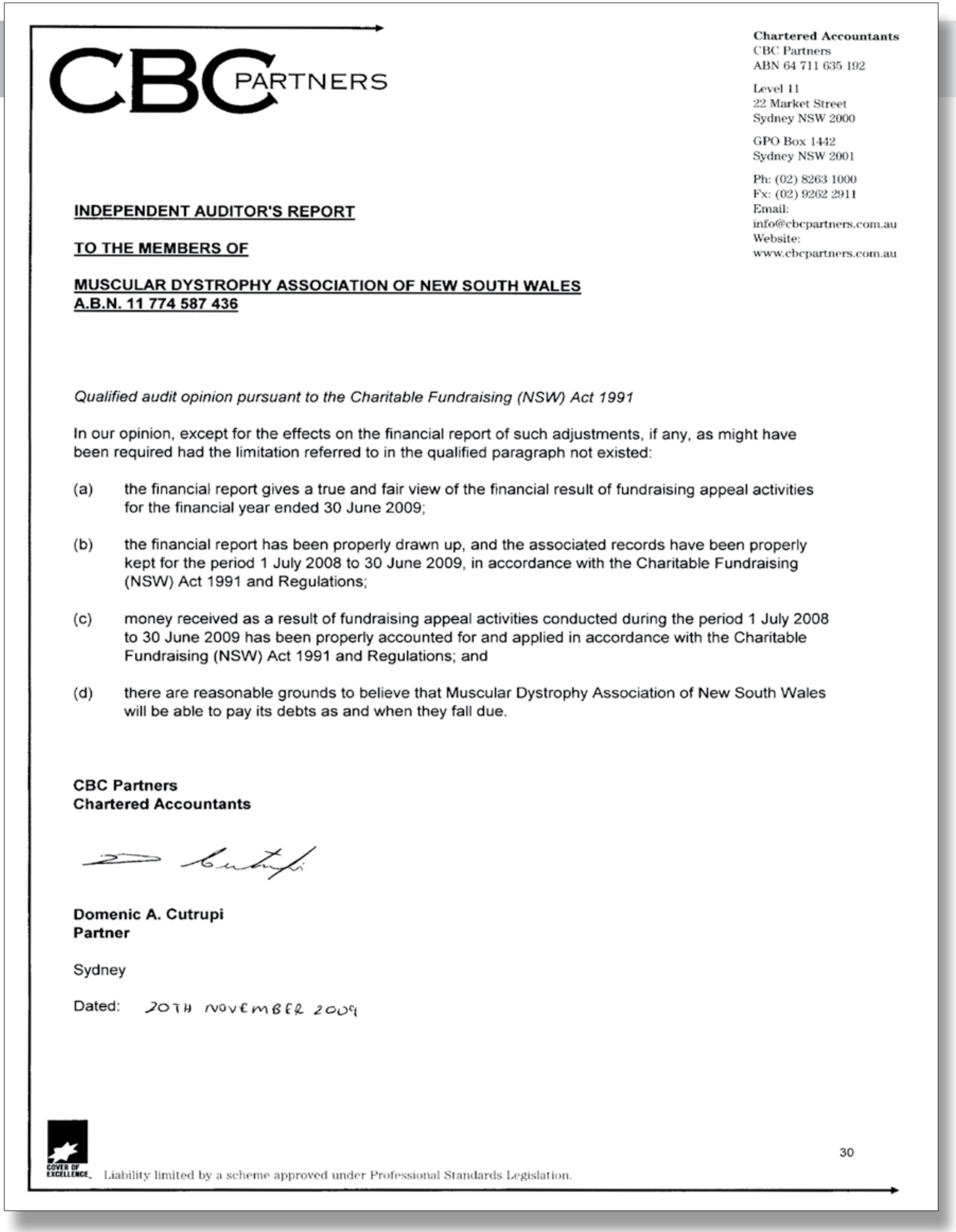
We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our audit opinion.

Audit qualification

Donations and fundraising income amounting to $436,106 are a significant source of revenue for the company. It is not always possible for the company to establish controls over the collection of all sources of fundraising and bequest income prior to entry into its financial records. Accordingly, as the evidence available to us regarding revenue from this source was limited, our audit procedures with respect to fundraising and bequest income had to be restricted to amounts recorded in the financial records. We are therefore unable to express an opinion whether the donation and fundraising income of the Muscular Dystrophy Association of New South Wales is complete.

Qualified audit opinion on the financial report

In our opinion, except for the effects on the financial report of such adjustments, if any, as might have been required had the limitation referred to in the qualified paragraph not existed, the financial report presents fairly, in all material respects, the financial position of Muscular Dystrophy Association of New South Wales as of 30 June 2009, and its financial performance and cash flows for the year then ended in accordance with the *Corporations Act 2001* and the Australian Accounting Standards (including Australian Accounting Interpretations).



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INDEPENDENT AUDITOR'S REPORT

TO THE MEMBERS OF

MUSCULAR DYSTROPHY ASSOCIATION OF NEW SOUTH WALES
A.B.N. 11 774 587 436

Qualified audit opinion pursuant to the Charitable Fundraising (NSW) Act 1991

In our opinion, except for the effects on the financial report of such adjustments, if any, as might have been required had the limitation referred to in the qualified paragraph not existed:

(a) the financial report gives a true and fair view of the financial result of fundraising appeal activities for the financial year ended 30 June 2009;

(b) the financial report has been properly drawn up, and the associated records have been properly kept for the period 1 July 2008 to 30 June 2009, in accordance with the Charitable Fundraising (NSW) Act 1991 and Regulations;

(c) money received as a result of fundraising appeal activities conducted during the period 1 July 2008 to 30 June 2009 has been properly accounted for and applied in accordance with the Charitable Fundraising (NSW) Act 1991 and Regulations; and

(d) there are reasonable grounds to believe that Muscular Dystrophy Association of New South Wales will be able to pay its debts as and when they fall due.

CBC Partners
Chartered Accountants

Domenic A. Cutrupi
Partner

Sydney

Dated: 20TH NOVEMBER 2009

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Thank you to our donors

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WE WOULD LIKE TO THANK ALL OUR DONORS BUT WISH TO ACKNOWLEDGE THE FOLLOWING GIFTS AND CONTRIBUTION FROM 1/7/08 TO 30/06/09

National Electric Wheelchair Sports 2009

The 2009 National Electric Wheelchair Sports was held from the 20th to 26th April. Once again, the games were held at the Sydney Academy of Sport at Narrabeen. The NSW Colts had an amazing tournament, winning the Roger Melnyk Trophy, the Hockey Championship and Rugby League Championship.

This year we had competing teams from Queensland, Victoria, South Australia, Western Australia and New South Wales. This year Australian Capital Territory was also represented, however, that team was made up of players from other states. This worked out well for NSW as their entire NEWS squad was able to compete at NEWS.

I had the pleasure of coaching the Colts again and the team was Stephen Webb (Captain), Chris Suffield (Vice Captain), Peter Dalrymple, John Shepherd and Dean and Jordan Crane. It was only the 2nd time in Colts history that brothers had played in the same team. Representing ACT, were Hamish Armitage, who was the Captain, and Alex Scollard who was making his debut at NEWS. Chris Suffield (as an athlete) and Rick Suffield (as an official) also received 10 year Service Awards.

Apart from coaching, I also have the dual role of National Director for NEWS, which involves the overall responsibility of running the tournament, while Martin Dalrymple is our National Umpires' Co-ordinator and deals with the on-field aspects of the games. The Association always supports NEWS. David Jack and Colin Gunn were responsible for putting together a NEWS section on the website and kindly put up all the scores throughout the week.

The format of the tournament involves three days of round robin competition, with a day dedicated to each sport. The top two teams qualify for the grand final, while the next two will play off for third. After a day off, we have the finals and play-offs. Teams receive two points for a win and one point for a draw. The team with the most points, after the three days of round robin competition, is awarded the Roger Melnyk Trophy.

The tournament began on Tuesday, 21st April, with the games being officially opened by Mr Alan Overton, OAM, AM, who is probably best known as a long serving Board Member and President of the Parramatta Leagues Club.

After the Soccer Round Robin, the Colts qualified for the final against Victoria. The next day the Colts would also qualify for the Hockey final and face Victoria again in the Hockey final. The third day of competition was Rugby League. During the year there was a major rule change whereby tackles had to be effected by wheelchair contact only. In the past those who were able to use their hands or feet to make contact with an opponent could do so. We had the biggest adjustment to make of all the teams, but we trained very hard and it seemed that we were rewarded. The Colts went through the Rugby League Round Robin undefeated. New South Wales has now won the most Roger Melnyk Trophies in NEWS history, with 8 in total.

Significantly the finals were held on ANZAC Day and proceedings began with a moving commemorative service.

We faced Victoria in the Soccer and led 1-0 early in the second half. With 2 minutes remaining in the match, Victoria made a break and scored to take the game to extra time. Unfortunately, for the second time in three years, we lost the Soccer final in a penalty shoot-out. New South Wales dominated Victoria in the Hockey final. At one time NSW led 7-4. Victoria got a couple of late consolation goals but the Colts held on to win 7-6. This was the second Hockey title for the Colts in NEWS history.

The Rugby League final did not start too well for New South Wales, as WA Captain, Adam Hart, scored the first try. The Colts re-grouped quickly and normal service resumed as we tied up the game. Once on top, NSW ran away with the game 28-6. This was only our fifth Rugby Title.

Colts players Chris Suffield and Stephen Webb were both selected in the All Australian Team for 2009. Stephen also received the Best and Fairest for NSW and was second in the overall voting. Hamish Armitage, from NSW, won Best and Fairest for ACT. The overall Best and Fairest was Andrew Brandreth from Victoria.

It was a great week, which was enjoyed by all involved. The games will be in Sydney again next year, when we will also be celebrating the 25th Anniversary of NEWS.

To be able to run a NEWS team, fundraising is a major part of the operation. Percy Baptiste and family run a Trivia Night and Golf Day each year and has some regular donors, while Margaret Dalrymple and family runs an Annual Charity Dinner Dance as well as assisting with other fundraising initiatives. Members of the squad also attend and support the events.

My parents, Percy and Eileen Baptiste and Martin Dalrymple work with me to put the games together when they are hosted in Sydney. I wish to thank them for their support as well as the Muscular Dystrophy Association and their staff for all their assistance and support for NEWS.

The NEWS training sessions have commenced this year with details available for anyone interested in getting involved through the Association.

Michael Baptiste

NATIONAL DIRECTOR AND NSW COACH

"My sincere thanks to the MDNSW team for all the kindness you have extended to our family over the last year – the support has been unwavering; it seems like you have been here all along"

Leonie Toohey

"When our precious little boy Noah was diagnosed with Duchenne, earlier this year it was the worst news of our life, we felt so alone. Since joining MDNSW we feel like we have been welcomed into your Muscular Dystrophy family. We truly appreciate all of your care and support – it makes a huge difference knowing you are there! Thank you."

Diane Rewa with son Noah

"Thanks to muscular NSW for supporting our family this year! We particularly enjoyed Hogs Day and Jerry Lewis. Also thanks to the Talking Point team - we look forward to every issue! It makes us feel connected with others that are in similar circumstances."

Lija Taylor

"This year has been the most active year we've had with MDNSW, and we've found it's been a really big benefit for Adam. He usually has limited exposure to other kids with MD, but MDNSW has really opened up a whole new world for him. He grew up so much that week at camp. He's more independent now he realizes he doesn't need me to be there all the time.

Jerry Lewis was fantastic, and both of the boys had a ball at Hogs Day. We've also had assistance with organising a ramp for our new house.

We don't have any family support, so it's such a relief to find people who are willing to provide that assistance for us. It's been quite a difficult year, and MDNSW has taken the pressure off which has been really good. It's just a benefit for the whole family."

Fiona Cook

md
muscular dystrophy
new south wales

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