

working together for a cure



MUSCULAR DYSTROPHY
ASSOCIATION OF WA (INC)

ANNUAL REPORT

2009

Vision & Purpose

Committee of Management

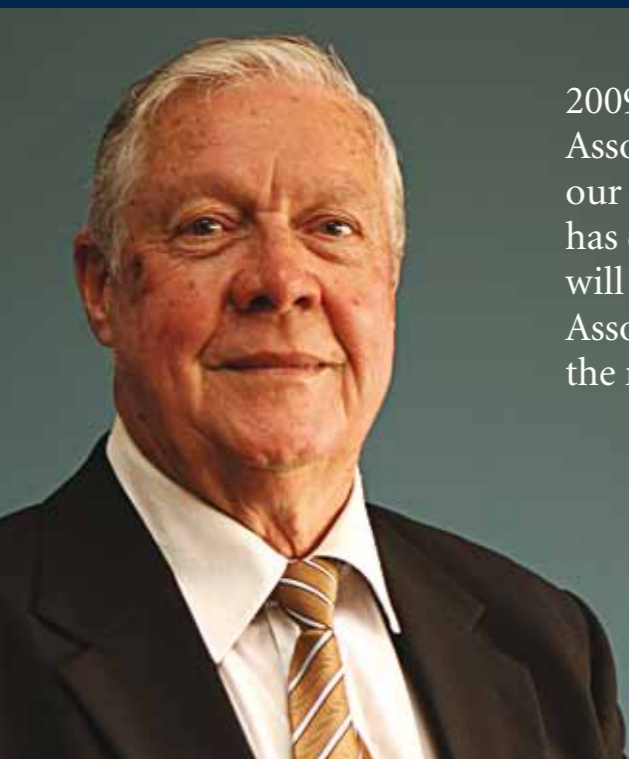


Patron	Mr Stan Perron, AM
Vice Patron	Prof Sasson Gubbay
President	Sqn Ldr B. Des McLean, MBE
Vice President	Mr Christopher Panizza
Co-Medical Director	Prof Byron Kakulas, AO Prof Frank Mastaglia
Treasurer	Mr Geoff Woods
Members of the Committee	Mr Patrick Emery Mrs Lesley Murphy Mr Dermot O'Keeffe Mrs Renae Rutherford Mr Robert Storey
Trustees	Mr Patrick Emery Sqn Ldr B. Des McLean, MBE Mr Geoff Woods
Honorary Solicitor	Mr Lionel King Hammond King Touys
Auditors	Owen & Plaistowe
Insurance Brokers	Grange Insurance Solutions

Our Vision The ultimate objective of the Muscular Dystrophy Association of Western Australia is to find a cure for muscular dystrophy and its related conditions and to make life better for those who have it.

Our Purpose The Muscular Dystrophy Association of Western Australia fundraises for research in neuromuscular diseases and to support the Western Australian neuromuscular community.

President's Report



2009 was a wonderful year for the Muscular Dystrophy Association of WA on a number of fronts. As a result of our Strategic Planning the Committee of Management has decided to appoint a Chief Executive Officer. We will welcome Mr John Gummer who brings to our Association a wealth of knowledge and experience in the not for profit fields of endeavour.

This year has seen the acknowledgement of the wonderful work of Professors Steve Wilton and Sue Fletcher with the publication of an article in the British medical journal, The Lancet. Human trials have been highly successful and their treatment will soon be available.

Community Support Director Lesley Murphy has now organised the largest collection of Cough Assist machines in the southern hemisphere, and already, results of the Cough Assist Campaign are showing up as people with muscular dystrophy are needing far less medical treatment to maintain good health. And on that note, how about the weekend at Point Walter with wheelchair abseiling for wheelchair bound boys, and a respite weekend for Mums at Woodman Point. Well done Lesley and Brianna.

People are very generous and I would like to acknowledge the contribution made by our sponsors and supporters. Brooke has worked

tirelessly on our many fundraising events, not the least of which was the Golf Day at the Vines. Thank you Toyota WA.

As mentioned earlier, the Muscular Dystrophy Association of WA undertook the process of a strategic plan throughout 2009. Working closely with the Committee of Management and Staff, we have recognised many areas of opportunity, growth and change. The Association believes we will strive and achieve our goals that were identified in our business plan.

We are overwhelmed by the enthusiasm of Lydia Tsvetnenko, who will be organising a major fundraiser, 'Party Like The Gods' in 2010. The Muscular Dystrophy Association of WA is the beneficiary of this exciting new event.

And where would we be without the support of Red Rooster, through collection boxes on their counters. Over the years, they have raised in

excess of \$700,000 for the Muscular Dystrophy Association of WA. And people like Josh and Rachael Davenport at Myattsfield Vineyard (who incidentally produce a fine drop of red) are great supporters of our cause.

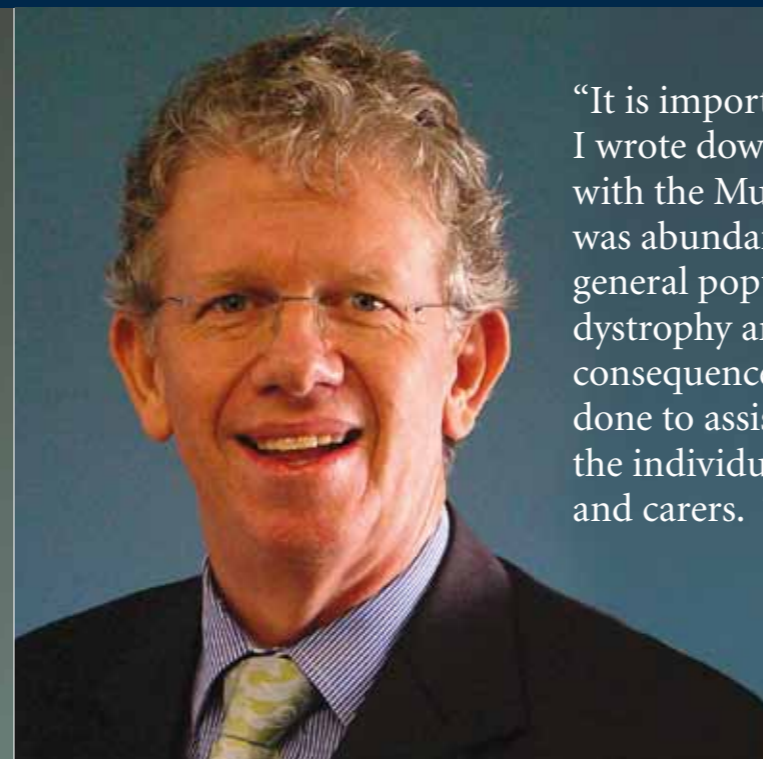
I know I have not mentioned all our supporters but you should all know how very grateful we are to have your encouragement and tangible support.

To our Committee members, John Gummer, and our staff - thank you all for your hard work and efforts throughout this very exciting time.

Kindest regards to all.

Des McLean MBE
President

CEO's Report



"It is important that we disturb your complacency." I wrote down these words at the end of my first day with the Muscular Dystrophy Association of WA. It was abundantly clear after such a brief period that the general population do not know enough about muscular dystrophy and they do not know about the devastating consequences of the disease. Moreover, not enough is done to assist those impacted by muscular dystrophy, be it the individual with muscular dystrophy or their families and carers. This situation cannot be allowed to continue.

The Committee of Management of the Muscular Dystrophy Association of WA appointed me to the role of Chief Executive in February 2010. My appointment followed a thorough review of the goals of the Association and the development of a five-year strategic plan in late 2009. The plan clearly addresses the Vision of the Muscular Dystrophy Association of WA - that is, to find a cure for muscular dystrophy and its related conditions and to make life better for those who have it.

The critical success factors identified in the strategic plan address issues related to increasing the capacity of the Muscular Dystrophy Association of WA to appropriately respond to the needs of patients, families and research partners, increasing and diversifying revenue

streams, increasing the profile of the Muscular Dystrophy Association of WA and maintaining the correct balance of support for research and patient / family services.

The achievement of these goals will ensure that the Muscular Dystrophy Association of WA is able to improve the quality of life for Western Australians with muscular dystrophy.

The generosity of the supporters of the Muscular Dystrophy Association of WA mirrors the generosity of the Committee of Management, the Staff and the Volunteers who devote themselves to supporting and achieving the goals of the Association. It is a real pleasure to work with such dedicated men and women. Individually and collectively, each of these wonderful

people is focused on making a real and sustainable difference to the lives of those with muscular dystrophy.

The goals of the Muscular Dystrophy Association of WA are undoubtedly lofty. They can be achieved with the assistance and support of Government, the corporate sector and the broader Western Australian community.

The Muscular Dystrophy Association of WA will continue to disturb the complacency.

John Gummer
Chief Executive Officer

Treasurer's Report



This is my seventh report on the Association's Annual Financial Report, which includes the Financial Statements and Independent Audit Report for the year ended 31 December 2009.

The Income and Expenditure Account shows a healthy Operating Surplus for the year of \$456,235. Last year, there was a surplus of \$84,791. This year \$110,198 was distributed to the Neuromuscular Foundation (NMF) compared to \$90,711 last year. The Fundraising income increased this year mainly due to some generous bequests totalling \$419,467 (last year we received \$33,426). A special thank you must go to the Estate of Valmai James. We received another generous Telethon Grant of \$91,818 (\$75,000 last year) that was spent directly on increasing our stock of Cough Assist Machines as part of our ongoing plan of increasing our Client and Patient Services. We also received a grant from Lotterywest for \$32,919 which was used to upgrade the Association's computers. Our General donations were down again this year from \$105,647 last year to \$90,549 this year. Unfortunately, our mail appeal donations were also down from \$135,466 last year to \$83,125 this year. This downturn in donations gives

special importance to the generous bequests we received during the year.

With the Global Financial Crisis during 2008 and the uncertainty in investment markets surrounding the crisis, the Board held off from investing in growth style equities until mid 2009. The timing of these investments turned out to be very good as the markets have improved significantly since then, providing good returns to the equities. Thanks must go to Board member Rob Storey for his wise counsel to the Board during this period. Our interest income decreased during 2009 as a result of these investments, but they were more than offset by dividends, trust distributions and unrealised capital growth. It is still anticipated that the prudent investment of these funds will ensure sufficient income growth to assist the funding of patient services.

Once again, we received generous support from many donors throughout the year. We were especially pleased with another successful Golf Day which raised \$21,000 this year (\$19,200 last year) and another steady inflow from the Red Rooster collection boxes totalling \$31,051 this year, which was up from \$27,781 last year.

Finally, the Net Assets of the Association increased from \$990,898 in 2008 to \$1,447,133 in 2009, which was a direct result of our generous bequests already mentioned above.

Once again, I would like to thank the Association's staff & volunteers for their dedicated work during 2009 and would like to wish our new CEO John Gummer and his very able team all the best for a successful 2010.

G R Woods B.Bus. CPA FTIA
Treasurer

Medical Director's Report



On behalf of my Co-Director Professor Byron Kakulas and myself, I am pleased to report that 2009 has been another good year for the Muscular Dystrophy Association of WA and the Australian Neuromuscular Research Institute (ANRI).

On the research side, an important milestone has been the commencement of the systemic trial of antisense oligonucleotide (AO) treatment for Duchenne dystrophy, developed at the ANRI by Professor Steve Wilton and Professor Sue Fletcher and their Molecular Genetic Therapies Research Group, and the preliminary reports are encouraging. Planning for Australian AO trials is also underway. The work on a new genetic treatment for spinal muscular atrophy is also progressing well. Our other research groups at the ANRI have also made good progress during 2009, including Professor John Howell's Gene Therapy Group which has been working on a new treatment for McArdle's disease of muscle using sodium valproate, and this is now also about to enter clinical trials. These are two excellent examples of translational ("bench-to-bedside") research supported by the Muscular Dystrophy Association of WA which are now about to enter the clinical arena. The Stroke Research Group headed by Professor Neville Knuckey and Associate Professor Bruno Meloni is working on new treatments for stroke; Dr Sherif Boulos and the Molecular Neurobiology Research Group are continuing their work on new approaches to the treatment of spinal muscular atrophy and neurodegenerative diseases; and Professor Gary Thickbroom and the Brain Research group are developing new brain stimulation protocols to promote brain plasticity. Although the funding for our research groups comes from a number of different sources, the contribution from the Muscular Dystrophy Association of WA is still a very important one and is greatly appreciated by all of our researchers.

specialised clinics not only for patients with Neuromuscular Disorders but also for patients with Parkinson's disease and other movement disorders, multiple sclerosis and epilepsy, as well as an Inflammatory Myopathies Clinic which is the only one of its kind in Australia. The Institute Clinics provide a botulinum toxin injection service and the Clinic is also the State Assessment Centre for deep brain stimulation surgery for patients with Parkinson's disease and other movement disorders.

I would like to acknowledge the continuing support of our Patron Mr Stan Perron, and the generosity of Mrs Enid Home, who recently passed away, and Mr O'Neill and Mr O'Reilly which have made it possible to establish new PhD scholarships in the Institute.

It has again been a pleasure working with our President Des McLean and the other members of the Muscular Dystrophy Association of WA team Brooke Anthony, Brianna O'Donnell, Bruce Baldock and Debra Harwood. I would like to thank each of them, as well as the members of the Committee of Management who so generously make their time and expertise available to the Association. I would also like to express our gratitude to all of our Muscular Dystrophy Association of WA members and volunteers who have so generously provided their time throughout the year and to Ms Jude Newberry and Mrs Cathy Donovan for their ongoing support and help throughout the year. As in previous years, I would also like to thank all of our other donors for their continued generosity and support.

Professor Frank L. Mastaglia
Medical Director

The clinical activities of the Institute have continued to expand and we now have



Fundraising & Events Manager Report



I am pleased to present the 2009 Annual Report for the Muscular Dystrophy Association of Western Australia.

This year has proved to be a successful year in fundraising ventures, sponsorship opportunities and the continued support of the Western Australian community. Thank you to our dedicated fundraising and community service support teams and the guidance and assistance of the Association's Board and the Australian Neuromuscular Research Institute. I look forward to 2010 as another successful year in fundraising, community service support and excellence in research.

Brooke Anthony
Fundraising & Events Manager

TOYOTA MUSCULAR DYSTROPHY GOLF CLASSIC 2009

The Toyota Muscular Dystrophy Golf Classic 2009 was the 4th corporate golf event for our Association. The event was held once again at the exquisite Vines Resort & Country Club on Friday 20th March 2009. MDAWA Patron Mr Stan Perron generously organised Toyota WA as our major sponsor for the event. Our Golf Classic raised \$22,000; a fantastic result! This year's tournament was a 4 ball Ambrose with a shot gun start at 12.30pm after a light lunch at the poolside bar. Along the course, teams enjoyed a number of novelty holes which included Myattsfield Vineyard wine tastings, corporate massage provided by Body Live Massage and a hole in one challenge. Our thanks must go to Mr Stan Perron for his support of our event and also to Toyota WA Staff; Managing Director Mr Mark Lauren, Mrs Sue Fidock and Mr Mark Doick. Without their valuable support, the day would not have been as successful. The Muscular Dystrophy Association of WA thanks and acknowledges the great support of Myattsfield Vineyard, who were our wine sponsor for the evening and who provided a range of their exceptional wines.

STREET APPEAL 2009

The 2009 Muscular Dystrophy Association of Western Australia's annual Street Appeal was held on Friday 27th March and raised over \$5,000. Our volunteers did us proud, working tirelessly to collect donations. A big thank you also goes to our dedicated supporters and volunteers and the students and teachers at Trinity College and Guildford Grammar for so successfully collecting on the day.

CHRISTMAS CHARITY AUCTION 2009

The Muscular Dystrophy Association of WA held its 37th Annual Charity Auction on December 3rd 2009. The auction was kindly run by our friends at A.J. Langford Fish Markets Pty Ltd. With the assistance of our kind donors and punters, we were able to raise \$11,000.00, a very successful and pleasing result, indeed. Many thanks to all the donors of goods, bidders, loyal customers of A.J. Langford & Son, Auctioneer Rick and to Michael and Theo Kailis and their staff for their continued support and making the 2009 auction the success it was. Without them, this event would not be possible.

Successful Funding Applications

CHANNEL 7 TELETHON TRUST

Following the submission to the Channel 7 Telethon Trust in support of nine (9) J.H. Emerson & Co Cough Assist Machines for the use of the Western Australian muscular dystrophy community, the Muscular Dystrophy Association of WA welcomed a \$91,808 contribution from the Trust. Those who have a neuromuscular disease are unable to cough and are prone to complications such as pneumonia and bronchitis. The regular use of the Cough Assist will greatly improve the health and well being of those with a neuromuscular disease. The Muscular Dystrophy Association of WA is grateful for the ongoing commitment of the Channel 7 Telethon Trust since the Association's establishment in 1967.

LOTTERYWEST

The Muscular Dystrophy Association of WA was successful in obtaining a grant of \$12,950

from Lotterywest in 2009. This funding has allowed the Muscular Dystrophy Association of WA to cover professional fees towards an organisational strategic plan. This strategic plan process allowed the Committee of Management and staff to work collaboratively in developing a five year plan for the Association.

The Association also received vital funds for website redevelopment to the total of \$2,818.00

In support of our Community Program, Lotterywest also granted \$8,254.00 to cover the costs of a range of activities for young people living in WA with a neuromuscular disease.

RED ROOSTER

The continued support of Red Rooster with our collection boxes is deeply appreciated. Thanks to management and staff, customers of Red Rooster and our volunteers, a total of \$31,051 was raised in 2009.

Bequests

The bequest gifts for 2009 totalled \$419,467.

General Donations

General donations totalled \$90,549.

Mr Stan Perron has been the Patron of the Muscular Dystrophy Association of WA for more than 20 years. We thank him for his Patronage, helpful advice and tangible support.

The Muscular Dystrophy Association of WA is especially grateful to Mrs Enid Home, OAM, Freeman of the City of Albany, for the establishment of the Enid and Arthur Home Scholarship. Mrs Home sadly passed away in March 2010. To the family of Mrs Home we would like to acknowledge her support over the many years and dedication to furthering research through the provision of the Scholarship.

MAIL APPEALS

In 2009, the Muscular Dystrophy Association of WA successfully raised \$83,125 from our mail appeals.

Community Support Program



The Association's Supporters



ROTARY CLUB OF WEST PERTH (INC)



2009 was another successful year for the community support programme.

The community outreach program has continued to grow with increasing numbers of self referrals, contacts from Local Area Coordinators and a range of health care professionals. We are also receiving more and more calls from the wider community asking for advice about equipment, respite, funding and so on.

We held a range of events over the year including two camps, one at Landsdale Farm School for younger children and a brilliant weekend at Point Walter for the older members and their families. The highlight of this weekend was the wheelchair abseiling, see the photos above. On the Saturday night, the campers had a gaming night with a professional croupier which was enjoyed by all. Special thanks to Rob Storey for attending the weekend. The feedback from this weekend was so good that we have already booked the

venue for 2010. Another very successful event was the family picnic with Muscular Dystrophy families and Spinal Muscular Atrophy families. Once again, we are indebted to the wonderful hospitality of Josh and Rachel Davenport of Myatt'sfield Vineyards in the Carmel Valley. The mothers respite weekend was a great success with 15 mothers enjoying Laughter Yoga, fellowship, food and some much needed time out at the Woodman Point Holiday Village. I extend my thanks to Lotterywest and Carers WA for their financial support of the camps and respite weekends.

Our Cough Assist Program now boasts 44 machines spread out from Derby to Albany. We believe that we now own more machines than any other organisation in Australia and we are very proud of the fact that we are helping to improve the quality of life for so many Western Australians. We continue to receive encouraging feedback from families and clients about the positive impact these machines are having. All report reduced incidence of the severity of winter colds and reductions in doctor and hospital visits.

We have also begun an adult support group. This group meets around 6 times year, with a range of guest speakers keeping the group informed of up to date details regarding equipment, funding, pension entitlements and other issues of interest to members.

The Facebook site continues to grow, with around 300 'friends' and allows us to spread news and information about our activities and hopefully encourage even more people to become involved in our organisation.

2009 was a very busy and fulfilling year. We are continuing to refine our community support program with a view to holding two camps a year, at least one mothers respite weekend, a fathers weekend and at least 2-3 informal picnic type 'get togethers' on an annual basis. The support of our superb office staff who have all worked together to make these initiatives work is warmly acknowledged.

Lesley Murphy
Community Support Director

The Muscular Dystrophy Association of WA acknowledges and thanks the following companies for their support: BGC, Big Rock Toyota, Entertainment Publications, Finsense Financial Planning Services P/L, IP Services (Australasia), iQuest, Kalamunda Toyota, Mail Makers, Midland Toyota, New Town Toyota, Prosser Toyota, The West Australian, Toyota Financial Services, Webarena.

Thank You!



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