

You tie. We win.

Muscular Dystrophy Association

MUSCULAR DYSTROPHY ASSOCIATION OF QUEENSLAND

ANNUAL REPORT 2005-06

My Wish

Every year I make the same wish,
To kick a ball, or toss a line and catch a fish.
To jump in the air, or tackle my mate.
To cut up my food and use a knife, fork and plate.
I'd really like to ride a bike to school,
Or get out of a car without looking the fool,
And how good it will be, just once in a while,
To do simple things without forcing a smile.
Like scratch my nose,
Or tickle my toes

What is Muscular Dystrophy?

The term Muscular Dystrophy simply means muscle wasting. The Muscular Dystrophies are a group of muscle diseases that have three features in common:

- They are hereditary
- They are progressive
- Each produces a characteristic selective pattern of weakness of muscle groups.

How does it affect a person?

It takes away body strength and as the disease progresses the simplest tasks become more difficult:

- Eating
- Dressing
- Going to school
- Turning over in bed
- Scratching an itch
- Breathing

Muscular Dystrophy in Queensland

There are over 4100 people in Queensland with muscular dystrophy and other neuromuscular disorders. Roughly 70% live in South East Queensland with the remainder scattered throughout the State, mostly in regional and remote areas.

Over 1000 families are affected by the disease and about 150 of them require a high level of support with some in varying degrees of crises.

Support and intervention is needed, not only to provide the best quality of life possible for those with the disease, but to maintain the emotional, mental, physical and financial health of the whole family unit.

Muscular Dystrophy Association of Queensland

In 1978 a group of families concerned about the lack of assistance for their children formed the Muscular Dystrophy Support Group. Without clinical or public recognition of the disorders the group began the challenging process of community education and fundraising while continuing to provide support to each other.

The Muscular Dystrophy Association of Queensland Inc. (MDAQ) today is building on the hard work of these early volunteers. The Association is incorporated and is recognised as a credible and accountable provider of services to clients with muscular dystrophy and their families.

MDAQ works closer than ever with other service providers, Queensland Health, Disability Services Queensland and other government agencies to ensure that people with muscular dystrophy and their carers are aware of, and have access to, preventative health education, services, and community support.

Mission

To assist people of Queensland affected by muscular dystrophy to meet their needs and enhance their quality of life by:

- providing products and services, and
- supporting research into the cause, treatment and cure of muscular dystrophy and other neuromuscular disorders.

Objectives

MDAQ has eight objectives:

- (1) Provide family and health support services to members, their carers and families, for example:
 - home/personal care counselling
 - community access services
 - emergency respite and support services
 - equipment and aids
 - allied health and domiciliary care
 - emergency support
 - home maintenance
 - advocacy
 - intensive health care services
 - response to grievances
 - advice and referral
 - specific information
- Support research into the cause, treatment and cure of muscular dystrophy and other neuromuscular disorders.
- Safeguard the rights of people with muscular dystrophy and other neuromuscular disorders.
- Increase public awareness and community education of muscular dystrophy and other neuromuscular disorders.
- Co-operate with or be affiliated with other kindred organisations.
- Provide equipment to assist members, their carers and families caring for the disabled.
- Provide advice and assistance on accommodation.
- Assist people and families affected by muscular dystrophy and other neuromuscular disorders to determine the direction of their lives.

Patron:	Her Excellency, The Governor of Queensland Ms Quentin Bryce AC.
Vice Patrons:	Andrew Bell Greg Bell
Honorary Life President:	Denis Thane
Board of Management	
President	Murray McNeil
Vice President	Graham Dyer
Honorary Secretary	Graham Newton
Honorary Treasurer	Peter Kearney
Honorary Medical Director	Prof Rick Jackson FRACP, MBBS, Bsc(Hons)
Honorary Solicitor	Ian Neil LLB
Board Members	Graeme Newton Janet Kiosses Graham Dyer Jayson Anderson Brian O'Sullivan
Darling Downs Support Group	
Chair	Jayson Anderson
Treasurer	Sid Cotter
Secretary	Patrice Latcham
Gold Coast Support Group	
Chair	Graham Dyer
Treasurer	Margit Warburton
Secretary	Neil Warburton
Executive Staff	
Executive Director	Peter Denham
Director of Operations	Sue Gilbert
Support Services Manager	Michael Quinn
Auditors	Rawsons
Bankers	National Australia Bank
Solicitors	McCarthy Durie Ryan Neil
Life Members	Pat Mills Peter Harry Mr & Mrs Hooker Gordon Voltz
Presidents Awards	Michael Christian Bryan Grehan Roger Williamson



The Muscular Dystrophy Association of Queensland Inc is a member based organisation providing information and services to the community. Membership is not exclusive to those who are living with the disease but encompass a variety of individuals and special interest groups that show commitment to, and are supportive of, the role the Association plays within the community.

As members of our organisation, when each year comes to an end we should reflect on the significant events that have shaped our organisation. These events provide both positive outcomes as well as challenges that need to be faced and conquered for our future sustainability and growth.

One of the many challenges our organisation faced this year is the increase in demand for services, particularly regarding access to information and specialist advice and care. We have strived to address the growing incidence of carer fatigue by providing increased support and respite to carers particularly in the Brisbane region.

Our organisation has been able to increase the equipment we have provided throughout the state. The two Cough Assist Machines that were recently purchased have already greatly enhanced the quality of life of a number of people with respiratory complications.

By far though, our greatest achievement for the year has been our ability to meet and face the challenges associated with the growth of the organisation. Our Association has proven that we have the ability to create and implement change in line with community and government expectation and demands.

Our Association would not have been able to achieve these goals without the continuing and ongoing relationship with the Queensland Government. The Department of Disability Services Queensland recognises the unique and complex issues surrounding families living with muscular dystrophy and other neuromuscular disorders and as such continues to support the organisations program of providing flexible solutions.

As a result of a continually converging relationship with The Department of Disability Services Queensland (DSQ) we welcome the new Disability Services Act recently released and currently being implemented throughout the state. It is a watershed document that recognises and promotes the rights of people with a disability and improves safety and quality of service within the disability sector.

The Association successfully continues to meet its internal deadlines to achieve quality certification (by 2008) in line with Disability Services Queensland Standards which will engender a culture of quality and quality improvement across the not-for-profit sector in Queensland. The system will support and enhance the Association's aim to deliver services that are responsive to the needs of people with muscular dystrophy and other neuromuscular disorders, their families and carers.

Once again, we are fortunate to have the support from various individuals and organisations throughout the state.

- Our Patron, Her Excellency, the Governor of Queensland, Ms Quentin Bryce, AC attended a number of social events during the year, mingling with our members, children and families
- Greg and Andrew Bell from Ray White Surfers Paradise yet again raised well over \$150,000 from their prestigious gala ball and auction held on the Gold Coast
- The dedication and ongoing support from the Harley Owners Group of Brisbane
- Red Rooster for supporting the donation boxes placed in various stores throughout Queensland

I look towards this oncoming year with excitement as I see the organisation cementing itself within the community. A new premises, expanding services and increased fundraising activities are all key indicators to a prosperous year ahead.

To our members and families I look forward to a year where we will improve, increase and develop new programs and projects that will add to our current services. I see a year where our Gold Coast and Darling Downs Support Groups will continue to extend their support to regional families and grow their profile within their respective communities.

“ our greatest achievement for the year has been our ability to meet and face the challenges associated with the growth of the organisation

My thanks to the commitment of our organisation's board of management for their support and guidance throughout the year, and our staff and volunteers who are creating the organisation's future.

Finally our condolences to those families who have lost a loved one in the past year, our best wishes go with you always, wherever your future takes you.

Murray McNeil
EXECUTIVE DIRECTOR

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This year in passing has seen the Association focus on its internal operations and structure as a platform for future development. We have concentrated our energies on continuing to get our basic structure and operations right with particular emphasis on ensuring that our internal systems are moving towards that of an exceptional standard. A foundation built on solid systems and procedures will ensure that positive growth is achievable and manageable. This process has been exhaustive, intensive and often frustrating when juggling the every day business that is required for the organisation to continue to function on a daily basis.

We started this year somewhat fatigued. Early on we struggled with staff shortages and concentrated our efforts on just getting through the daily operations. At times some staff were doing two or three roles other than their own. Some days we scratched our heads trying to find another five hours in a day just to get the basics done! The tide quickly turned, however, and our organisation now has many new faces. People that have bought a variety of expertise, experience, knowledge and ideas. All of whom show determination, creativity and enthusiasm to make change work, and to work with change. We quickly developed a renewed energy and enthusiasm that has come from a year that started with turmoil and change. A new home, a changing service structure and fresh faces, have rejuvenated our organisation and injected us with a stronger commitment for the future.

“When you work towards a dream, success comes more easily.”

This renewed energy is reflected in the projects and programs the Association has developed in the last year. It is with this same enthusiasm that we look towards the oncoming year with new priorities added to our ever expanding list.

Our partnership with the Queensland Government continues to develop new opportunities for both the Association and people with muscular dystrophy. Both Disability Services Queensland and Queensland Health provide us with funds to support people within their homes that are struggling with the daily strain of living with their disease and to link with their community.

Our goals for the oncoming year are also focused around these issues.

Our priorities are to further increase our services to regional and remote areas. Currently our services are predominantly accessed in the South East quarter of the state. We are hoping to develop a regional service that will enable us to provide a greater service to people outside of our current localised area and take services directly to the users.

It is essential for us to increase support to long term carers. Recent advances in treatment for people with muscular dystrophy has meant that people, particularly with duchenne are living longer. This creates a dichotomy where carers are now required to work longer in a physically and mentally demanding role and their own health and wellbeing dramatically deteriorates. Added flexible respite options need to be available to ailing carers to support them and address their health issues.

These goals are certainly achievable and will come with the development of closer working relationships with not only Government, but just as importantly, other key organisations within the community. We are keen to forge closer working relationships with organisations such as Parent Project, Northcott Society, Multiple Sclerosis Society, Montrose Access, Spinal Injuries Association of Queensland and many of the other not for profit organisations that are working to support people within the community with muscular dystrophy.

I would like to thank our Patron Her Excellency the Governor of Queensland, the Board of Directors, medical researchers and staff for their dedication and commitment throughout this busy year.

Peter Denham
Executive Director

It is not unusual to look back at the end of another year, and feel that not much was accomplished. And in terms of just fundraising, that is, cold, hard dollars and cents, that may be so. But given that support groups comprise solely of volunteer families, all of whom are struggling with this disease in one form or another, most silently, just surviving another year is progress. And supporting each other is ultimately our goal.

People not afflicted by muscular dystrophy or any other disease have difficulty enough just coping with life. Many fail. We have the added burden of caring for a family member(s) as well as for ourselves. Each day brings a new challenge. And no-one lets us know in advance what tomorrow's new challenge will be. Yet most of us succeed in overcoming whatever new difficulty today brings and extracting maximum quality out of the limited time we have. An outsider may come along and say: "I don't know how you do it. I couldn't do it." Of course, we just "do it." We don't dwell on it; we just "do it." There are no prizes or medals, but there is great satisfaction in deriving the most we possibly can out of life, for ourselves and for our family members. We are far less likely to waste opportunities than are those who do not face the obstacles we face.



Max Davy

We lost our own son (age 22) to Duchenne in April of this year. And there was a litany of surprises toward the end, which we could not have foreseen, as each boy is different. One complication in Max's case was the loss of muscle in the jaw and throat, which affected his eating. As far as we know, that is fairly uncommon. By comparison, Max's heart function remained comparatively strong. Respiratory complications were the greatest concern.

Another was the thin line we discovered that exists in the medical profession between palliative care and euthanasia. Such is the fear of breaching any law, on the part of those in the profession, that we were confronted with situations where we wondered if Max was going to get the treatment he needed. This was quite alarming, and I urge all parents who have yet to meet this challenge to do all the homework possible on what can and cannot be done for their family member, so they are well prepared.

I must make special mention of the Cough Assist machine lent to us by MDAQ. What a godsend! That machine can be a lifesaver. And we had no difficulty whatsoever with its operation.

Max suffered so much in the latter stages of his disease that in a perverse sort of way it made our loss easier to cope with. Six months later there are still moments of overwhelming grief, but they are getting further apart and greatly reduced in intensity. Yes, we would love to have Max back. But not in that body. We are just grateful that he is at peace and not suffering any more.

Max was a star. We are content in the knowledge that in 22 years he left a bigger mark on this planet than most of us will leave in 70 or 80 years.

I hope that our experience might, in some way, be of value to others. Don't ever hesitate to ask other families how they deal with certain situations. They may be too busy to volunteer suggestions, or may not like to intrude. But chances are they will prove to be a source of strength if you ask.

And don't forget the support staff at MDAQ. There is every likelihood they have seen it before.

Graham Dyer
President
Gold Coast Support Group

Over the last twelve months the Darling Downs Support Group has encouraged more involvement from our families by initiating a biannual newsletter. Personal visits would be optimum, but as all Committee members work full time, we don't have the resources to make this possible. It has also been a priority to ensure all families are aware of the financial support we can provide to assist families with the purchase of equipment.

This year we have noticed an increase in contact and referrals from schools in our region. From this we have identified the need to enhance our profile within the community and further provide information and advice to educators and schools alike. This service needs to also be balanced with the acknowledgement that not all people with muscular dystrophy are of school age. In order to increase support to the number of people in the Darling Downs region with muscular dystrophy we need to develop a communication strategy that will expose our services to all people living with over 60 disease types!



Christmas Party

The 2005 Christmas party included cars, clowns, coffee and of course presents. The day started with some friendly rivalry (& some pretty impressive driving) of the slot car kind. Danny from Thunder Alley not only opened especially for us but also had the cars

and track in top condition for some top class racing action. Janelle & Melissa of Xpresso Mobile Coffee Bar not only squeezed us into their already booked schedule, but they generously plied us full of coffee at no cost! While adults ate & drank, the kids were entertained by Clowns on the Run, who not only painted faces (and arms and legs and hands and feet.....), but they made all sorts of balloon creations. It was a fantastic day with the focus purely on giving the kids a day that was all about them!

Restoration in Warwick

The Darling Downs Support Group assisted a family in Warwick with some modifications to their home in 2006. The Grafton St renovation created a lot of interest and the open day was supported by nearly 400 people, who in turn have generously supported muscular dystrophy. Since the publicized opening we have been contacted by three Warwick based families. Sid Cotter, Darling Downs Support Group treasurer and myself managed to visit Warwick and provide a Neo Computer to an inspiring young man as well as visit two other families. The Warwick muscular dystrophy community is very eager to have more involvement with the Darling Downs Support Group, and we are trying to make sure this enthusiasm is nurtured.

Bow Tie Day

For Bow Tie Day this year, we screen printed shirts to use as a uniform. Not only did these look extremely professional and provided another means of advertising, but have also been used as thank you gifts for people who have donated their time for our cause. The Muscular Dystrophy Bow Tie Day banner was strung across Toowoomba's main street and no doubt drew a lot of attention! However, the effort of incorporating these two advertising forms, as well as a newspaper advertisement, was not reflected by the income raised. We strongly feel that to raise notable awareness and funds, some form of television advertising must be arranged. People only support causes they are aware of, and this will hopefully be something that can be looked into next year.

AGM

The highlight of the AGM this year was the increased number of members on the Committee. We managed to introduce two General Committee Members and even though these positions were filled by partners of those already on the Committee, we feel we have taken the first baby steps to getting more people involved. We had a relative turnout, and were extremely grateful for Murray McNeil and Peter Denham's attendance, as well as Renee Cornford-Nairn from Associate Professor Andrew Hoey's research team. Our aim for the 2007 AGM is to introduce new office bearers that will bring new contacts and referrals to our group.

The support group is presenting a cheque to University of Southern Queensland researcher Associate Professor Andrew Hoey at the Race Day in November. This way people attending will see first hand where and how their generous donation is used.

In all it has been a fairly quite year, but we have completed a lot of ground work and achieved some goals that will provide us with a good foundation for the years to come.

Jay Anderson
President
Darling Downs Support Group

The Muscular Dystrophy Association of Queensland Inc has a strong commitment to supporting locally based research into the treatment and cure for muscular dystrophy and other neuromuscular disorders.

We are proud to support the valuable research currently being undertaken by the University of Southern Queensland and Griffith University.

Both research units have reached significant milestones in their work that will see continued change in the way we treat muscular dystrophy and other neuromuscular disorders.

The University of Southern Queensland

The last few years has seen a significant positive change in the level of optimism for Muscular Dystrophy research. Steroids have now been clearly shown to improve respiratory function, cardiac function and ambulation for patients with Duchenne Muscular Dystrophy and as a consequence, patients are living longer than before. Furthermore, promising research has been progressing in on several fronts.

Exon skipping strategies to restore production of dystrophin have advanced to a stage where clinical trials commenced this year. This is a major milestone, although there is still a long way to go to ensure that this treatment is safe and effective. Another approach that involved clinical trials in 2006 was read-through strategies for patients with premature stop codons using drugs such as PTC124. Premature stop codons cause about 15% of cases of DMD and again, if PTC124 or similar drugs are shown to be safe, patients with such mutations could be treated with PTC124 or other similar drugs in the future.

There continues to be ongoing research on several other fronts in addition to those mentioned above. Some of this research is focussing on understanding and regulating the inflammatory chemicals in the body that contribute to muscle loss, reducing the development of scar tissue within muscles and improving cardiac function. Our laboratory has been particularly active in these areas and we are looking at a range of drugs and potential treatments that may improve muscle strength and cardiac function.

Our laboratory is appreciative of the support provided to it by the Muscular Dystrophy Association of Queensland and its members.

***Assoc Professor Andrew Hoey
Centre for Systems Biology
Faculty of Sciences
University of Southern Queensland***

There are a number of different promising approaches to treatment of muscular dystrophy that are currently being pursued by various research groups in Australia and the world research community. Some of these are:

- Alteration of myostatin expression/action

Myostatin is a natural protein produced by muscle cells after muscular stimulation and contraction has occurred. It appears that this is a method of ensuring that the muscles do not overdevelop as a result of exercise, since the role of myostatin is to inhibit the hypertrophy of muscle. In patients with muscular dystrophy, myostatin inhibition might lead to a decrease in muscle wasting. This is an approach that is close to trialed in humans by other groups.

- PPAR-delta agonist activity

During the course of research into the peroxisome proliferator activated receptor (PPAR) system, a research group in California led by the renowned nuclear receptor scientist, Dr Ron Evans, decided to work on the nuclear receptor, PPAR-delta. The PPARs are receptor molecules in the cell's nucleus which are known to be critical in maintaining normal metabolism of glucose and lipids(fats) in the body.

There are drugs that decrease lipid levels(PPAR-alpha stimulators), such as "Lopid", that have been on the market for decades. More recently, drugs that stimulate PPAR-gamma,such as "Avandia", have been marketed which decrease blood glucose, and, hence, are used in the treatment of diabetes. A new drug that stimulates the PPAR-delta has been developed by a major pharmaceutical company. This drug was developed as a potential treatment for diabetes. However, it was noticed by Dr Evans group that when a so-called PPAR-delta transgenic mouse, which makes more of the PPAR-delta protein than normal, was created, this mouse had an unusual side-effect -- it developed muscles that had an extraordinary amount of stamina.

This has led to the idea that this PPAR-delta agonist drug of the pharmaceutical company might be useful not only for the treatment of diabetes, but also for maintenance of healthy muscle in states where there is muscle deterioration, such as muscular dystrophy. My group is currently working with a drug that is similar to the PPAR-delta stimulator, called a PPAR-pan stimulator. We may be able to get access to the PPAR-delta stimulator in the near future, as it is made by the same company that makes the PPAR-pan stimulator. If these negotiations are successful, we would like to start human trials of this PPAR-delta stimulator in the near future in patients with muscular dystrophy.

***Prof Richard V Jackson, MBBS, BSc(Hons), FRACP
Director, Neuroendocrine Research Unit
Consultant, Endocrinology and Internal Medicine
Professor of Medicine, Logan Campus
School of Medicine
GRIFFITH UNIVERSITY***



Glenda, Michael and Kelly from our Support Services team

This year has seen a dramatic increase in respite services to our client base, particularly those in the Brisbane region who are in critical situations.

Providing respite to a family addresses a number of issues. The health and wellbeing of the carer, as well as the person with muscular dystrophy, respite assists in keeping the family unit

healthy and functioning as well as providing support and addressing siblings needs. Respite provides a break to ensure that ongoing care at home can continue.

The flexible combination respite service provided by the Association is tailored to each individual. It is not a centre based respite service but can take place in the person's home or at a separate location. It is developed in consultation with the family to address their particular needs and lifestyles and can encompass the whole family or just the primary carer and the individual.

It is a unique program and has proven highly successful for those taking part. The service is partially funded by Disability Services Queensland and from donations received by the Association.

This partnership has also enabled us to develop an aged care respite program designed to support carers who are over 65 years. Due to the complex nature of the many different types of muscular dystrophy, and the debilitating nature of the disease, aged carers are at particular risk of suffering injury or breakdown. This service has also assisted a number of families to continue to care for their family member at home rather than have to place them in a nursing home or other care facility.

We have also provided a number of school holiday respite opportunities for families with one or more children with muscular dystrophy. Due to the flexible nature of the respite we are able to provide this service ranges from sending families to *Seaworld* for the day, through to providing overnight in home support to ensure an uninterrupted night's sleep to parents. All families accessing the school holiday respite expressed their thanks and relief that such a program was available during what is regarded as a highly volatile time in the year.

We have continued our equipment loan service with a consistent number of pieces of equipment being placed in homes around the state. This service is particularly important to our families in rural and remote areas, as it is often the only tangible way they are able to access support from us. It is part of our goal over the next twelve months to address this and concentrate on developing a program of support and contact to clients outside of the Brisbane area that will be applicable and meaningful to them and at the same time address their needs.

The Association has a long tradition of bringing families together to celebrate and enjoy life irrespective of their disease or disability. We conduct a number of events for both children and adults in a supportive and light hearted environment.

Funding for these events come from a number of sources but it is important to note that the majority of funds raised to run the Associations social events come from our own staff. Various fundraising events are conducted within the office environment each year to help fund these activities.

Staff also freely give of their time of an evening and a weekend to ensure that these events are enjoyable for all those who attend. Our sincerest thanks to the staff of the Association for their fundraising and voluntary efforts throughout the year in support of our social events.

Following are some of the highlights from this year's support services social calendar.



Childrens Christmas Party

The Children's Christmas Party for 2005 was held at Pandanus Beach, Wynnum on Sunday 27th November. It was a great day with the water breezes keeping the heat at bay. Approximately 120 people attended including Her Excellency the Governor of Queensland Ms Quentin Bryce.

“Santa gave me this special pony and it has its own stable where it can sleep at night. I love my pony and I call her princess pony.”

The children enjoyed taking part in games, guessing competitions and trivia questions much to the joy and merriment of all present. It was wonderful to see everyone laughing and having fun.

Our thanks go to the volunteer staff from the Association who co-ordinated the days events and activities as well as the Kiwanis Club for a traditional BBQ lunch with accompanying salads.

Of course the real thrill of the day was the arrival of Santa Claus. The looks on the children's faces said it all. Santa presented gifts to all the children and Christmas Hampers to each family.

The party came to an end early in the afternoon and it was time for the tired but happy families to journey home from as far a field as the Sunshine and Gold Coasts.

Childrens Easter Party

An exciting day of fun and games marked the Association's Annual Children's Easter Party held Sunday 9th April, 2006. The very popular Pandanus Beach was chosen as the venue with its recently renovated play area and pool. There were over 50 families attending and it was a glorious day with clear blue sky, mild conditions and children with chocolate covered faces thoroughly enjoying themselves.

Activities included wheelchair races, egg and spoon races, and mystery parcels with prizes of chocolate Easter eggs for the winners. There was much laughter, happiness and enjoyment all round.

The smiles on the faces of the children when our very own Easter Bunny appeared are precious memories for all the mums and dads. Everyone was so excited as he handed out Easter eggs to all the children.

Again our thanks go to the Kiwanis Club who provided a BBQ lunch and sausage sizzle. The Easter Bunny also presented bunnies to the Club members, much to their surprise and enjoyment.

Adults Support Group

The Adults support group is an informal group of people living with muscular dystrophy and their carers and partners that get together to share each others company throughout the year. Most participants live in the Brisbane region, but sometimes we are lucky enough to welcome friends from both the Sunshine and Gold Coasts and Darling Downs regions as well.

There are a number of formal activities conducted throughout the year, but as a group they also arrange their own informal gatherings and activities outside of the Association. Here are some highlights from the last 12 months.

Christmas Party

Club 83 at the Crushers Leagues Club was the venue for the Adults Christmas party held on Thursday 17th November, 2005. 50 people attended and it was an opportunity to renew old friendships, make new ones, relax and have a great time.

Christmas hampers and other prizes were drawn on the day and everyone agreed that it was a great event to end the year.

Easter Party

The inaugural Easter party for adults was held at Club 83 at the Crushers Leagues Club on Thursday 13th July 2006. About 45 people attended and all agreed that it was an excellent opportunity to meet up with friends. It was great to see some new faces celebrating Easter with the group.

Hampers and other prizes were again raffled on the day and everyone attending received an Easter egg to help celebrate the occasion.

The generous smorgasbord luncheon, and the opportunity to meet and have a relaxing day out, was so well received it is sure to become a regular event on the social calendar

Christmas in July

The traditional Christmas in July function was held on Thursday 13th July 2006. Everyone was invited to share with us an "Eggstra Special Day", that ended up full of laughs where all attending received the gift of a novelty egg cup, all of various shapes and sizes with different themes.

Christmas Hampers were raffled and other prizes drawn including a Lucky Door Prize. Everyone thoroughly enjoyed the day.

The weather was warm, not at all like a real Christmas in July, so the beanies and scarves were left at home for another day.

If you would like further information on any of the social activities conducted by the Muscular Dystrophy Association of Queensland Inc, or would like to receive regular invitations to any of our events, phone 1800 676 364

The Trust Company of Australia and the Muscular Dystrophy Association of Queensland Inc. joined forces in 2004 to establish a three year support project for young people with muscular dystrophy called *Reach Out for Kids* (ROK).

The project provides support to young Queenslanders with muscular dystrophy by providing them with vital equipment, services and access to special educators to ensure each person's social, education and home life prospers.

Up and Running ...

Not all forms of muscular dystrophy equates to life in a wheelchair. There are over 60 different types of muscular dystrophy and neuro-muscular disorders ranging in spectrum from rapid onset at an early age to late age onset commencing generally around retirement. Myotonic muscular dystrophy is often diagnosed early in a young person's life but with strength and commitment people with the disease can work to combat some of its more aggressive symptoms.

In 2004 Kie Wilson-McNaught, a young boy with myotonic muscular dystrophy, bought everyone to their feet at Homebush Stadium when he won the national athletics gold medal for his age category.

"Kie was advised by specialists that he would be confined to a wheelchair by the time he was three years old. Kie is determined to remain out of a wheelchair for as long as he possibly can and concentrates his efforts to ensure his health and fitness remain at their peak." Kie's foster mother Robyna McNaught said.

Kie participates in swimming, athletics and track and field in all levels of state and national competition.

When hearing of Kie's extraordinary achievements and his struggle to overcome his disability, there was little doubt that Kie was exactly the young person that we had envisaged assisting when developing the *Reach Out for Kids* project.

With this in mind it was decided early on that through the Trust Company of Australia we would assist Kie for the full term of the *Reach Out for Kids* project and help him and his family with the financial burden of competing throughout Australia.

His amazing ability to continue to produce stunning performances culminated in Kie's recent disqualification for swimming 15% faster than his submitted personal best time, just weeks after having heart surgery.

Kie is currently in training for the 8th annual Special Olympics National Games to be held on the Gold Coast in early October 2006.

trust

The relationship between the Muscular Dystrophy Association of Queensland and the Trust Company of Australia commenced with the administration of the Fred P. Archer Charitable Foundation. During Mr Archer's life he had worked in Papua New Guinea developing a number of successful coffee plantations throughout the region.

MDAQ has a long history of supporting people from Papua New Guinea with muscular dystrophy. We have in the past hosted families when travelling to Queensland for medical treatment, provided wheelchairs to people in Papua New Guinea and worked closely to develop an information and referral service to people living in tribal and remote areas.

More recently MDAQ has worked with the Trust Company to develop creative yet often simple solutions to a myriad of complex problems faced by people with muscular dystrophy.

Drawing on advances in technology we have developed solutions to issues surrounding communication, community access and self development by providing innovative and personalized products and services to our clients.

The Reach Out For Kids project has directly affected the lives of 18 young people with muscular dystrophy – giving them opportunities and experiences that will last for their lifetime.



Kie Wilson-McNaught

As the Association continues to undergo a period of growth part of our challenge has been to fundraise to meet the increasing financial demands of our expanding support services. This year we secured over \$402,748 in support from corporate donors, trusts and foundations, government agencies and individuals who found themselves in a position to make a substantial donation to the Association

Our sincerest thanks go to the following corporate supporters of MDAQ

- The Seymour Group Pty Ltd
- The Cory Charitable Foundation
- Coral Homes (Brisbane) Pty Ltd
- Disability Services Queensland
- Tour De Kids
- Queensland Health
- Reuben Pelerman Benevolent Foundation
- ANZ Charitable Trusts Flo Royal Sporting Wheelies
- The Ian Potter Foundation
- The CM & JA Whitehouse Foundation
- Wagstaff Piling Pty Ltd
- Jupiters Casino Community Benefit Fund
- Trust Company of Australia
- Macquarie Bank Foundation
- Perpetual Trustees Australia Limited
- St George Foundation Limited
- The Estate of the late David Duyvestyn
- The Christopher Chee Foundation

These funds were utilized to either wholly or partly fund a range of specialized medical equipment and aids including

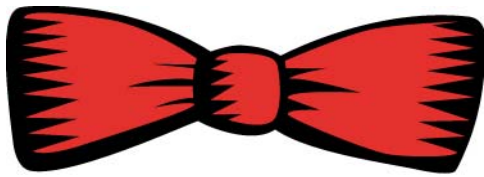
- Specialist Hi Lo Electrical adjustable beds
- Manual and electric powered wheelchairs for both children and adults
- Specialist voice imaging software with lightweight notebook computers and printers for school-age children
- Bathroom equipment such as hoists, shower and toilet chair
- Sling chairs
- Seating systems
- Hoists and lifting frames
- Modified school desks
- Portable air conditioners
- Cough Assist machines
- Ventilators
- Wheelchair modifications and accessories
- Wheelchair ramps
- Vehicle modifications and accessories

We have a number of special donors who wish to remain anonymous, with without their valued support we would not be also able to assist some of our clients who truly are in necessitious circumstances. To those reading this report in this special group, our heartfelt thanks from the Assocation and those who have benefited from your generosity. With your help we were able to fund the gap between the cost of equipment (such as wheelchairs and wheelchair accessories) and the Queensland Health allowable limit.

There are many other needs for people with a disability that we have been able to either fully or partly meet as a result of receiving the generous support from our donors, including:

- Internet connections to enable sick children to access their school from home
- Financial support including assisting families with funeral expenses
- Payment of basic utilities in times of crisis
- Funding social outings and support groups to encourage community access
- Attendance at national disability competitions and meetings
- Enabling children to attend mainstream school camps
- Client advocacy

We look forward to another year as we develop and nurture stronger partnerships with government, business, community groups and individuals.



Annual Appeal – Bow Tie Day

Another successful Appeal that exceeded our budget for the year. This is our most important event on the Association's calendar as it

is our signature event and provides us with the unique opportunity to showcase the organisation as well as the disease throughout Queensland. Not only is it our only statewide fundraising event, but also our one opportunity throughout the year to highlight Muscular Dystrophy and its impact on the community.

The Premier launched the event with a generous donation of \$25,000 to kick start the appeal throughout the state. We set ourselves the challenge of increasing the number of point of sale bow tie boxes by 500 and were successful of reaching this target as we placed well over 2500 point of sale boxes throughout Queensland, filled with bowtie products for the local communities to purchase during March.

The most distinctive aspect of Bow Tie Day is the sight of hundreds of girls from All Hallows School as they converge on the city rattling tins and selling bow tie pins. Our sincerest thanks to both All Hallows students and staff for making our Bow Tie Week celebrations such a huge success.



Ray White Surfing Paradise Gala Ball and Charity Auction

Greg and Andrew Bell, principals of Ray White Surfing Paradise celebrated the twelfth anniversary of their wonderful Gala Ball and Charity Auction. This year's event raised over \$150,000, putting their combined support to MDAQ over twelve years to well over \$1.2million. The Muscular Dystrophy Gala Ball and Charity Auction is regarded as the most sought after event on the Gold Coast Calendar. It is always a sell out event and is a wonderful night of fun and entertainment.

Some of this year's top auction items were an all inclusive trip to Los Angeles for two people, a unique piece of jewellery from *Calleja* diamonds and lunch with the Prime Minister in his private dining room at Parliament House, Canberra.

As our longest and most committed supporters it is with much appreciation that we say thank you to Greg and Janine, Andrew and Sandy Bell, their families, friends and staff at Ray White Surfing Paradise. The funds raised by the ball provide essential support and equipment to people in South East Queensland. This significant and generous support has enabled many families over eleven years to have much needed equipment in their home and live a more dignified lifestyle by enabling them to access their community.

red rooster.

Red Rooster has supported Muscular Dystrophy throughout Australia for many years. Initiated

in Western Australia the signature "Quokka Boxes" have been placed in stores throughout the country and patrons are asked to make a donation.

The Rottneest Island Quokka is susceptible to a paralysing degeneration of the voluntary muscles. In 1960 extensive research into the problem showed the animals made a dramatic recovery after treatment with vitamin E. More importantly it was found that, after a few weeks, microscopic restoration of the afflicted muscle structure had occurred. Prior to this discovery it was accepted that diseased muscle possessed only limited powers of regeneration. This work so many years ago continues to give great hope to all those living with muscular dystrophy and other neuromuscular disorders.



Red Rooster has taken part in this program for a number of years and their support is greatly appreciated, especially around Bow Tie Day when they also take our Bow Tie Boxes statewide and conduct a month long campaign on our behalf. By simply placing your small change at the various donation boxes throughout the state patrons are contributing to more than \$39,000 in regular donations each year. Our continued thanks to Red Rooster and their patrons for their many years of dedicated support to Muscular Dystrophy.



**HOG 2006
Charity Ride**

The Brisbane Harley Owner's

Group annual ride for Muscular Dystrophy was again very well supported and successful. This event gains popularity each year with a dedicated group of HOG riders and pillion enthusiasts keen to take part.





115 riders and HOG members left Morgan & Wacker in Newstead and headed north along the Bruce Highway stopping for morning tea at Bribie Island. On leaving the island, riders

then travelled through Dayboro, Mt Nebo and the Samford Valley before stopping for lunch at Ferny Hills. Riders and pillion alike exercised their legs and rubbed some tender spots before the final leg of the journey that had the roar of 115 bikes rumble through the streets of western Brisbane, stopping briefly at JC Slaughter Falls and finishing the day back at Morgan and Wacker.

A special mention must go to the partners of the riders who give up their seats to raise money for charity and rush ahead of the rumbling to prepare morning and afternoon tea, decorating venues and all round setting the scene for an amazing day! Donating their time and bikes, the Brisbane HOG members raised approximately \$10,000 again for Muscular Dystrophy in 2006.

Special thanks and appreciation goes to the Brisbane Harley Owners Group for their continued support of the Association and our very special families not only for the ride day, but for all the other support they provide us with during the year.

Donations and Art Union ticket sales generated by the Contact Centre is the primary source of income for the Association. During the past year we have purchased a new database and computerised the Art Union in order to decrease operating costs. A new purpose built contact centre with capacity for 30 staff and a rotating shift of 60 people per day has been completed. This centre has been developed to assist us in growing a number of business service opportunities.

The three year project of upgrading obsolete technology and equipment is complete and we now have a fully digital telephone network and each staff member within the contact centre has access to computers and the latest technology.

It has also been a year of excitement and change as the contact centre has continued to evolve and develop into a more commercial enterprise. Contract work that was piloted in 2005 has proven to be successful and has developed into regular consultancy work.

The ongoing dilemma in accessing prospect lists since the withdrawal of Marketing Pro and Oz on Disc from the market in 2004 is still continuing. Staff undertake three hours of prospecting per week. This has yielded a pleasing result in the past - especially in the Art Union department.

The sale of Art Union tickets has fluctuated in the last year. Losing a number of long term employees due to ill health and our move to new premises left us struggling to find experienced staff. Our ticket buyer acquisition program was postponed due to the shortfall in staff that has led to very few new ticket buyers in the last two Art Unions. To compensate for the loss of staff we implemented a direct mail campaign to ensure all previous ticket buyers had the opportunity to purchase.

We have welcomed new members to the team including a new Business Service Manager with extensive experience in contact centre management and the associated technology and infrastructure.

New commercial opportunities continue to arise and it is with excitement that we look towards sub-contracting our services to interested clients in order to curb expenses and increase and maximize our fund-raising dollars.

Support of the Association comes from many areas not least our volunteers who feel it very important to help others. Our sincerest thanks to the Kiwanis Club of Brisbane who continually support the organisation by providing volunteer services and fundraising barbeques. They give freely of their time to enable us to raise funds or entertain our families living with muscular dystrophy. The Harley Owners Group of Brisbane assists the Association throughout the year not only for the muscular dystrophy ride day, but often by providing hampers for families who are in neccessitous circumstances. Individually they wish to remain anonymous but combined they make a profound difference to those they help.

A special recognition to Mrs Jennifer Blythe and Mr Ross Jobling for their long and dedicated volunteer service to the Association. MDAQ are fortunate to receive support in the following formats:

Community Service

This is an important two-way program where the participants can complete their obligation to the government and the community by providing valuable manpower to MDAQ. These people come to us with varied backgrounds and skills and undertake basic and semi-skilled tasks, the most valuable being support to Bow Tie Day.

Centrelink Volunteer Scheme

People undertake to work two days per week for a charity instead of seeking employment, usually due to medical reasons.

Work for the Dole

CADET Training and Employment provides people to assist with office maintenance, painting and general administrative tasks.

Volunteers

Continue to offer loyal and helpful assistance to the Association. As well as providing administrative and general office support our volunteers add an important cheerful element to our association's day to day activities.

We Remember With Love...

Tim Alkin	Nathan Ebelt	Michael Kerle	Ray Robinson
David Andrew	Audrey Evans	Michael King	Daniel Riley
Adam Astill	John Exall	Lionel Kropp	Philleppe Savy
Chas Barry	Carol Fairbank	Fook Man Lai	Nicholas Schulz
David Bawden	Cheryl Finch	Matthew Larkin	Diana Selby
Kevin Beazley	Andrew Gardner	Stephen Lloyd	Mark Selby
Shaun Beazley	Mr Gerald	Brett Martland	Kyle Shay
Lesley Biddle	Sebastian Gonzalez	Darren Masson	Heath Singleton
Peter Bradick	Joseph Goodman	James Matuszcak	Douglas Smalley
Eric Bennett	Phillip Gordan	Michael Matuszcak	Clinton Smith
Neil Bennett	Phillip Haller	James McBrien	Ethan Douglas Smith
Hazel Bugden	Herb Harch	Kirk McCarthy	Michael Smith
Olive Bullen	Keith Harcombe	Steven McClure	Shayne Smith
Craig Bullock	Clifford Daniel Hemburg	Dean McEalean	Tanya Smith
Trent Burley	Wayne Heilbron	Darren McKee	Wallace Spark
Patrick Butler	Klinton Henderson	Mark McKee	Steven Spidalieri
Betty Cawkwell	Michael Henderson	Shaun McKee	Rogan Stanyon
Anthony Ciesiolka	Peter Hodges	Terry McLaren	Daniel Styles
Shaun Cleland	Warren Hooker	Daniel Mihaly	Helena Styles
Ashley Cochrane	Gregory Horsburgh	Allan Morris	Angel Rose Sustic
Brett Colby	Andrew Houghton	Russell Mossman	Triston Timor
Jonathon Coombes	Sean Ivers	Nowell Norris	Adam Trevor
Shane Corby	Bridgett Jenkins	Matthew O'Brien	Andrew Trevor
E Cleary-Hynes	Gordon A Johnsen	Lawrie O'Keefe	Peter Trevor
Warren Daly	Ross J Johnsen	Dylan Pacey	Rhys Tripp
Wayne Davy	Judy Johnson	Ian Paulsen	Eric Waite
Joan Defteros	Allan Jones	Bruce Percy	Joseph Wale
Russell Diefenbach	Ashley Jones	Robert Phelby	Simon Wale
Kim Dixon	Charmaine Jordan	Daniel Pocock	Kylie Wootton
Mr Draper	Michael Krcevinac	Michael Powell	Greg Wright
John Wease	Amanda Robertson	Max Davy	Joshua Tongs
Robert Bonfield	Robert Davies	Stephen Bellamy	Jeremy Ziebell
Maria Duyvestyn	Andrew Kelly	Matthew Puffet	Joey Zarnke
David Duyvestyn	Daniel Kelly	Mr Raak	

If you would like your loved one included in our honour roll please call 1800 676 364



MDAQ Staff and Volunteers 2006