

## What your support means: A client's story

When Scott was just six years old, in 1981, he and his younger brother were diagnosed with Duchenne muscular dystrophy. Unaware of what the future held, the family came to Muscular Dystrophy Queensland for support. Ever since we have been there to share in their joys and triumphs and, when things get tough, to guide and support them.

Throughout his life, Scott has benefitted from almost every service available for our clients. He shares memories of friendships established through sporting and social activities facilitated by Muscular Dystrophy Queensland. Although many years have passed and many friends have been lost to this cruel disease over the years, he values his friendships dearly and remains connected with people all over the world because of that early involvement.



When our long term equipment loan program was in its infancy, he and his brother were two of the programs first recipients – they were even involved in selecting suitable beds for the program. They've benefitted from this service ever since, sleeping each night in a bed provided and maintained through the program.

At his lowest point, it was the support of Muscular Dystrophy Queensland that helped him keep fighting for a better life. He says, "Having Muscular Dystrophy Queensland backing you up really put that extra oomf behind you so that you could stick up for yourself." A few years ago, Scott and his brother found themselves in living arrangements that were totally unsuited to their needs – a group home that provided no say in who they lived with, who provided their care. They couldn't even come and go as they pleased. With the support of the community behind him, Scott and his brother secured a unique housing arrangement that meant they were in control of their home, their care workers and their lives. It was truly life changing. He says, "A good way to look at it is that if MDQ wasn't there my life would be halved. I wouldn't be where I am today because I wouldn't have that backup."

When asked what the support of Muscular Dystrophy Queensland has meant to him, he says "It isn't just one thing. It's support that I don't think can be provided in any other way. It's not just the unique set of skills, it's the understanding of our lives and the specialist knowledge. It's support I can't get anywhere else."

Scott is pictured above in his new home with this Muscular Dystrophy Queensland Caseworker, Maryanne.

## Why I give: A donor's story

An observation at a football game on a cold winter's night got Bett thinking. She noticed a couple of spectators who used wheelchairs, very rugged up for the game and realised how difficult it must have been for them to keep warm. An avid quilter and a regular donor to Muscular Dystrophy Queensland, she offered to make wheelchair friendly quilts for clients the next time she was chatting to staff. We gladly accepted. She says, "It is good therapy for me. As I am 87 years of age and making these quilts keeps me young at heart and my brain active. I make and donate my quilts to MDQ to let their clients know someone in the community really cares for their welfare. I get as much pleasure out of creating them as they do receiving them." With regard to her donations she said, "Firstly, I feel that MDQ is grossly underfunded by all tiers of government. I have learnt that you get far more enjoyment out of helping someone less fortunate than you do helping yourself. Muscular Dystrophy Queensland is a worthy cause."



Your donation today will help provide help for today and hope for tomorrow for Queenslanders living with muscular dystrophy  
Call: 1800 676 364  
Web: [www.mdqld.org.au](http://www.mdqld.org.au)

**Muscular Dystrophy Queensland**  
Post to: Locked Bag 3000, Eagle Farm BC Qld 4009  
Office Location: 1149 Sandgate Rd, Nundah Qld 4012  
T: 07 3243 9700 F: 07 3123 6606 E: [info@mdqld.org.au](mailto:info@mdqld.org.au)  
ABN: 14 908 553 738



MUSCULAR DYSTROPHY  
QUEENSLAND

Impact Report  
2014-2015

## Impact Snapshot

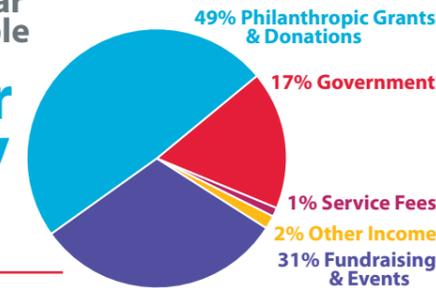
**CLIENTS SUPPORTED** **16**  
complex casework enquiries attended to EVERY DAY

**DEDICATED CASEWORKERS** **470**  
hours of casework addressing the needs of clients provided EACH MONTH

**DIFFERENT CONDITIONS** **60**  
different muscular dystrophies & neuromuscular conditions supported EACH YEAR

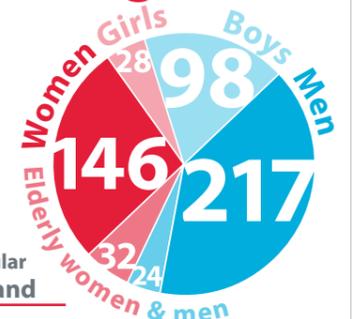
**NEWLY DIAGNOSED** **42**  
families with a new diagnosis registered THIS YEAR

**\$ 1.759 million raised**  
this financial year to support people living with **muscular dystrophy** and other **neuromuscular conditions**



**545 people registered** to receive whole of life **care & support**

**4,500 people** living with neuromuscular disease in Queensland



**Our Mission: Muscular Dystrophy Queensland is committed to work in partnership with Queenslanders living with muscular dystrophy and other neuromuscular conditions to address their needs.**

## A message from our CEO

I am constantly impressed by the difference our small organisation makes to the quality of life of people with muscular dystrophy and their families. I am particularly moved by our case workers' support of families of children, recently diagnosed with the most severe, life limiting forms of these conditions. I am proud that we are also able to assist people at the other end of life, as demonstrated by our recent case work which enabled an elderly woman with muscular dystrophy access improved and less isolated housing.

I am so very grateful to our supporters - people who give through donations, volunteering and by fundraising on our behalf. Without them we simply could not offer services and support for so many.

For many decades I have worked in the charitable sector and I believe that this is the most tumultuous time as small organisations aim to sustain themselves in an increasingly competitive fundraising environment and with governments seeking to minimise their direct service funding to the not-for-profit sector. Despite all of that, you will read that Muscular Dystrophy Queensland continues to be effective in its service provision.

With the help of all our wonderful supporters, we will continue to provide an innovative program of services, which meet the real needs of people living with muscular dystrophy and other neuromuscular conditions.



**Through provision of case management, information and support services Muscular Dystrophy Queensland builds the ability of people living with muscular dystrophy and other neuromuscular conditions, and their families, to manage their health and well-being and improve their quality of life.**

**HOUSING**  
  
 assisting to create  
**choice and control**

For many of our clients, housing has continued to be a major concern this past year. We have worked with a number of clients whose living arrangements were not suited to their needs and assisted them to find alternatives. This diverse and labour intensive work can include anything from assessing accommodation facilities, advocating for independent living arrangements, or advising clients of their rights regarding public housing. We have also assisted clients who wished to stay in their homes do so, by providing needed equipment and/or support workers, through the support of generous funders, including YoungCare.

**HILO BEDS**  
  
 200+  
 improving  
**independence & safety**

We are very proud that each morning 200 clients all across Queensland wake up in a bed provided and maintained through Muscular Dystrophy Queensland's long-term equipment loan program - people who have retained or regained some level of independence and face reduced risk of injury simply by having this equipment in place. Operating uninterrupted for almost 30 years, this program relies on funding from our generous donors, charitable trusts and foundations. A substantial grant from the Gambling Community Benefit Fund enabled the purchase of 17 beds placed with clients right around the State and briefly reduced our waiting list to zero.

**OUTREACH**  
  
 meeting regional  
**families one on one**

Outreach builds better connections with our families in regional areas. Some common themes raised during the trips included; the need for children with muscular dystrophy to have better support in place to attend school, better access to specialist health services, support through life transitions, and managing progressing disability. Muscular Dystrophy Queensland is committed to extending our outreach program further. We are very grateful to have the support of the ANZ Staff Foundation, which has generously supported the outreach program for a number of years.

**SPORT & REC**  
  
 better access  
 to life changing  
**sporting opportunities**

Muscular Dystrophy Queensland has a long history of assisting our clients to access sport and recreational opportunities. From this early support, we now have a group of clients who participate at state and national level across a number of sports. A position funded by the Queensland Govt (Dept. of National Parks, Sport and Racing), created some outstanding outcomes for people who had previously not had the opportunity to participate in sports. We are proud that four clients have found this experience 'life changing' and are currently pursuing their Paralympic dreams.

**NETWORKS**  
  
 enabling  
**connections and shared experiences**

People who live with neuromuscular disease face similar experiences. There is a wealth of knowledge and support available to those who reach out and make connections with others in the muscular dystrophy community. For this reason Muscular Dystrophy Queensland continues to support our clients to build and maintain local community networks, that enable people to connect, share experiences and discuss life lessons. This past year a new adult peer support group has been established in North Brisbane adding to groups in Toowoomba, the Coral Coast and Cairns.

**READINESS**  
**NDIS**  
 preparing  
**people for the transition to a national disability insurance scheme**

Preparing our clients for the move to the new National Disability Insurance Scheme (NDIS) has also been a major focus this year. This new scheme will provide funding and services in an entirely new way. It is so important for our clients to begin preparing for the transition as early as possible. Muscular Dystrophy Queensland became a Your Life Your Choice (YLYC) Host Provider to enable our clients to self-direct their Disability Services funding packages. This program is widely considered to be a precursor for the NDIS. By appointing a YLYC Coordinator, we have been able to work closely with clients to encourage them to prepare for the NDIS.

**EMERGENCY**  
  
 assisting  
**families in crisis with no other option for support**

Each year, families facing extreme hardship seek our support. Our crisis support program is funded solely through donations and allows Muscular Dystrophy Queensland to offer assistance when no other alternatives are available. Through the service this year, we provided groceries for a hungry family, paid electricity bills to keep power on for a child's medical equipment, covered petrol costs to help get kids to school and for an isolated, elderly lady whose only family lived in Switzerland, we provided an iPad which enables her to regularly keep in touch with them with no ongoing costs.



Through outreach, MDQ meets clients in regional areas, in their homes, learning about their lives, needs and goals.



Each week MDQ's case workers assist families attending the Lady Cilento Hospital's Childrens' Neuromuscular Clinic.



MDQ facilitates group activities to enable people living locally to connect and share experiences (like this day at Australia Zoo).



Four of MDQ's clients are now pursuing their Paralympic dreams thanks to our Sport and Recreation Program.



Independence, safety and comfort - the key outcomes for each person to benefit from MDQ's long term equipment loans.



People connect, share their lives and experiences with others, through peer support groups facilitated by MDQ.