MOTOR NEURONE DISEASE ASSOCIATION OF
QUEENSLAND INCORPORATED

# ANNUAL REVIEW 2018

mnd
Queensland

# ABOUT MOTOR NEURONE DISEASE

Every day in Australia two people are diagnosed with Motor Neurone Disease (MND) and two people pass away. As a result, this fatal and debilitating disease has a massive impact on hundreds of lives.

It turns the world upside down for not only the person who is diagnosed, but their family, friends and colleagues. They become carers, helpers, backup support crew. Those who are closest often leave their jobs and homes to move in with their loved one because of the intense care that is eventually required. While they wouldn't have it any other way, these dedicated and passionate people are changed forever. Their hearts break as they watch their loved one lose their capacity.

## WHAT IS MOTOR NEURONE DISEASE?

Motor Neurone Disease is the name given to a group of diseases in which motor neurones progressively die. Motor neurones are nerve cells that control the movement of voluntary muscles, that is, muscles that are under conscious control. These include all the muscles of the arms, legs, back and neck and of speech, swallowing and breathing. With no nerves to activate them, muscles gradually weaken and waste, and paralysis ensues. Weakness is often seen first in the hands or feet, or the first sign may be swallowing difficulty or slurred speech. Muscle twitching and/or cramps may also occur.

MND affects each person differently in respect of initial symptoms, rate and pattern of progression, and survival time. There are no remissions. The key feature of the disease is the speed of progression, which poses huge problems of adjustment for people who have MND, an escalating burden on carers and families, and a challenge to health, disability, aged and community care professionals involved in meeting the variable and complex care needs.

## KEY FACTS

- MND is a rapidly progressive, terminal neurological disease
- There is no known cure and no effective treatment for MND - yet
- Each day in Australia two people die from MND
- Each day in Australia two people are diagnosed with MND
- People with MND progressively lose the use of their limbs and ability to speak, swallow and breathe, whilst their mind and senses usually remain intact – this is why the effect of the disease is sometimes described as "locked-in"
- Average life expectancy is 2.5 years from diagnosis. While some people live for 5 years or more there are others that may only live for 5 months.

## OUR VISION

A world free of the impact of Motor Neurone Disease.

## OUR MISSION

Our mission is to help reduce the impact of Motor Neurone Disease on people living with MND, their families and carers. We do this by:

- Providing support to people living with MND, their carers and families
- Delivering information and education
- Raising awareness of MND and its impact
- Supporting efforts to find the cause and a cure for Motor Neurone Disease

## THE CORNFLOWER

The cornflower is the symbol of hope for people living with MND - hope for finding the cause, hope for development of treatments, and for a cure. The cornflower represents positive hope for a future free from MND.

# PATRON, BOARD & STAFF

## PATRON

His Excellency the Honourable Paul de Jersey AC, Governor of Queensland

## VICE PATRONS

Dr Robert Henderson, Neurologist

Dr Pamela McCombe, Neurologist

## PRESIDENT EMERITUS

John Wearne AM

## GOVERNANCE STRUCTURE

The Governance of the Association in 2018 was the responsibility of the volunteer Management Committee (Board).

## OUR 2018 BOARD MEMBERS

- President - Peter Denham
- Secretary/Vice-President - David Schwarz
- Treasurer - Elizabeth Holyer
- Board Director - Moya Denham
- Board Director - Graeme Holyer
- Board Director - Dean Palmer
- Board Director - Richard Kilgour
  *(elected at 2018 AGM and resigned October 2018)*

Pictured (L-R) - Elizabeth Holyer, David Schwarz, Moya Denham & Peter Denham

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## OUR STAFF

**Chief Executive Officer**
Lisa Rayner

**Fundraising and Communications Manager**
Jason Russo

**Administration Coordinator**
Telisa Sekona (resigned October 2018)
Suzanne Wells (commenced October 2018)

**MND Equipment Officer**
Mal Farrow (resigned June 2018)
Ricardo Brule (commenced June 2018)

**MND Support**
Denise Plunkett-Mansell

**Membership and Community Liaison Coordinator**
Leigh Gilbert (commenced November 2018)

## MND ADVISORY TEAM

**Senior MND Advisor**
Eirlys Pijpers (resigned September 2018)
Kylie Kellalea (commenced November 2018)

**MND Advisor (North Queensland)**
Sharon Edwards

**MND Advisor (Central Queensland)**
Mark Whitley

# HONOUR BOARD

We acknowledge the wonderful contributions of our Foundation Members along with our Life and Honorary Members.

## FOUNDATION MEMBERS

Charles Graham
Shirley Graham
John Wearne
Margaret Wearne
David Taylor
Lesley Taylor
Anne Martin
Frank Soos
Vera Stevens
Evelyn Moore
Stan Douglas
Barbara Douglas
Eddie Kudzius
Vida Kudzius
Peg Herbert
Mr F Herbert
Mrs F Herbert
Desley Atkinson
Mrs D V Atkinson
Ray Underwood
Alex Underwood

## LIFE MEMBERS

1987 Shirley Graham OAM
1990 John Wearne AM
1991 Evelyn Jacobs
1991 Violet Leggat
1993 Norman Isdale
1993 Patricia Fahey
1994 Margaret Wearne
1994 Lesley Taylor
1995 Frank Rough
1996 James Lawson
1996 Dawn Mahoney
1996 Muriel Roser
2001 Bill Dixon
2004 Judy Maker-Field
2005 Fr Malcolm Bell
2006 Keith Brown
2008 Rod Downes
2008 George Talyor
2009 Dianna Robinson
2009 Beris Milburn
2010 Johanna Dinon
2011 Lyn Sharp
2014 David Schwarz
2014 Vicki Forrest
2015 Marian Schwarz
2018 Margaret Graham
2018 Graeme Holyer
2018 Elizabeth Holyer
2018 Lorraine Lovatt
2018 Lorraine Lynch

## HONORARY MEMBERS

1987 Dr Jack Schlink
1995 Roy Colquhoun
1995 Dr Kerry Larkin
1998 Fr Malcolm Bell
2006 Yvonne Herbert
2008 Paul Coogan

# PRESIDENT PETER DENHAM'S REPORT

## 'Nobody cares how much you know, until they know how much you care.'

It is with considerable pleasure that I write to you as the Motor Neurone Disease Association of Queensland marks its 35th Anniversary. Whilst battling his own diagnosis with this disease Charles Graham acted to help others and formed the Association in 1983 and he knew that 'nobody cares how much you know, until they know how much you care.'

We are proud that this Queensland Association continues to support people and their families living with Motor Neurone Disease and help find a cure. Charles Graham's legacy lives on to achieve his vision of supporting others with the disease, searching for a cure, providing the very best services, and caring for each other.

Your wonderful support enables the Association to continue to reach out to others, deliver the very best services, and to support our researchers to find treatments, causes, and a cure.

Your membership to the Association is critical as **we are the only membership-based charity in Queensland focused on helping the people of Queensland with this disease.**

Held at the Oxley CWA Hall on 26th February 1983 supporters gathered to form the Association. 21 people became the founding members including Charlie's family and in that small community hall the dream of finding a cure, giving hope to others, sharing and supporting, and committing themselves to a long journey of dedication. Today, you are carrying on their dreams.

Today, it is your dream and devotion that enables the Association to provide services to over 250 people with MND, support over 3000 family members, and to help hundreds of communities from Bamaga in the north to Banora Point in the south.

As President I thank you and I thank our Management Committee, Staff, Volunteers, Stakeholders, Suppliers, and all Queenslanders who help the families living with this dreadful disease.

I recall when our current Secretary David Schwarz asked me to join the Association and it was an easy decision to make, as I firmly believe that by helping others they in turn help you. Meeting the most resilient and courageous people with this disease has been a very great privilege and both my wife Moya and I enjoy travelling to visit them and their families on your behalf.

Since 1983 we have seen the great leaps in technology and today the Association provides on loan some of the most advanced assistive technology such as the Eye-Gaze machine that enables the eye to operate a computer or I-Pad. When your voice and speech fail it is vital to be able to communicate and have conversations with your loved ones. Your support is making the difference and only together can we achieve great things.

This year the Association has delivered vital equipment, medical aids, and assistive technology to over 125 people with MND. Over 450 items are spread across the State of Queensland. The donation of items has also made a huge difference to our loan equipment pool and we wish to thank everyone who has donated something to the Association.

Tomorrow will bring new hope of a cure and our special thanks go to our research teams who each day take a step closer to finding answers. As one carer said to me 'MND is like chasing rabbits around the paddock'. Every day this disease does something different. Professor Perry Bartlett, a world leader in neuroscience, has one of the largest research laboratories located at the Brain Institute University of Queensland searching for answers and cures. The Charles and Shirley Graham Memorial Research Fund and the Annual Ice Bucket Challenge supports the work of this amazing facility.

Only through your deep commitment will we be able to unravel the many mysteries and complexities of this disease and find a cure. Charlie's believe was to 'Never Give Up' and together we will continue the fight against MND.

Thank you again for your wonderful support and dedication.

# TREASURER'S REPORT

It is with pleasure that I submit the 2018 audited financial statements to you.

The 2018 calendar year results have been extremely pleasing, following on from a challenging year in 2017 (and a number of challenging years prior to that).

Some of the key financial highlights are as follows:

We achieved an overall profit of $48,644 during the 2018 year, that included the re-evaluation of the property and this is a $161,904 improvement on the deficit of $113,260 in the prior year.

Our total revenue for the 2018 year of $887,177 represented an increase of 22% over the prior year.
Net assets as at 31 December 2018 were $1,076,389.

The improved results in 2018 reflect our renewed focus at both Board and operating level on growing our fundraising capabilities.  By growing our fundraising capabilities, we can invest more in our core services and external research programs.

We are continuing our program to enhance fundraising capabilities during the 2019 year (and beyond). This will involve a number of actions including investment in new staff and marketing activities.  We anticipate that the returns on this investment will start to show from 2020 onwards.

I would like to thank our finance team for their ongoing commitment, as well as my fellow board members and the entire MNDAQ team.  Also, to our auditors, Merrotts Chartered Accountants and Business Advisors, for their support.

I recommend the 2018 Audited Financial Statements to you and move that they be accepted.

## Annual Financial Summary

| Item | 2018 | 2017 |
|---|---:|---:|
| Total Income | $887,177 | $748,733 |
| Total Expenditure | ($869,952) | ($861,993) |
| **Annual Result: Profit or (Loss)** | **$48,644** | **($113,260)** |
| | | |
| Total Assets | $1,153,832 | $1,065,765 |
| Total Liabilities | ($77,443) | ($38,019) |
| **Net Assets** | **$1,076,389** | **$1,027,745** |
| | | |
| **Total Member's Funds** | **$1,076,389** | **$1,027,745** |

## Source of Income by %

| Income Source | % |
|---|:---:|
| Membership Fees | 0.2 |
| Client Service Fees | 5.4 |
| Donations & Bequests | 50.98 |
| Fundraising | 34.0 |
| Sale of Merchandise | 1.5 |
| Other | 1.92 |
| State Government Funding | 6 |

# MND ADVISORY & EQUIPMENT SERVICES UPDATE

## MND ADVISORY SERVICE

Over the last 35 years our specialist services have grown to provide the very best service to people with MND and their families.

We understand that the family bears the heavy load of caring, however, our services along with family doctors, neurologists, allied health professionals, and other agencies can make the journey so much easier.

Our services are tailored to each individual and sometimes with the vast distances of Queensland the delivery of each service can be complex and challenging. To overcome this challenge, in 2018 we had MND Advisors located in Townsville (servicing North Queensland) Bundaberg (servicing Central Queensland) and Brisbane (servicing South-East Queensland).

Working with other charitable groups and agencies across Queensland also ensures we deliver the very best services at a local level and we wish to thank other charities, Regional Councils, Queensland Health, Queensland Department of Communities, Disability Services, and Seniors, Blue Care, Anglicare, Karuna Hospice, and the many local and regional services. Together we can make a difference.

The National Disability Insurance Scheme (NDIS) that only supports people under 65 years of age now covers the whole State and we work closely with many service providers. Each person with MND now has a choice of providers under this scheme. In 2018 much work was undertaken to get our Equipment Service operating under the NDIS so that we can generate an income.

## MND EQUIPMENT SERVICE

The Equipment Service has been designed as a short term loan service offering medical equipment and assistive technology. Each piece or item may only be required for a short time period, it is then returned, cleaned, checked for any maintenance issues and made ready for the next client.

In 2018 we received a major grant from Fight MND which allowed us to purchase 16 eye-gaze communication devices to loan out to clients. We also received a grant of almost $18,000 from the Honda Foundation to purchase two Cough Assist Machines to aid with ventilation and breathing.

Demand for our Equipment Service in 2018 has continued to be high and unfortunately, at times some of our clients have had to go on waiting lists for particular pieces of equipment. We know that this is an area where we need to improve as people with MND don’t have time to wait.

Many new items have been donated to the Association and we thank you for your kindness. Donations have kept our Equipment Service running over the years and we are truly grateful for our donors’ support for this expensive program.

The following figures reflect the minimum output for 2018 *(due to staff changes some figures are incomplete so the real output will be slightly higher)*

### MND Client Support, Coordination, Information and Referral Services 2018

Phone Calls - 3,469

Emails sent or answered - 5,592

Home Visits undertaken - 229

Support groups facilitated - 42 *(This does not include those facilitated by volunteers)*

### MND Equipment Service Client Support 2018

Calls and emails - 2,797

## MND RESEARCH

Over 100 people are diagnosed with MND in Queensland each year and this number is increasing as the population grows. The disease seems to be prevalent amongst farming communities, military personnel or people who have been exposed to hazardous materials. Our researchers are searching for the clues and biomarkers that may trigger the disease.

We thank the Queensland Brain Institute of the University of Queensland and other Universities for their outstanding work in the search for a cure.

## MND SUPPORT GROUPS

Support Groups and some Social Groups meet continuously throughout the State.

It is heartening to know that your dedicated support is helping so many people with this disease. Each Group is chartered to provide information, support and care specifically for people with MND and their families.

The North Brisbane and Caboolture Support Group celebrated their 25th Anniversary in 2018 and it is an amazing milestone. Many founding members continue their work tirelessly to help others and they always welcome new members. The Gold Coast Support Group meet every other month and play a vital role in helping new members and engaging with other support agencies.

Smaller groups have met in Cairns, Mackay, Townsville, Bundaberg, and the Sunshine Coast.

Looking to the future, the Burdekin region has always seen many people diagnosed with MND and now the Fraser Coastal area will require Support Groups as their population grows and the prevalence of the disease increases.

Your wonderful contributions enable our Groups to come together so that we never give up and continue to fight the disease.

# FUNDRAISING & COMMUNICATIONS REPORT

Jason Russo commenced as MND Queensland's Fundraising and Communications Manager at the beginning of 2018. Fundraising income grew in comparison to previous years and this was due to a number of factors including more events being held across the State along with fantastic support from our donors in response to four appeals sent out during the year as well as increased community fundraising efforts.

We were successful in securing grants from the Gambling Community Benefit Fund, Fight MND and the Honda Foundation. Grant writing is an area that we seek to grow in the future.

Five 'Walk to D-Feet MND' events were held around the State with walks happening on the Gold Coast, Brisbane, Innisfail, Toowoomba and Redcliffe. Two of these centres held walks for the very first time (Innisfail and Redcliffe) and the success of these two new events was largely volunteer driven. Income for the Brisbane walk set a new record with over $56,000 raised from this walk alone. The Gold Coast walk also set a new record (after not being held for a couple of years) with over $26,000 raised.

Four donor appeals were conducted throughout the year (Easter, Tax, Spring and Christmas) asking our supporters to donate to assist our work. The Tax Appeal netted an amazing $86,575 which is the highest response to a tax appeal that we've ever had.

The Ice Bucket Challenge (which began in 2014) was reinvigorated in 2018 with a small group of brave people taking on the icy challenge and raising a total of $7,145.

Community fundraising remains as important as ever to the Association and in 2018 there were many events including Creevey Russell Lawyers 'Art by Allan' Art Show in Toowoomba, Mariska and Bill's Brisbane Valley Rail Trail Ride, the Bundaberg Car Run, and the fantastic effort of the Wolters family who began riding around Australia fundraising for MND Queensland at the end of January on their 'One Year on Our Bike' campaign (which concluded in January 2019).

One of the largest community fundraising efforts was the Mackay Chillfactor Challenge and MND Blue Tie Ball, two events held on the same day at Magpies Sporting Club, Mackay. Almost $31,000 profit was made between these two events and we are grateful to the Magpies Sporting Club, event volunteers and sponsors for the continued success of this event. Sponsors of the event included Rio Tinto, Workpac and Tucker & Cowen.

Three newsletters were also printed and sent to clients and supporters in 2018 with editions of 'The Cornflower' released in autumn, spring and summer (the autumn and spring editions also coincided with the Easter and Spring Appeals).
Three electronic newsletters were also emailed to our clients and supporters who choose to receive electronic communications.

Social media followers and engagement have grown with Facebook being our largest form of communication with our supporters. Follow us at www.facebook.com/MNDAQ.

# FUNDRAISING EVENT PHOTOS

## Creevey Russell Lawyers ‘Art by Allan’ Art Show - Toowoomba

## Walk to D-Feet MND Innisfail *(photos courtesy of Maria Girgenti)*

## Ice Bucket Challenge #EveryAugustUntilThereIsACure

## Walk to D-Feet MND Redcliffe

# FUNDRAISING EVENT PHOTOS CONTINUED

## Walk to D-Feet MND Brisbane

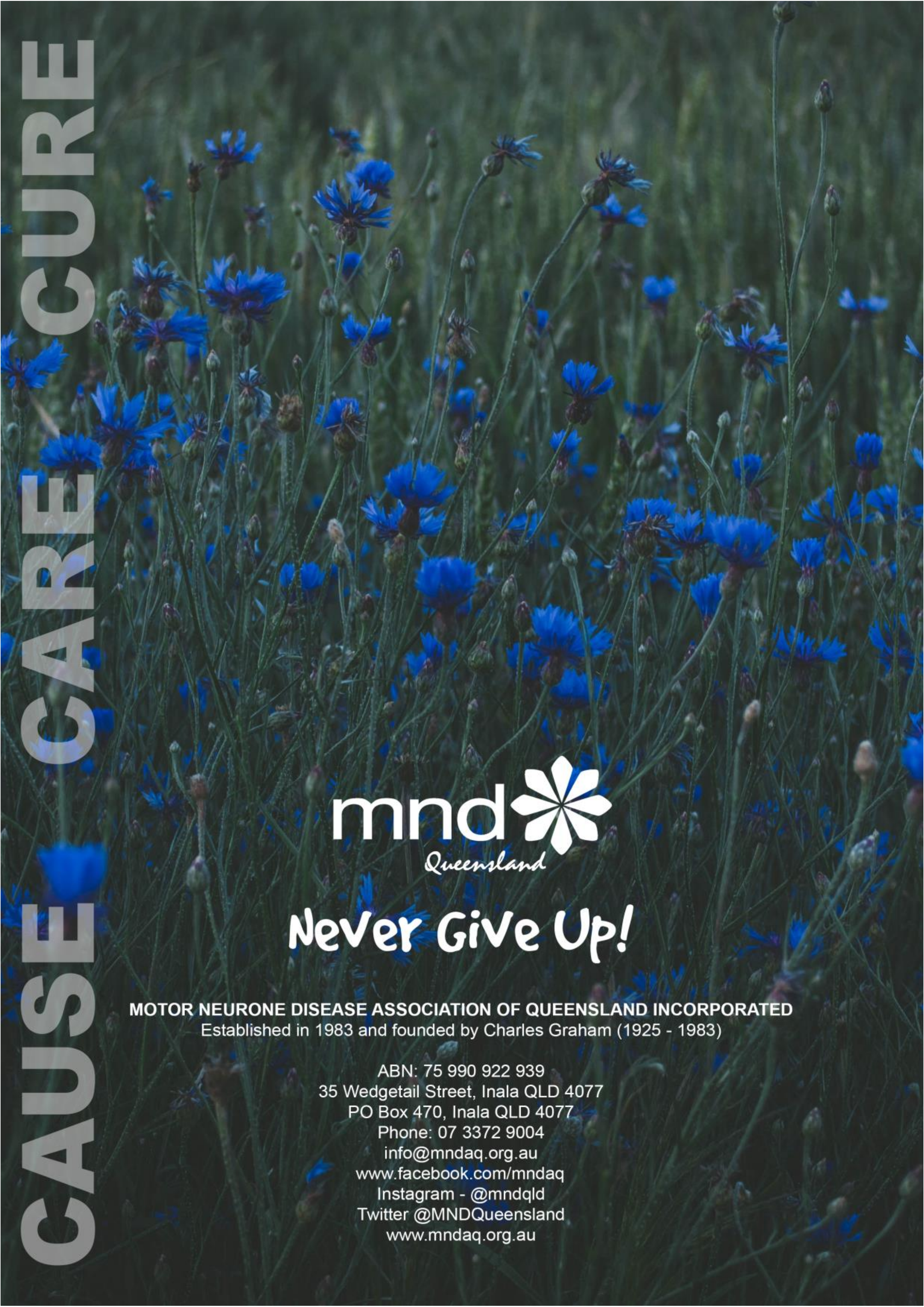

## Walk to D-Feet MND Toowoomba



## Mackay Chill Factor Challenge



## Walk to D-Feet MND Gold Coast

CAUSE CARE CURE

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Never Give Up!

**MOTOR NEURONE DISEASE ASSOCIATION OF QUEENSLAND INCORPORATED**
Established in 1983 and founded by Charles Graham (1925 - 1983)

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