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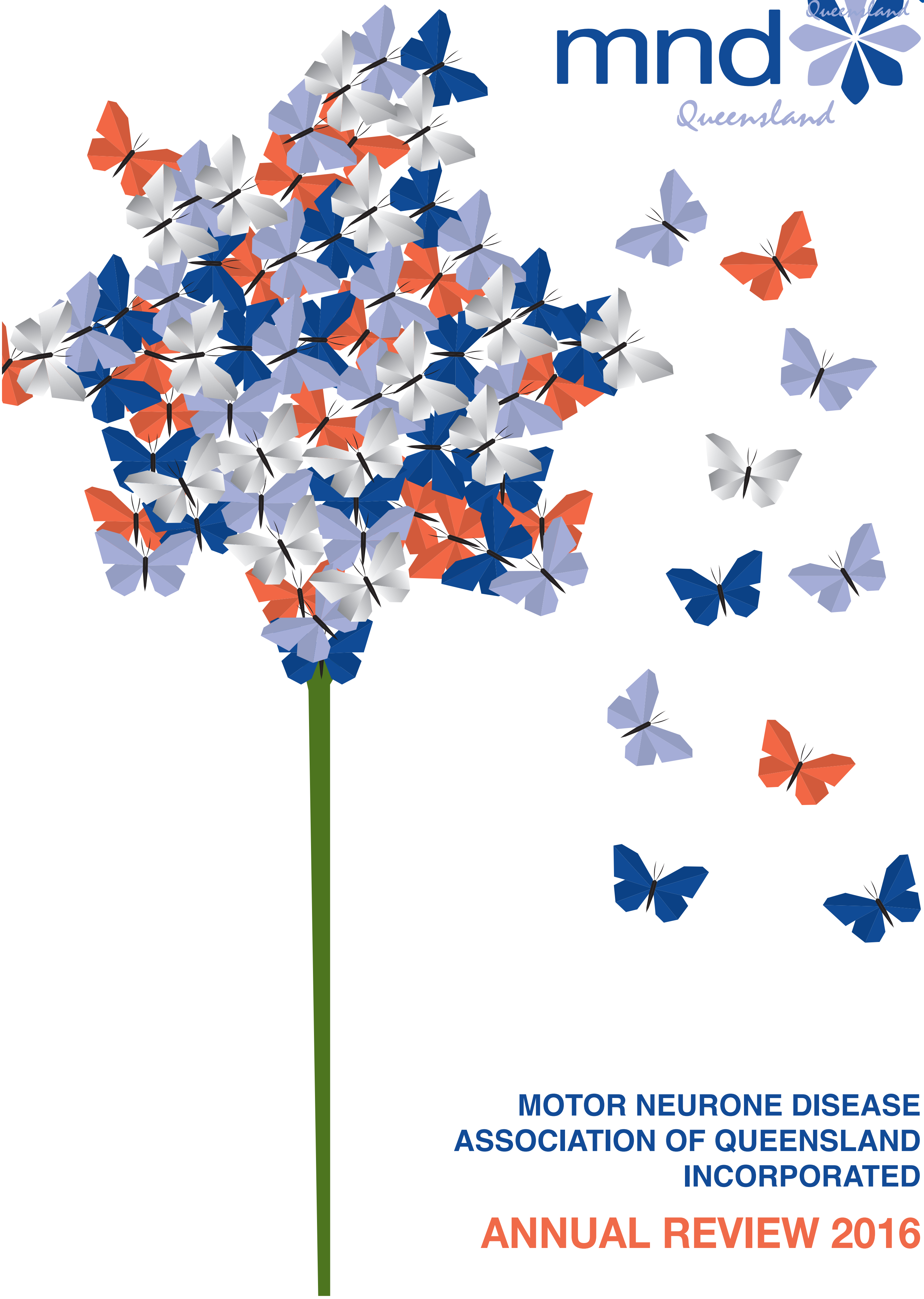

MOTOR NEURONE DISEASE ASSOCIATION OF QUEENSLAND INCORPORATED

ANNUAL REVIEW 2016

Motor Neurone Disease

Motor Neurone Disease (also known as ALS - Amyotrophic lateral sclerosis or Lou Gehrig's Disease), is a devastating and incurable neurological disease affecting more than 2000 people in Australia.

The term 'motor neurone disease' (MND) describes a group of related diseases affecting the nerves in the brain and spinal cord. These nerves are known as motor neurones. As the nerves become damaged the muscles they control weaken and waste.

There are no clear-cut definitive symptoms that immediately indicate a diagnosis of MND. The disease affects different people in different ways. Early symptoms can be mild, indicated by problems with walking, difficulties holding objects due to weakness of hand muscles, slurring of speech or a swallowing difficulty due to weakness of tongue and throat muscles. The senses remain intact.

Recent research has shown that cognitive changes occur in up to 50% of cases. A key feature of the disease can be its rapid progression creating a significant burden of adjustment for individuals, carers and families responding to complex care needs.

This terminal illness takes the life of at least two Australians daily, with an average life expectancy of 2½ years after diagnosis.

Currently there is no known cure or treatment for MND, although many symptoms can be managed effectively with multi-disciplinary care.

Research in Australia is conducted by the Motor Neurone Disease Research Institute of Australia (MNDRIA) and various tertiary institutions and private research organisations, and is ongoing throughout the world.

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

Our 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.

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Patron, Board and Staff

Patron

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

Vice Patrons

Dr Robert Henderson, Neurologist

Dr Pamela McCombe, Neurologist

Governance Structure

The Governance of the Association in 2016 was the responsibility of the volunteer Management Committee (Board) and its two standing sub committees, the Audit & Finance Committee and Governance & Review Committee, composed of Board members and other members of the Association with relevant expertise and experience.

Our Board

- Peter Denham
- Elizabeth Holyer
- Jackie D'Alton
- Moya Denham
- David Schwarz

Our Staff

MARK HOSKING
Chief Executive Officer

LISA RAYNER
Fundraising & Communications Manager

Office & Support Services

TELISA SEKONA

MAL FARROW

DENISE PLUNKETT-MANSELL

MND Advisory Team

AMANDA PAVEY
Head of Service

MND Advisors

BRAD MILLER

SHARON GRAY

MARK WHITLEY

JOHN HART

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
1990 John Wearne
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 Taylor
2009 Dianna Robinson
2009 Beris Milburn
2010 Johanna Dinon
2011 Lyn Sharp
2014 David Schwarz
2014 Lesley Taylor
2015 Marian Schwarz

Honorary Members

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

PRESIDENT'S REPORT

Peter Denham

It is with great pleasure that I report to you that our 33rd year in 2016 was one of great achievement. Our ability and capacity to help more families throughout the state of Queensland was due to your continued dedication to our Association. Together, we were able to provide vital services and support to people with Motor Neurone disease.

The profile and awareness of Motor Neurone was greatly enhanced this year with the promotion by Neale Daniher, the Cure for MND Foundation, and the Australian Football League (AFL). More people in Australia are now aware of the disease and its impact upon people and their families.

We thank all our sponsors and supporters for their continued especially the CWA, Gasoline Alley Harley Davidson Group, Dickensons Accountants, Brookwater Golf, Beaudesert Bowls, Tucker & Cowen, the Defence force, John Holland, Suncorp, National Australia Bank, Fundraising Services, KHB Australia, Rotary Clubs of Queensland, the CFMEU, and many small businesses around the State.

The Cure for MND Foundation has generously donated vital equipment to our equipment service. This service is becoming more important each year and in partnership with Spark Neurocare and the National Disability Insurance Scheme (NDIS) we will be able to assist clients and families with new technologies.

There are some exciting new technologies coming onto the market to assist with speaking, breathing, communicating, and providing entertainment. More funds are needed to help us provide this equipment.

Medical research is also at an exciting stage with advances in the understanding of the disease, stem cell research, drug development, and improving patient care. We urge everyone to support us in finding a cure and consider leaving a bequest to the Association through your Will as my family have done. Together, we can make a difference and find a cure.

Project Min E is an international collaboration of researchers that aims to analyse 22,500 DNA profiles to better understand sporadic MND. Also, now you can watch a video presentation from leading researchers that is available on our national website.

The State Associations founded our National body –'MND Australia' some years ago. Today, it plays a pivotal role in coordination and standardisation of Service delivery to people with MND. This year new national publications will be available on the website and they will play an essential role in improving service delivery throughout Australia.

Around Australia and Queensland the 'Walk 2 D-Feet MND' events are growing strongly. It is our premium national walking event. Supporters of all ages put on their joggers, walk and raise vital funds for research and services. Thank you walkers.

Our Association relies on the support of many other agencies and we thank in particular the Premier and the Queensland Government, Palliative Care agencies around the State, Local Health Care teams, Hospitals, The MND and Me Foundation, Spark Neurocare, and the NDIS.

Lastly, my personal thanks to our CEO Mark Hosking and our dedicated Staff team, members of our Management Committee, our many volunteers around the State, and most importantly our members of this wonderful Association. Let us remember to: NEVER GIVE UP

TREASURER'S REPORT

Elizabeth Holyer

It is with pleasure that I submit the 2016 audited financial statements to you.

The 2016 year resulted in a $226,773 loss following charges for a number of "extraordinary items", totalling $103,483, being expensed in the year. These charges are one-off events. The adjustments made this year by the Management Committee represent improvements to the Association's reporting and relate to adopting more recognised accounting practices. After excluding these charges, the Underlying loss including Depreciation/Amortisation was $123,290 (2015: loss $4,116) while the Underlying Operating loss excluding Depreciation/Amortisation, was $58,502 (2015: $47,398).

Specifically, the adjustments relate to adopting accrual accounting, liability recognition for Long Service Leave, ensuring there is no mismatch between Research Income and Expenditure across financial years, providing against the uncertainty of recovery of BBX "trade dollars" and bringing Inventory back to a more manageable number of items.

Each of these actions were discussed with the Auditor, who has provided the Independent Auditors' Report in association with the Financial Statements.

Set out below is a table showing the Underlying Result excluding one-off, "extraordinary items".

2016 Financial Statements – Underlying result

	Reported 2016 $	Extraordinary Items $	Underlying Result 2016 $	2015 $
Income	741,340		741,340	983,911
Expenditure*	903,325	(103,483)	799,842	936,513
Operating loss	161,985		58,502	7,398
Depreciation/Amortisation	64,788		64,788	51,514
Loss for the year	$226,773		$123,290	$4,116

*excluding Depreciation and Amortisation

The following extraordinary items are incorporated in the 2016 Financial Statements:

- Adoption of accrual accounting as opposed to cash basis reporting. This only has an impact in its first year of application. Accrual accounting, has been applied to Salaries & Wages, Superannuation, Insurances and audit fees. Net impact $12,932
- Recognition of Long Service Leave liability when Employees reach seven completed years of service. Impact $7,479
- Similar to the accrual accounting matching process, adoption of the position to match Research Income and Expenditure in the same year even if the amount has not been paid out by year end I.E. recognise a future payable. This is to ensure there is no mismatch between Research Income and Expenditure across financial years. While this has nil impact over composite years, it can lead to a distortion in the Income and Expenditure Statement in an individual year. This mismatch occurred across the 2015 and 2016 years but will not be repeated. Impact $25,000
- Streamlining Inventory to more manageable levels and more closely aligned to merchandise only. This is in line with the view to only carry items in Inventory that are readily saleable and fast moving. Impact $28,275
- Provide for potential loss of Income received as "trade dollars" from BBX Limited. There has been concern about the recoverability of this asset given problems with the

Issuer BBX. After investigation, it was concluded that these amounts are unlikely to be recovered.

- However, the provision does not remove the possibility of future recovery. Impact $29,093
- Write off Formation Costs. Impact $704

Income 2016

Excluding the Inventory adjustment and research receipts (both as described above), Income for 2016 was down by 24.9% on the prior year. It is important to note that 2015 included substantial revenue from large events including Wantz Ball, Brad Drewett PROAM, an MND and Me Foundation donation and substantially more Bequests – items that were not repeated in 2016. However, the success of great events such as the Brookwater Golf Day, Walk to D-Feet in three locations, HOG Ride, Ian Short Foundation lunch and Bowl for Mobility were particularly pleasing and made considerable contributions to Income. Contributions from Trusts and Community Funds/Grants during the year recorded an increment $46,071 above the 2015 figure.

Expenditure 2016

Expenses for 2016, excluding research payments and the above year end adjustments, were 14.4% down on the 2015 levels after including the contribution to the Neurocare Alliance. Net expense reductions across 2015 and 2016 were the result of: a changed, less ambitious, fundraising and communications strategy (and related expenses) in 2016, a more appropriate treatment of the Equipment "low cost pool" write off towards recognition as capital items and the purchase of a variety of information resources in

Annual Financial Summary

Item	2016	2015
Total Income	$741,340	$983,911
Total Expenditure	$968,113	$988,027
Annual Result: Profit or (Loss)*	$(226,713)	$(4,116)
Total Assets	$1,251,642	$1,425,142
Total Liabilities	$142,872	$89,599
Net Assets	$1,108,770	$1,335,542
Total Member's Funds	$1,108,770	$1,335,542

*Includes Extraordinary Items

Source of our income by %*

Income Source	%
Membership Fees	0.49
Client Service Fees	3.25
All Fundraising Activities	71.35
Trust & Community Foundations	9.03
State Government	7.1
Commonwealth Government	-
Bequests	7.5
Other	1.28

*Excludes Research Income

CEO’S REPORT

Mark Hosking

The 2016 year can best be described as a year of disruption and transformation. An unprecedented number of staff and role changes combined with unavoidable absences had the significant impact you might expect on such a small organisation. These disruptions, whether positive or negative in nature, required our creative and incisive analysis/review to develop suitable and sometimes, innovative solutions.

Notable developments included

- Donna Tunbridge returned to her Fundraising and Communications role after a period combining this role with that of Acting CEO
- Bruce Milligan commenced as CEO
- A staff member experienced a serious medical condition
- The writer commenced as CEO
- Donna Tunbridge resigned from her role in September to pursue a new opportunity
- The “remaining staff’ produced the Xmas Newsletter without the guidance of a professional in that area
- Employment of casual Equipment Officer to revamp our Equipment Service
- Employment of John Hart as MND Advisor (part-time) on the Sunshine Coast.

Amanda Pavey also took maternity leave during 2016 after the birth of her daughter and Brad Miller got married. While these were positive and normal events in the lives of two valued team members, and we wished them well, their absences were more keenly felt during this time of change and lack of staff resources.

Despite these challenges we still delivered services, raised donations, undertook events, provided information, kept Support Groups meeting, engaged in the Neurocare Joint Venture, developed a better understanding of NDIS and built stronger relationships with Allied Health Professionals, among other things.

As we headed towards the end of the year, life started to get back to a bit more normality with the commencement of the redesign of the Equipment Service function, Amanda and the Services Team getting more reach (“touch points”) to Clients than ever before and the search for a new Fundraising and Communications Manager beginning. The emphasis across all of the Association activities became about “efficiency of process” and Customer/Client service. At the same time, we became far more familiar with the NDIS, its requirements and the potential impacts on our Clients.

Revenue for 2016 while hosting some outstanding events and activities, was $143,000 down on the 2015 year (excluding one-off year-end adjustments – refer later in this Report and the Treasurer’s Report). The prior year had benefited from revenue from large events including Wantz Ball, Brad Drewett Pro Tennis PRO AM, MND and Me donation and sizable bequest amounts. The 2016 year produced memorable events including the Brookwater Golf Day, Walk to D-Feet in Brisbane, Toowoomba and Chinchilla, Harley Owners’ Group ride, Ian Short Foundation Lunch, Bowl for Mobility and sizable contributions from clients and individual supporters. We never take bequests for granted and welcome them as contributions to support our services. Additionally, we express our appreciation to the Queensland Government for their contribution through the Department of Communities, Child Safety and Disabilities.

Our relationship with MND Australia continues to strengthen as we build awareness together and work through co-operative events such as MND Awareness Week. This important week in May was particularly effective through the lighting up the bridges in Brisbane. The State CEO's also meet monthly with Carol Birks, CEO of MND Australia, to discuss issues across the disease and further strengthen our bonds.

As the efficiency drive was applied to the Association activities, it was also applied to the Balance Sheet at 31 December 2016. While the final loss was $226,773 for the year, it includes a number of one-off charges which are considered necessary to present a tidier Balance Sheet. The Underlying Operating Loss, after excluding the extraordinary items, was $123,290 and $58,502 after excluding Depreciation. The one-off charges, detailed in the Treasurer's Report, involve adoption of more appropriate accounting treatments at year end, provision for potential loss of donations made as "trade dollars" and take up of merchandise inventory with emphasis upon stock which is readily saleable. These items will not be repeated in the 2017 year.

The 2016 year has laid the foundation for 2017 year with:

- Preparation for release of the Equipment Service as an on-line activity direct to Allied Health Professionals and other health professionals
- A streamlined MND Advisory Service with enhanced ability to achieve increased touch-points with Clients. This has set up the service to have a greater reach for engagement with our Stakeholders and, in particular, having a greater presence on the Sunshine Coast with Clients and health professionals including the Neurology Department at the new Sunshine Coast Hospital
- Commencement of the rebuild of the Fundraising and Communications function to a more robust and agile provider of support with the employment of Lisa Rayner from February 2017
- Development of a deep understanding of NDIS and its interaction with the Neuro-care joint venture

Two thousand and seventeen offers the opportunity to return to a stable staff situation which will only enhance the continuity of focus towards our goals.

The 2016 year would not be complete without thanking the staff at the Association as they showed great resilience to absorb operational difficulties and bounce back. Additionally, I must thank our Volunteers for their endless assistance and to you the Members. I trust that we have been supportive and if not, that you would feel free to tell us where we can be better.

MND Advisory and Equipment Service Future Insights

Amanda Pavey

In 2016 the Advisory team continued to provide an exemplary service to people with MND throughout Queensland. The learnings from that year and the impending rollout of the NDIS have informed our direction for 2017 and we thought it timely to highlight the implementation of a range of changes which have commenced this year.

Since January 2017 the MND Advisor and Equipment Service has undergone a number of major revisions to its service. Changes have been made to how we operate so that we can provide a more streamlined service to our clients. This includes a complete overhaul and modernisation of our equipment loan service to prepare us for the gradual introduction and integration into the State-wide National Disability Insurance Scheme. The MND Advisors have embraced many changes, and have done amazing things in their respective areas to build networks and improve the support and care people with MND receive.

At the start of this year a review process was undertaken to examine how we track our progress monthly and annually. Again, a number of new initiatives were identified and introduced to more effectively monitor our performance and impact on an annual basis. The way to increase such knowledge is to monitor trends within our client base more thoroughly. Tracking aspects such as where and to whom the registration packs are being sent, what percentage of these turn into client registrations, frequency of client visits, our total numbers of incoming and outgoing contacts with a client, Allied Health and 'other' persons, and what kind of reach we are getting across the State in terms of education sessions and networking opportunities.

Tuning our thoughts towards the NDIS and Aged Care systems these figures are going to produce an empirical base capable of tracking our Advisor and equipment activity, and how this relates to clients in the over or under 65 age group. These figures can also provide assistance for fundraising campaigns and reporting annual statistics for MND Australia ensuring we, as a State, are standing up to be counted on the National platform.

I believe it is easier to see the impact the Association has when we look at the output generated.

Therefore, these figures reflect the output of the MND Advisor and Equipment Team from January 2017 to June 2017. By the next annual report these will span the full 12 months of services.

- Number of phone calls undertaken by the MND Advisors – 945
- Number of emails sent or answered by the MND Advisors – 1,118
- Number of home visits undertaken by the MND Advisors – 161
- Number of support groups facilitated by MND Advisors – 21 (This does not include those facilitated by volunteers)
- Number calls and emails undertaken by the Equipment Officer – 877

The support groups have been a particularly pleasing growth area, with groups happening all over the state. So far, 21 groups having taken place already this year, well in excess of our annual total last year. Education to Allied Health and other Health Professional audiences are another focus for our team. Currently this year there is an average of two per month taking place ranging from Far North Qld all the way down to the Gold Coast.

Although I am unable to provide a full 12 months of figures, taking into account of the monthly averages it is possible to perform some early extrapolation of where the annual output may be by the end of the year:

- 5000 MND Advisor service phone calls and emails
- 450 home visits
- 60 MND Advisor facilitated support groups
- 2,500 phone calls and emails regarding equipment

The MND Advisor and Equipment Team currently have a full time equivalent staff level of 3.1, so I hope this brings into perspective how much we have undertaken and the positive results that are already evident. I look forward to being able to provide a comprehensive report next year with a full set of data as a result of changes made, including a report on the positive impact of our modernised equipment loan service by the end of the calendar year.

Motor Neurone Disease Support Groups

In 2016 we held support groups for people living with MND and for carers and others who are close to those living with MND. The groups varied in format and type of venue and reflected the needs of clients and their families. Most of the groups were coordinated by an MND Advisor, with some featuring guest speakers who spoke on topics of interest. The support groups have provided a great outlet for connecting with others going through the challenges of an MND diagnosis, and a chance to share ideas and experiences, ask questions and learn about what to expect.

Support Groups in 2016 were held in the following areas:

- Cairns
- Townsville
- Bundaberg/Childers
- North Brisbane
- Gold Coast

We plan to increase the formal support groups in 2017 into additional areas as we develop the geographical scope of our Advisory Team.

There were also a number of informal groups run by dedicated volunteers who sometimes incorporated small social and fundraising events into their activities. These helped provided interaction and connection for attendees as well as some additional fundraising income.

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Motor Neurone Disease Association Incorporation of Queensland
Established in 1983 and founded by Charles Graham (1925 - 1983)

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