



# OUR JOURNEY TOGETHER

Annual Report 2015-2016

**MJD**  
FOUNDATION



Hydrotherapy with Michelle Collins and Melinda Fajerman

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**MJD Foundation**

PO Box 414  
Alyangula NT 0885

[www.mjd.org.au](http://www.mjd.org.au)

1300-584-122

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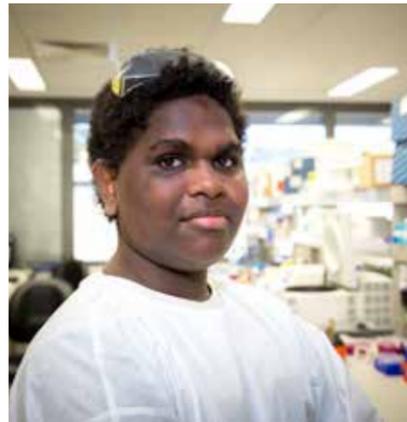
“ One of the most remarkable organisations in north Australia, the MJD Foundation plays a central role in helping patients and raising awareness of the condition. ”

Nicolas Rothwell, THE AUSTRALIAN, June 2012.



p.5 Vice-Chair Gayangwa Lalara from Groote Eylandt

p.4 Mary Galipiyawuy Bukulatjipi visiting the Zebra fish laboratory at Macquarie University. Photographer: Paul Wright



## THE MJD FOUNDATION

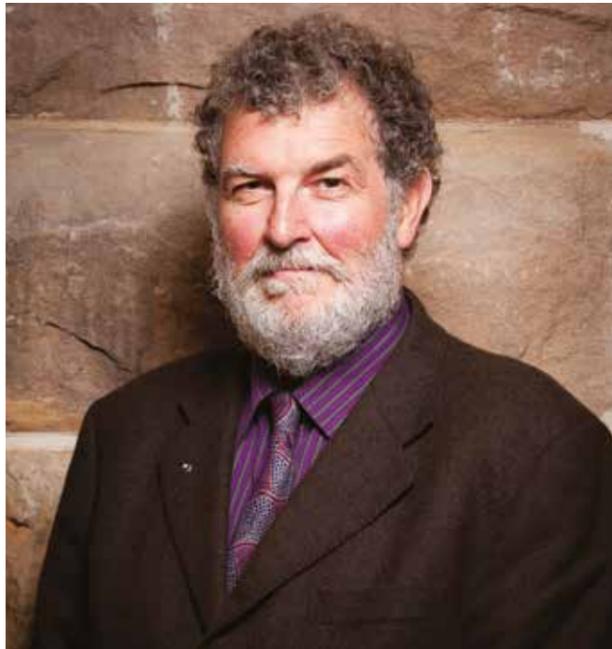
**E**stablished in 2008, the MJD Foundation seeks to improve the quality of life for Indigenous Australians and their families living with Machado Joseph Disease (MJD) in Arnhem Land and beyond.

Activities commenced on Groote Eylandt and have now rolled out to Bickerton Island (Milyakburra), Yirrkala, Elcho Island (Galiwin'ku), Darwin, Ngukurr, Urapunga, Numbulwar, Papunya (near Alice Springs), Hermannsburg (Ntaria), Santa Teresa, Goulburn Island (Warruwi), Oenpelli (Gunbalunya) and North Queensland, where the disease is prevalent.

The MJD Foundation is a charity with deductible gift recipient status. It prides itself on strong community and family connections, and working from a grass roots level to understand the needs of families affected by MJD.

The activities of the MJD Foundation are broad and ambitious for such a small organisation, but a great sense of pride is held in delivering on promises.

Activities range from provision of equipment and improving community services, to greater education opportunities for care workers and families and supporting critical research into MJD. The MJD Foundation is also a strong voice for clients and puts significant effort into advocating to government and other service providers in a collaborative manner.



## CHAIRPERSON'S REPORT

Neil Westbury PSM

“ MJD Foundation can again report a year of solid outcomes and achievements. Despite funding challenges and system changes, the organisation continues to improve on their critical role of service delivery, research and education.

”

This year has been full of challenges, yet the MJD Foundation has maintained holistic support of its clients. Fearless advocacy for its families, coupled with meaningful and credible engagement with Aboriginal people through employment in their communities, is how this is achieved.

The Foundation's achievements have been maintained despite the absence of any Northern Territory Government operational funding, and its fight for justice in the federal court against Minister Scullion's decision to overturn a previously approved and announced grant.

Aboriginal people affected by disabilities in the Northern Territory (NT) and their representative organisations face a watershed moment. Given the reality of current market failure and higher costs of service delivery in remote Aboriginal communities, it's timely for the Commonwealth and NT Governments to urgently rethink their approach to genuinely empowering Aboriginal people. Meaningful engagement is needed and consideration given to how Aboriginal people in remote communities will benefit from the National Disability Insurance Scheme (NDIS).

### National Disability Insurance Scheme

MJD Foundation have maintained a continuous effort to engage with the Commonwealth and NT Governments regarding the design and implementation of the NDIS in remote communities (predominantly at its own cost), with the aim to ensure the continuous mistakes of the past are not repeated. With the bilateral agreement signed by the Federal and NT Governments in May, the MJD Foundation is looking forward to continued opportunities to highlight those areas we feel need to be addressed in order for the NT rollout to be successful.

### Aboriginal Benefits Account

Minister Scullion's appeal against Justice Flick's previous Federal Court judgement overturning his decision to overturn the \$10m Aboriginal Benefit Account (ABA) grant to MJD Foundation was heard on 2 May 2016 by the full bench of the Federal Court. At the time of writing the Federal Court appeal decision is still awaited. The timing and outcome of this decision has implications for the continuation of substitute funding (i.e. equivalent to earnings from the \$10 million being invested) beyond the original 3-year grant subsequently approved by Minister Scullion that is due to expire on June 30th 2017.

### Genetic Education and Counselling

The ground-breaking and critical work in genetic counselling and education initiated by MJD Foundation in partnership with the late Associate Professor John MacMillan has been given a new and welcome impetus via our association with Victorian Clinical Genetics Services. Despite the importance of this work in prevention, we have sadly been informed by the Commonwealth Department of Health that continued funding support for this work is now unlikely.

### Facing Challenges

At the Board and organisational levels MJD Foundation has continued to evolve. With a view to meeting current and future challenges the Board commissioned an independent review and evaluation of what structural and organisational changes are needed to ensure continued support and credible outcomes for clients and their families. The review findings will be integrated into the Board's 3-year Strategic planning meeting to take place in February 2017. Thanks go to Beth Fiedler who undertook the review on a pro bono basis.

### Education and Resource Development

Extending the reach of service delivery and improving the overall care of people with MJD can be achieved through increasing health professionals awareness of the disease and its treatment approaches.

This year MJD Foundation in partnership with Remote Area Health Corp and the Federal Department of Health focussed their effort on developing a series of resources for health practitioners that outline best practice treatment methods for managing clients with MJD. Online resources are supported by educational workshops delivered by MJD Foundation.

### The People who make our work possible

Many thanks to Nadia and Libby and all the staff of MJD Foundation for their tremendous work and tireless effort helping our people. I again sincerely thank and acknowledge our many partners, sponsors, funders and volunteers whose contributions make this work possible.

Additionally I'd like to acknowledge the Warnindilyakwa Traditional Owners and thank Board members Tony Wurramarra and Gayangwa Lalara for their extraordinary joint efforts in securing an additional \$1m contribution from the Anindilyakwa Land Council (ALC) towards the MJDF's research activities. This contribution is of critical importance and will enhance the outcomes of the 2015 International Conference on MJD convened by MJDF in Cairns.

My appreciation also goes to South 32/GEMCO for their continued 3 year commitment to MJDF's work, not only on Groote Eylandt but in other Aboriginal remote communities in the NT.

Neil Westbury PSM

# HIGHLIGHTS 2015-2016

- Federal Court's decision to uphold our ABA grant, validated our decision to fight for the resources our people need - despite the federal government's decision to appeal.
- The opening of our first 'town' office in Darwin, reflecting the increasing numbers of clients moving into Darwin to access services.
- Awarded 'Excellence in Community Accesibility' at the National Disability Awards and Highly commended for 'Excellence in Innovation' at the NT Disability Awards.
- The heart-warming smiles of many of our clients as they return home for much needed 'Kin Connect' trips or have the opportunity to see new places with their families in the 'Holiday of a Lifetime' program.



Holiday of a lifetime to Sydney enabled Mary Galiplyawuy Bukulatjpi the opportunity to visit and understand the research at the Zebra fish lab at Macquarie Uni and experience some of Sydney's best sites, including Bondi Beach.

## WHERE THE MONEY COMES FROM



# FOCUS AREAS

## EDUCATION



- Finalised draft Medical Protocols and submitted for peer review
- Provided MJD education to CDU/Flinders University medical students for the 5th consecutive year
- Conducted Genetics education workshop for our Aboriginal Health and Community Workers
- Educated 40 care-workers on 'caring for people living with MJD'

## RESEARCH



- Increased our research focus by appointing a dedicated Research Officer to our staff
- Anindilyakwa Land Council announce \$1 million towards MJD research
- Kicked off a PhD study into Communication and MJD
- Commenced physical activity research to look at the benefits for people with MJD

## EQUIPMENT



- MJD Foundation vehicles are now all accessible
- Delivered 140 pieces of equipment to remote communities
- Purchased \$161,000 of new equipment
- Provided \$13,000 repairs and maintenance
- Acquired a Darwin dedicated office in Coconut Grove

## ADVOCACY



- Liaised regularly with NDIA and other stakeholders around the imminent rollout of NDIS across the NT
- Awarded 'Excellence in Community Accesibility' at the National Disability Awards
- Highly commended for 'Excellence in Innovation' at the NT Disability Awards
- Zebra fish research lab at Macquarie Uni received national coverage on the ABC

## IMPROVED SERVICES



- Established a partnership with Victorian Clinical Genetics Services to provide genetic education and counselling to remote communities
- Expanded our "Staying Stronger for Longer" therapy program across more communities
- Learnt more about MJD family pedigree by visiting Numbulwar

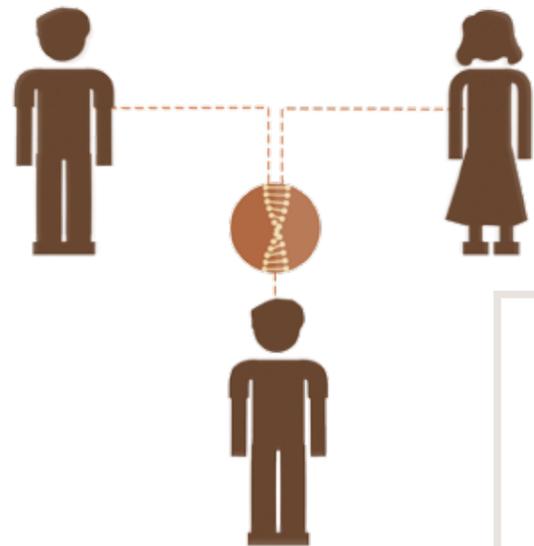
# WHAT IS MACHADO JOSEPH DISEASE?

MJD occurs because of a fault in a chromosome that results in the production of an abnormal protein. This protein causes nerve cells to die prematurely in a part of the brain called the cerebellum. The damage to the cerebellum initially causes muscular weakness and progresses over time to a total lack of voluntary muscle control and very significant permanent physical disability.

MJD is an inherited, autosomal dominant disorder, meaning that each child of a person who carries the defective gene has a 50% chance of developing the disease. In addition the mutation is typically expanded (worsened) when it is passed to the next generation (known as an 'anticipation effect'). This means that symptoms of the disease can sometimes appear around 8 to 10

years earlier each generation and are more severe.

There is no known cure for MJD. Progression to dependence occurs over 5 to 10 years after the onset of symptoms and most people are wheelchair bound and fully dependent for all activities of daily living within 10 to 15 years of the first symptoms emerging.



Machado Joseph Disease is a hereditary (genetic) neurodegenerative condition. It is in a 'family' of neurodegenerative diseases that includes Huntington's Disease.

## MJD IN ARNHEM LAND AND BEYOND

The effects of MJD have been known to the Aboriginal people of this region for at least four generations, although the first confirmed case was not diagnosed until 1995. Research that was released in 2012 used DNA Haplotyping and linked the genetic strain of MJD found in Australia to that found in Asia.

Although it is impossible to predict the number of Indigenous Australians who

will develop MJD, there are currently over 650 indigenous Australians thought to be "at risk" of developing the disease across the top end.

(At risk individuals are individuals alive today, who are direct descendents of those with the disease. If a parent has MJD, their child has a 50% chance of being born with MJD and therefore developing the symptoms at some stage in their life)

## HOW MJD AFFECTS YOUR BODY

"Worse and worse until I'm in a wheelchair then worse and worse still"



## WHERE WE WORK



The MJD Foundation seeks to provide a better quality of life for Indigenous Australians and their families living with Machado Joseph Disease in Arnhem Land and beyond.

### OBJECTIVES

**To provide a better quality of life for Indigenous Australians and their families living with Machado Joseph Disease in Arnhem Land and beyond by:**

- Providing improved services by working with and supplementing those services provided by the government
- Contributing to local and international research, and gaining an understanding of how this research can benefit Indigenous Australians living with MJD
- The implementation of practical solutions to help individuals understand and manage their symptoms
- Providing greater levels of community infrastructure and

transportation options to support the needs of individuals and their families living with MJD

- Facilitating comprehensive genetic education programs
- Advocating on behalf of individuals and families to all levels of the community and government
- Ensuring flow on benefits to the wider international MJD community through research and advocacy

**Our objectives are achieved through our five focus areas:**

#### Focus Areas

- Research
- Education
- Equipment
- Advocacy
- Improved Services

## ABOUT US

This year has been all about service. How to improve the service that we offer our clients; how to assist others to provide services that are the best fit for people with MJD and their families; and of course, gearing up for the National Disability Insurance Scheme (NDIS).

**For the first time in our history we are considering the MJD Foundation's place in the fee-for-service environment. Our investigation into the NDIS has encouraged us to analyse the services we provide and to identify the unique and challenging elements of what we do – and most importantly, what factors enable us to deliver remote services where others have failed.**

Our team has continued to develop their capacity, with a focus of learning from each other. This 'two way learning' is the bedrock of how we work. We have had several workshops during the year to share our experiences and consider better ways to do things. Given the multisite nature of our work, this has been an important and valuable means of keeping our staff strong - so that they can help people with MJD and their families stay stronger for longer.

We have also worked hard to develop resources that provide clear, accurate information about MJD. They provide best-practice methods of dealing with symptoms and people as a whole, to a range of health and community service practitioners. These have included the popular '[Clinical Approach](#)' and '[Proper Approach](#)' audio-visual resources. Additionally we have provided one-day face-to-face workshops for primary and allied health care practitioners in Darwin.

Several exciting research opportunities have also been planned that will be developed over the next few years.

Our association with Victorian Clinical Genetics Services (VCGS) continues to evolve and we are steadily establishing a body of evidence-based practice in genetic counselling, molecular testing and the education realm.

### HIGHLIGHTS

The November 2015 decision of the Federal Court to uphold our ABA grant was an important validation of the decision to fight for the resources our clients need - despite the decision to appeal by the Australian Government. The opening of our first 'town' office in Darwin. This decision reflects the increased numbers of clients moving to Darwin to access services and has already proven an invaluable asset in providing care to our MJD families.



Libby Massey - Director, Research & Community Services



Nadia Lindop - Chief Executive Officer

There is no doubt that the next twelve months has more to teach and that we as a service organisation have more to contribute.

**We look forward to it!**

## OUR WORK

**Improving service delivery has been the focus of this year. How to improve the services we offer and how to ensure other service providers offer the best quality of care for people living with MJD.**

For all of our staff and volunteers, both frontline and administrative, improving the quality of life of our clients and making memories for their families, provides the impetus to strive - in what is frequently very challenging work. It is the heart-warming smiles of many of our clients as they return home for much needed 'Kin Connect' trips or have the opportunity to see new places with their families in the 'Holiday of a Lifetime' program, that keep us all inspired.



Mary Galpiyawuy Bukulatipi visiting the Zebra fish laboratory at Macquarie University. Photographer: Paul Wright



Kaitleen Garrawurra attended Riding for the Disabled whilst in Darwin for respite

## RESEARCH

**Research Activities have emerged as a strong focus this year, building on the momentum of the International MJD Conference held in August 2015 in Cairns.**

The generous contribution of the Anindilyakwa Land Council (ALC) to the Foundation's research work, announced by Tony Wurramarrba at the Darwin office opening in February 2016, has enabled additional research activities to be scoped and planned. There are two exciting projects due to commence early 2017.

### 1. Mobility Study

Investigating the importance of mobility for people with MJD, which

aims to assist with the development of optimal therapeutic plans.

### 2. Communication Study

Investigating the communication challenges, needs and goals of individuals and families with MJD, and how mobile digital technologies (such as iPads) support these goals.

### 3. Sleep Study

A further study to investigate the prevalence and nature of sleep disorders in MJD has also been approved by the MJD Foundation Research Advisory Committee and will also commence in 2017.

The MJD Foundation is also a partner

in the "Better Indigenous Genetic (BIG) health services" Genetic Education Evaluation partnership project jointly funded by both the NHMRC and the Lowitja Institute which also commenced during this period and will continue until 2019.

The existing MJD Zebra fish lab relocated to Macquarie University and the team continues to work hard to investigate potential treatments with very encouraging results. Our clients remain very keen to visiting the lab in Sydney, and we hosted Mary and her family in early 2016.



## IMPROVED SERVICES - CHANGING LIVES

The provision of health services, along with social & emotional support is a critical component of the MJD Foundation's work – providing physical and psycho-social support to improve the lives of people living with and affected by MJD. Highlighted below are a few areas of focus for 2015-16.

The MJD Therapy Program 'Staying Stronger for Longer' has continued with renewed enthusiasm, following research presented at our 2015 International Conference which strongly indicated the long-term benefits of physical activity, in particular physiotherapy, for people living with MJD at all stages of the disease. 'Physio on Country' trips are popular on Groote Eylandt as are stationary bike races!

Home exercise programs are monitored during community visits to Galiwin'ku and Ngukurr. Thanks to South32 (GEMCO) who continue to sponsor Active Performance's time.

Our Darwin clients continue to enjoy hydrotherapy, group physiotherapy and communication sessions.

The benefits are both physical and emotional, providing the opportunity to share and enjoy time together.

Our Groote Eylandt clients also benefit from regular speech therapy thanks to our wonderful Groote based volunteer speech therapist.

Responding to clients' needs as expressed by them is core to the way that we function. Emerging this year is a new program to assist the children in families with MJD to attend and flourish at school. Parents impacted by MJD experience very high levels

of fatigue, which can make schooling issues difficult for them to manage.

We have assisted with schooling liaison and applications, as well as contributing to the fundraising for a new accessible bus for Shepherdson College at Galiwin'ku with Variety NT.

For those clients who are living away from their home communities because of their care requirements, connecting to country is an important component of social and emotional well-being.

The impact of our Kin Connect program is seen on the faces of our clients who display huge smiles when they return home. It is these smiles that let our staff know we are really making a difference.



Physiotherapy session, Elcho Island



Careworker Education Workshop in Darwin  
Photographer: Kate Freestone

## EDUCATION

### Workshops

In keeping with our commitment to building capacity for people living with MJD and care providers, focused training for careworkers, health professionals and families affected by MJD were conducted throughout the year.

These included targeted sessions for medical and community services students at Charles Darwin University (CDU), conducted by both MJD Foundation clinical staff and clients living with the disease. The sessions provided unique first-hand insight into life with MJD. Sessions were also conducted for residential and community support staff in Darwin.

### Genetic Education

The Genetic education program has also gained momentum and our partnership with Victorian Clinical Genetics Services has enabled both more visits to communities by our genetic counsellor and the review of existing educational resources.

A workshop was held in Darwin in May 2016 and genetic education was also provided in the communities of - Galiwin'ku, Ngukurr and Urapunga, Angurugu, Hermannsburg and in Darwin and Alice Springs.

## ADVOCACY

The MJD Foundation continues to seek ways to raise the profile of the organisation and our Indigenous clients living with MJD in remote communities, where service delivery encounters many complex barriers.

In 2015-2016, a highlight for us was being recognised for our work in improving remote community accessibility at the National Disability Awards.

Much of this year has been dedicated to the National Disability Insurance Scheme (NDIS), and advocating for ways the National Disability Insurance Agency can improve their design when rolling out to remote communities.

The NDIS full rollout will begin from 1st January 2017, and we look forward to working hard to ensure our clients get the best NDIS plans possible.

This year we worked on a submission to the NT Department of Housing to highlight many of the deficiencies and inequities in 'fit for purpose' housing available for people living with disabilities in the NT. We will continue to meet with the new NT Government next year to ensure positive changes are made in this area.



New disability access ramp, Groote Eylandt Lodge



Nadia Lindop (CEO) MJDF collects the award for 'Excellence in Community Accessibility' at the National Disability Awards on behalf of the organisation

## EQUIPMENT

For many years the MJD Foundation has been working on improving community transport options for people with a disability, and in 2016 we now have vehicles on Groote Eylandt, Elcho Island and in Darwin that are all accessible. They either have wheelchair ramp access or passenger seat turny's that allow the front passenger seat to swivel out of the vehicle for easier access.

We were also thrilled to be involved in raising the last \$6,000 (through a crowdfunding campaign) needed to purchase a wheelchair accessible bus for Shepherdson College on Elcho Island, thanks to the Variety NT sunshine bus program.

And we were very excited to see the implementation of the new access ramp at Groote Eylandt Lodge that now allows wheelchair access directly from the car park to the disability accessible rooms. Thanks to GEBIE for funding the project and doing a wonderful job implementing our design.

### Highlights

- All MJDF vehicles are now accessible
- 140 pieces of equipment to remote communities
- Purchased \$161,000 of new equipment
- \$13,000 repairs and maintenance
- Acquired a Darwin dedicated office in Coconut Grove



# OUR PEOPLE

## The people who make it possible.

It's the combination of our dedicated staff, amazing volunteers, patrons, donors, community organisations we work with and our wonderful clients and families who make this work possible. You make us laugh, sometimes cry, but allow each day and each year to be different and provide us with the opportunity to grow – thank you for making this possible!

## STAFF

Chief Executive Officer	Nadia Lindop	Travel/Respite Coordinator	Kathy Massey
Director, Research and Community Services	Libby Massey	Manager, Education	Roslyn Kempton
Senior Cultural Advisor	Cayangwa Lalara	Community Worker	Joyce Lalara
Operations Manager	Morag Maclellan	Community Worker	Steve Wurramara
Manager, Community Services	Ali Beckwith	Community Worker	Brett Mamarika
Manager, Community Services	Mark Kilpatrick	Community Worker	Julie Gungunbuy
Manager, Community Services	Kate Pope	Community Worker	Wunungmurra
Manager, Community Services	Desireé LaGrappe	Community Worker	Hilroy Mangurra
Manager, Community Services	Melinda Fajerman	Community Worker	Bronwyn Daniels
		Procurement and Administrative Officer	Maymuna Yunupingu
		Accounts	Tina Hebblewhite
		Projects	Zeng Jones
		Projects	Peter Robson
		Genealogist	Emma Murphy
		Physiotherapist	Janine Ryan
		Physiotherapist	Nick Kenny
			Simon Mead



Our partners are the organisations that work directly with the MJD Foundation, to allow us to directly achieve our objectives. We wish to thank our partners and government, philanthropic and corporate sponsors for helping us achieve our objectives in 2015-2016. Your contribution makes an enormous difference.



Board, staff and clients take a fishing trip on Groote Eylandt

## BOARD MEMBERS

Chairperson	Neil Westbury
V-Chairperson	Gayangwa Lalara
Treasurer	Janice Oake
Secretary	Kathy Massey
ALC Rep	Tony Wurramarrba
Family Rep	Jennifer Baird
Ex-Officio	Libby Massey
Ex-Officio	Nadia Lindop

## PATRONS

Professor Garth Nicholson

## VOLUNTEERS

Michaela Jackson, Melinda Lalara, Bryan Massey, Greg Creecy, David Conley, Sally Lang, Nicola Rangeley, Karen Munro, Lorna Brunton, Nan Jamieson, Peter Fisher, Ashlee Coleman, Ashton Kealy, Ben Ngwele, Brendan Kenny, Colleen Kenny, Melinda Simmons, Jill Simmons, Philip Meadors.

## DONOR ORGANISATIONS

South32 (GEMCO), Groote Eylandt & Bickerton Island Enterprises (GEBIE), Telstra Corporation, Groote Eylandt Aboriginal Trust (GEAT), Overgrove P/L, Alyangula Swans Football Club, Rotary Club of Sylvania, Workpack group, CWA Alyangula.

## GRANTS

Telstra Foundation (Digital Inclusion communication program), Department of Prime Minister and Cabinet, Federal Department of Health, Variety NT, Youngcare, NT Government.



Henrik Pallos climbs Mount Dixon to raise funds and advocate for MJD Foundation.  
p.25 Henrik Pollas, Mount Dixon. Volunteers and clients stop for lunch

## EVERYDAY HEROES

“ A hero is somebody who is selfless, who is generous in spirit, who just tries to give back as much as possible and help people. A hero to me is someone who saves people and who really deeply cares. ”

Debi Mazar

### In the business of making change, going the extra mile is something that makes our work possible.

The gift of a volunteer's time or the effort to raise funds that support the MJD Foundation, are the everyday acts of heroes.

Henrik Pallos, a Senior Lecturer of Anatomy and Physiology at Charles Darwin University, Northern Territory, Australia, Iugged Marieb & Hoehn: Human Anatomy and Physiology up Mount Dixon in December 2015 – why?

He was lecturing on motor-neuron diseases when a student shared information about the MJD Foundation and he felt drawn to raise awareness about MJD and the work of the Foundation.

His decision to climb Mount Dixon was personal, but his choice to raise money and awareness about MJD and the work of the MJD Foundation was heroic. The \$2500 he raised contributed to the work of the organisation. Thank you Henrik and all the remarkable people who contribute to the Foundations efforts.



## INDIVIDUALS

Alice Lloyd, Prof Bart Currie, Sarah MacMillan, Barrie Spalding, John Payne, Anne DeSalis, Lorraine Richardson, Scott Charles, Matthew Stormont, WR Hearn, Janine Agzarian, Isobel & James Walker, Kenton Amshoff, Asiya Ashraff, Leanne Baird, Emily Barrows, Ruth Barrows, Susan Barrows, Jess Bayly, Margaret Beattie, Beth Black, Lily Bonnici, Janet Bradbury, Emma Branigan, Karin Brown, Matilda Cameron, Eloise Campbell, Karen Clark, Lauren Clark, Jackie Coates, Katie Cox, Marian Davis, Mandy Doherty, Emma Dumas, Anne Edmonds, Lucy Edmonds, Melinda Fajerman, Natalie Falzon, Jess Fatnowna, Graeme & Jane Frazer, Rachel Golden, Shirley Golden, Michael Gray, Lorna Gregory, Jacinta Gurruwiwi, Geoff Guymer, Marie Tina Hebblewhite, Joy Hogg, Caroline House, Denise Hoyle, Dung Huynh, Rod Inglis, Rosslyn Jennings, Shea Jones, Yvonne Jones, Ann Kakaliouras, Ashton Kealy, Micaela Kemm, Katherine Kerr, Santana Khurana, Mary LaGrappe, Neil Lanceley, Cheuk Keun Li, Nadia Lindop, Morag MacLennan, Russell Martin, Libby Massey, Beth McMullan, Simon Mead, Catherine Mellors, Elizabeth Milewicz-Tyson, Frank Mofflin, Darcel Moyle, Patrick & Sabine Doherty, Ian O'Reilly, Anne Patton, Alisha Pengelly, Natalie Perry, Eric Peterson, Alan Phillips, Rev Reg & Margaret Platt, Kate Pollard, Richard Preece, Kelly Rafferty, Elyce Richards, Lesley Robertson, Justine Rogers, Naomi Ruluminy, Anita Sharma, Renee Shephard, Sam Sheridan, Alexandra Soloman, Cathy Spur, Pascale Stendell, Michael Turbett, Jessica Waggoner, Lynne Walker, Polly Wheen, Georgina Whitehead, Jo Whitehead, Judy Wolff

# OUR FINANCIAL STORY

## STATEMENT OF PROFIT OR LOSS

FOR THE YEAR ENDED 30 JUNE 2016

	Note	2016 \$	2015 \$
<b>REVENUE</b>	7	2,206,697	2,472,909
Administration Fees		(24,715)	(121,824)
Advertising & Marketing		(17,277)	(25,243)
Bank Charges		(1,345)	(833)
Computers & Office Supplies		(16,175)	(14,786)
Clients Care & Support		(399,764)	(303,151)
Depreciation Expenses	8	(51,358)	(28,448)
Employment Expenses		(824,311)	(721,003)
Freight, Postage		(9,089)	(14,405)
Insurance		(2,766)	(10,752)
Interest		-	(1,031)
Legal & Accounting		(6,900)	(4,220)
Assets written Off		(1,293)	(244)
Medical Research & Resources		(2,000)	(155,479)
Motor Vehicle Expenses		(21,788)	-
Office Building Expenses		(9,045)	-
Rent & Storage		(10,813)	(9,427)
Repairs & Maintenance		(12,910)	(29,877)
Travel		(323,086)	(247,821)
Other Expenses		(114,237)	(87,896)
Total Expenses		<u>(1,848,173)</u>	<u>(1,776,440)</u>
Profit/(Loss) for the year		357,824	696,469
Other Comprehensive income for the year		-	-
<b>Total comprehensive income for the year</b>		<u>357,824</u>	<u>696,469</u>
<b>Total comprehensive income attributable to the entity</b>		<u>357,824</u>	<u>696,469</u>

## STATEMENT OF FINANCIAL POSITION

AS AT 30 JUNE 2016

	Note	2016 \$	2015 \$
<b>CURRENT ASSETS</b>			
Cash & Cash Equivalents	15(a)	325,846	417,507
Receivables	9	229,255	188,729
Other Assets	10	11,921	7,746
Investments	11	8,087,915	8,038,408
<b>TOTAL CURRENT ASSETS</b>		<u>8,654,937</u>	<u>8,652,390</u>
<b>NON-CURRENT ASSETS</b>			
Property, Plant and Equipment	12	673,676	226,018
<b>TOTAL NON-CURRENT ASSETS</b>		<u>673,676</u>	<u>226,018</u>
<b>TOTAL ASSETS</b>		<u>9,328,613</u>	<u>8,878,408</u>
<b>CURRENT LIABILITIES</b>			
Payables	13	130,118	47,746
Provisions	14	48,955	42,230
<b>TOTAL CURRENT LIABILITIES</b>		<u>179,073</u>	<u>89,976</u>
<b>NON-CURRENT LIABILITIES</b>			
Provisions	14	32,050	28,766
<b>TOTAL NON-CURRENT LIABILITIES</b>		<u>32,050</u>	<u>28,766</u>
<b>TOTAL LIABILITIES</b>		<u>211,123</u>	<u>118,742</u>
<b>NET ASSETS</b>		<u>9,117,490</u>	<u>8,759,667</u>
<b>EQUITY</b>			
Retained Earnings		9,117,490	8,759,667
<b>TOTAL EQUITY</b>		<u>9,117,490</u>	<u>8,759,667</u>

# OUR FINANCIAL STORY

## STATEMENT OF CASH FLOWS

FOR THE YEAR ENDED 30 JUNE 2016

	<b>2016</b>	<b>2015</b>
	<b>\$</b>	<b>\$</b>
<b>Cash Flows from Operating Activities</b>		
Grants, sponsorships and donations received	1,779,139	2,024,957
Receipts from operations	(1,864)	49,803
Payments to suppliers and employees	(1,785,228)	(1,833,995)
Interest received	182,575	28,880
Dividends received	256,428	299,340
Net cash provided by (used in) operating activities	431,050	568,985
<b>Cash Flow from Investing Activities</b>		
Proceeds from sale of property, plant and equipment	-	-
Payment for property, plant and equipment	(509,373)	(143,266)
Proceeds from sale of investments	5,794,592	6,017,555
Payment for purchase of investments	(5,807,930)	(6,281,379)
Net cash provided by (used in) investing activities	(522,711)	(407,090)
Net increase (decrease) in cash held	(91,661)	161,895
Cash at beginning of the year	417,507	255,612
Cash at end of the year	325,846	417,507

## INDEPENDENT AUDITOR'S REPORT

MJD Foundation Limited ABN 65 159 208 867

In accordance with the requirements of section 60-40 of the Australian Charities and Not-for-profits Commission Act 2012, as lead auditor for the audit of MJD Foundation Limited for the year ended 30 June 2016, I declare that, to the best of my knowledge and belief, there have been:

- no contraventions of the auditor independence requirements of the Australian Charities and Not-for-Profits Commission Act 2012 in relation to the audit; and
- no contraventions of any applicable code of professional conduct in relation to the audit

HILL ROGERS ASSURANCE PARTNERS

  
Brett Hanger

 hillrogers

## WHY ARE THE TRAVEL COSTS SO HIGH?

Travel expenditure is one of the MJD Foundation's largest expenses. The difficulty we face is that provision of services in remote communities comes with a very high travel cost. Many grants that we apply for do not allow travel to be a large component of a project's cost, and in some cases the grant-giver stipulates no travel at all. Our Holiday/Respite Support/Kin Connection travel costs are also high with these trips being absolutely vital to the social and emotional wellbeing of our clients.

### Travel to remote communities is expensive

- A small single engine air charter from Groote Eylandt to Elcho Island (return) costs \$2,500
- A small single engine air charter from Groote Eylandt to Bickerton Island (return) costs \$520. (This is a 10 minute flight)
- For many months of the year communities are cut off because of the wet season, therefore accessing communities (such as Ngukurr) is only viable by chartered aircraft
- Many communities are islands or very remote and do not have a regular passenger service therefore the only option to access the community is by charter
- More of our clients are moving into residential care in Darwin and the MJD Foundation supports clients via our Kin Connect program to be able to go home to their home community each year
- Commercial flights from Gove to Darwin (return) can be up to \$800 (for a 1 hour flight)
- To take a client with high needs who lives permanently in residential care in Darwin back to their community for a Kin Connect trip costs up to \$10,000
- We conduct education and research in communities, and therefore bring specialists into communities

### How we reduce travel costs?

- All MJD Foundation Board, staff, medical specialists, researchers and clients always fly economy class
- The travel allowance for Board, staff and volunteers is well below the ATO recommended allowances
- The MJD Foundation aims to partner with other organisations to borrow vehicles and stay in free of charge accommodation where possible
- Coordination of charter requirements with other organisations to share costs
- The MJD Foundation has some wonderful sponsors who assist to keep our costs down:
  1. The Groote Eylandt Lodge provides us with free accommodation on Groote Eylandt and in 2015-2016 saved us over \$30,000 in accommodation
  2. Airlnorth donated 8 return flights to the MJDF in 2015-2016.
- Clients are registered with a QANTAS carer concession card to receive discounted flights
- Board meetings are scheduled where possible at non-peak travel times

## AWARDS

MJD Foundation received an Award for Excellence in Community Accesibility at the National Disability Awards and was highly commended in the category of 'Excellence in Innovation' at the NT Disability Services Awards



### NATIONAL DISABILITY AWARDS

MJD Foundation was honoured to receive an award for 'Excellence in Community Accessibility' at the National Disability Awards held by the Federal Government to celebrate International Day of People with Disability.

The Awards aim to honour and recognise the outstanding achievements of individuals and organisations that have improved the lives of people with disability and thereby contributed to increased recognition of equality and human rights for all Australians.

The Award categories celebrate and acknowledge people and organisations who demonstrate excellence, passion, vision and a commitment to assisting people with a disability to achieve their goals.

### NT DISABILITY AWARDS

In the category 'Excellence in Innovation', MJD Foundation received a 'highly commended' award at the NT Disability Services Awards..

The NT Department of Health, in collaboration with National Disability Services NT, has been running these awards since 2011. The awards set out to promote the value of a career in the disability workforce and to celebrate the positive contributions of the NT community in creating opportunities for people with a disability

# DEDICATIONS

## DAVID DANIELS

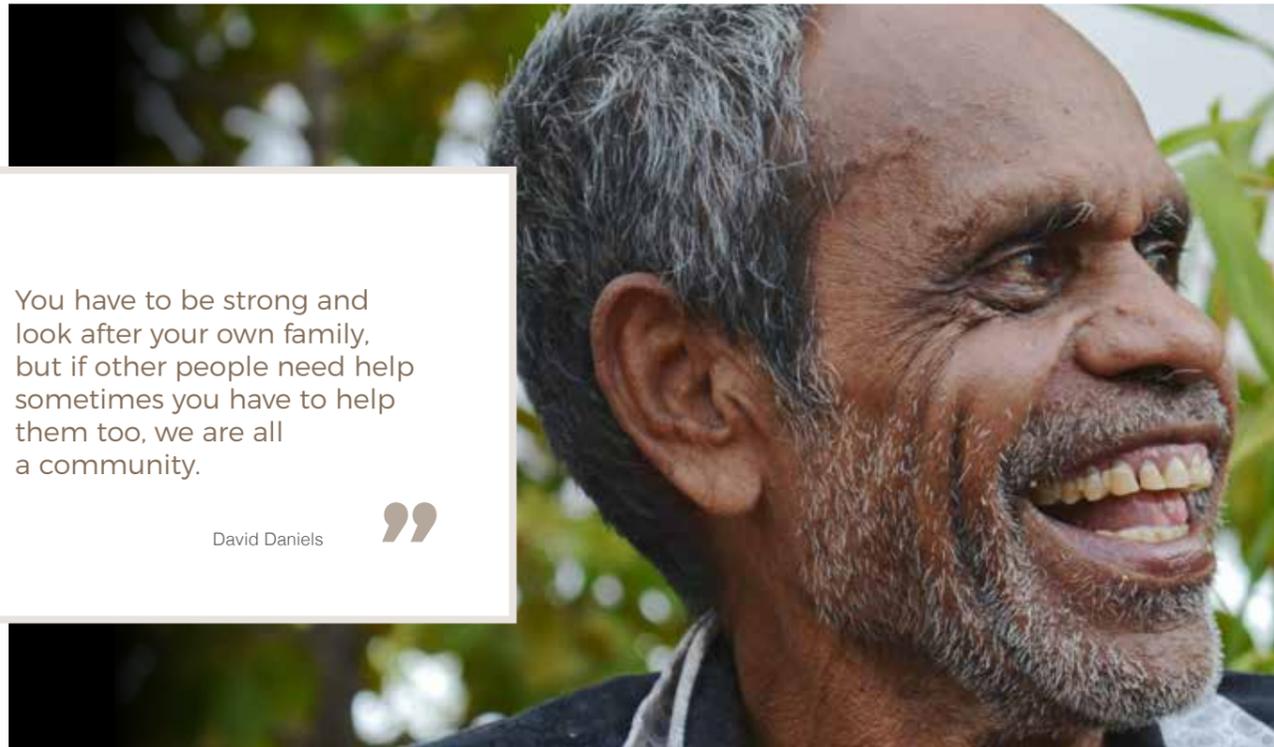
27/12/1946 – 21/06/2016

David was the boss man, not big in stature but big in heart and strong in mind. When he talked people listened and followed him. He always wanted the best for his people and he wasn't afraid to ask for it. His life was dedicated to caring for his family and other children who didn't get the love and support he felt necessary. It didn't matter to David if they were blood relatives, in his eyes they were all kin and he extended his heart and home to anyone.

As the community leader at Ngukurr for over 30 years, he was proud of his people and passed down his traditions through stories and sharing his skills as a bushman. He believed "blacks and whites had to work together" and often said "we all have to learn from each other". His legacy has been documented in many books about the area.

Even when he was getting old and weak he still tried to visit country in his electric wheelchair. One day he even drove it all the way to Wilton until he got stuck in the soft sand and fell out. Lucky he was found and taken home before it got dark. Even though he was in a wheelchair for the last few years of life he was always trying to walk around as much as he could and stay strong and active with exercise. He loved to go swimming and fishing in the creek and going for long drives around his country.

He was much loved and will be greatly missed, but very happily remembered.



“ You have to be strong and look after your own family, but if other people need help sometimes you have to help them too, we are all a community.

David Daniels



“ We are all visitors to this time,- this place. We are just passing through, our purpose here is to observe, to learn, to grow, to love... and then we return home.

Aboriginal Proverb



## THANK YOU

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It makes me more comfortable now to know that there are people helping my family and other families with this disease. I am proud of the MJD Foundation and when I finish up I will know that the MJD Foundation will be around for a long time to keep helping.

**Gayangwa Lalara**  
Vice Chairperson



THANK YOU FOR BEING  
PART OF THE JOURNEY  
IN MAKING A BETTER  
FUTURE FOR PEOPLE  
LIVING WITH MJD



"The MJD Foundation is extremely appreciative of the support of South32 in funding the publication of this Annual Report. It is through this publication that we are able to provide an annual picture of the important work being done for families living with MJD".



Front cover: Kaitleen Garrawurra doing her physiotherapy on Elcho Island. Photographer: Nick Kenny

Back Cover: Back cover: Out and about on Groote Eylandt (top), (left to right) Stationary bike races a hit at physiotherapy, Libby Massey and Gayangwa Lalara work with families at Numbulwar, MJD staff members Desireé LaGrappe, Brett Mamarika and Mark Kilpatrick attend Safe Driver training

