



**MJD
Foundation
Annual
Report
2013/2014**

THE IMPORTANCE OF LANGUAGE



On Friday 16th August 2013, the Governor General of Australia Quentin Bryce visited Groote Eylandt to launch the MJD Foundation's DVD "MJD Family Business – Messages for Women". Here is an extract from her speech.

"As many of you may know, earlier this year Tony Wurramarrba accompanied me as part of a small delegation to Canada to meet Indigenous Canadian leaders and exchange ideas. I very much enjoyed my conversations with Tony and it was during this time that I became aware of Machado Joseph Disease and in particular its devastating impact in Arnhem Land. Since 2008 this community, your community, has been the key driver in establishing and supporting the MJD Foundation and has helped form an organisation that is strongly community driven in meeting the needs of people living with MJD.

I understand that there are now over 550 Indigenous Australians alive today in the Northern Territory who are at risk of having MJD. And Groote Eylandt is not the only community affected. It is also highly prevalent on Elcho Island, Yirrkala near Nhulunbuy and Ngukurr on the Roper River. And, there are also families in Central Australia with the disease.

The MJD Foundation has a challenging task ahead to support the growing number of people with MJD, and education tools such as the Women's DVD we will see to this evening will play a vital role in being able to reach more people. It is my pleasure this evening to officially launch the DVD 'MJD Family Business – Messages for Women'. This DVD will be an important way for women and families to learn more about Machado Joseph Disease. It has been developed by Aboriginal women in communities affected by MJD to ensure that people in families with the disease are able to have access to information about the genetic / inheritance features of MJD that is clear and simple and in their own language.

The MJD Foundation is to be congratulated on taking the approach of developing these important messages in language.

If I can quote from the great man Nelson Mandela 'If you talk to a man in a language he understands, that goes to his head. If you talk to him in his language, that goes to his heart.'

Thank you"

MJD Foundation

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Cover Photos:

Groote Eylandt physiotherapy session

Stephanie Nganjmirra and Ellen
Christian

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Chairperson's Report 2013-2014

As this year's staff report makes clear it has been yet another very challenging 12 months for the MJDF Foundation, but one that reflects continued steady and concerted progress across a wide range of fronts.

This has included a further expansion of MJDF's staff presence on the ground in the communities where its work is primarily focused. This expansion is in direct response to the growing needs and numbers of clients and the fact that many of the normal mainstream government services that are required still remain virtually non-existent in many remote Indigenous communities.

Other highlights include the development of first language tools and the continuing focus on improving peoples' understanding and knowledge of both the causes and impacts of MJD at the individual, family and local community levels. This educational role being fulfilled by MJDF also extends to raising awareness in the broader community more generally, be it with service providers and their staff who play a variety of critical roles in the lives of individuals and families living with MJD, or those charged with developing policy and programs under the National Disability Insurance Scheme (NDIS).

In this latter context Libby, Nadia and myself were invited to make a presentation to a number of senior officers of the National Disability Insurance Agency (NDIA). These discussions have already borne fruit with MJDF being invited to participate in a reference group that is providing advice to the NDIA on the challenges and opportunities available in helping ensure the NDIS is designed in ways that most directly benefit our clients and their families. Some solid ground work has also been continued in building relationships and alliances with the First Peoples Disability Network and other groups advocating on behalf of people living with disabilities.

These discussions have also served to again highlight that by virtue of the Commonwealth legislative requirement that the NDIS primarily target those people with the most severe disabilities; this will mean that most of MJDF's current and projected work will not be supplanted by the NDIS, and will remain as relevant as ever for the foreseeable future.

We are also undertaking some critical work with Telstra, who is kindly assisting us to examine ways in which we improve our own internal and external communications utilising the latest technologies and software. Being an organisation that is spread far and wide across vast areas, this work should prove invaluable and also help directly inform a review of our organisational structure in 2015.

In last year's Annual Report I referred to the fact that Minister Scullion was reviewing a \$10m grant from the Aboriginals Benefit Account (ABA) approved and publicly announced by the previous Minister. These monies were to be specifically directed to the needs of people living with MJD in communities with inadequate services. Despite MJDF's best efforts to meet and convince him otherwise, plus strong support from our clients and corporate supporters, the Minister still proceeded to overturn the previous grant approval. Whilst the Minister subsequently agreed to funding equivalent to what would have been earned by interest from the grant, these are limited to three years and fail to provide the same flexibility to respond to our clients' complex needs.

I again want to acknowledge and thank all our staff and fellow Board members for their dedicated efforts over the last year. You are all magnificent and the Board is very proud of your achievements.

Our various partners, sponsors, funders and volunteers have again all been critical in ensuring MJDF can continue its work. Many of our supporters have been with MJDF for either the entire or substantial part of the journey so far. In many cases you have enhanced your support over time as your confidence has continued to grow in MJDF's work. We are very mindful and grateful for this continued support and the critical importance of our relationships with you all.

In closing I would like to reiterate Libby and Nadia's comments regarding the successful application through the NHMRC for continuing the ground breaking research in partnership with the ANZAC Research Institute and the Brain & Mind Research Institute. It's important to again acknowledge that this research was only possible due to a significant seed fund from the Anindilyakwa Traditional Owners of Groote Eylandt from their mining royalties.

In this context it is therefore important to take time to reflect on just how critical the role of the MJDF has become, and that the vision of our Vice-Chairperson Gayangwa Lalara and others who originally conceived the need for the MJDF continues to be vindicated.

A handwritten signature in blue ink, appearing to read 'Neil Westbury'.

Neil Westbury PSM
Chairperson

Staff Report 2013-2014

This report has been one of the most challenging that we have written since the MJD Foundation was launched in 2008.

There is no doubt it has been a year of incredible growth and change. It has also been marked by some significant and distracting hurdles and sadly, it is also the first year when we have had to farewell more of our MJD family than can comfortably fit on the back page of the annual report – a page that in many ways is the most important one in this document.

The people who have gone this year have lost their battle with MJD, but they remain the inspiration for an incredible team - now numbering 17 staff members, 6 board members and a growing volunteer team, who are dedicated to changing the world that others with MJD live in. The experiences of those who have passed will continue to colour and inform the work of the MJD Foundation and their bravery will always inspire us.

From the inception of the organisation, the clear message from our families has been the need for MJD to be dealt with in community, in language and with the endeavours of local people first and foremost.

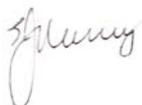
This has been our focus and has been the genesis of some remarkable partnerships. Our team of community workers is growing steadily, with families slowly and surely guiding the appropriate people into the roles. They in turn mentor and assist our team of skilled health professionals, enabling genuinely community driven responses to the issues that living with MJD raises. This remains an imperative as the numbers of those with symptoms in communities continues its inexorable climb.

During this year we have prioritised the use of first language tools developed by the MJDF to explain the genetics and care requirements of MJD to people at risk and dealing with MJD. The DVDs were crafted and voiced by our team of community workers, staff and visiting specialists. It is difficult to accurately reflect the difference that first language teaching brings - it is genuinely profound.

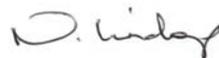
The core work of the MJDF continues across the education, research, improved services, equipment, and advocacy spheres. Of note, this year has been the first delivery of hands on physiotherapy to families on Groote Eylandt with Ngukurr and Elcho Island planned for 2014/2015 - through the collaboration between BHP Billiton, Active Performance (Nick Kenny) and the MJDF.

The MJDF has also partnered with Flinders University and Charles Darwin University providing education to their medical students. A wonderful team of volunteers have assisted clients to return home via the 'kin connect' program and holiday trips and the MJDF has been thrilled to learn that the ANZAC Institute/Brain & Mind Institute zebra fish research project has been granted NHMRC funding – guaranteeing progress for several more years.

We are tasked with some significant strategic work over the next 12 months, considering and positioning the MJDF in the context of the changes that the new National Disability Insurance Scheme (NDIS) will bring. We welcome the opportunity to be part of this exciting initiative and to generate the improvements needed to genuinely provide for the care of people living with MJD.



Libby Massey
Director, Research & Community Services



Nadia Lindop
Executive Officer



What is Machado Joseph Disease?

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

MJD in Arnhem Land and beyond

Previously known as "Groote Eylandt Syndrome", the effects of MJD have been known to the Aboriginal people of this region for at least four generations.

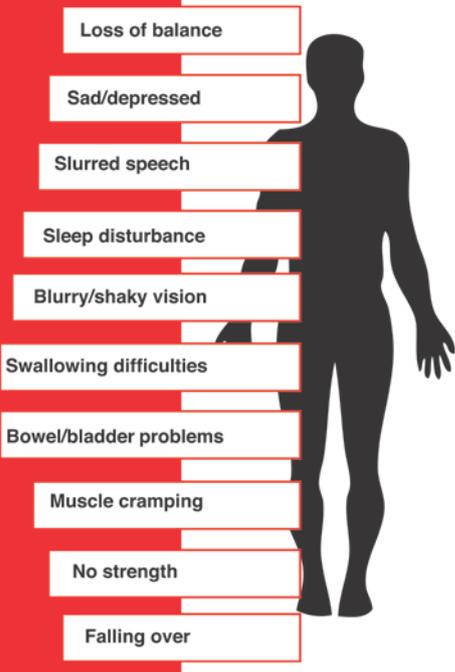
Following the discovery of the gene for MJD, "Groote Eylandt Syndrome" was confirmed as MJD in 1995 and there are people living with the disease on Groote Eylandt (Angurugu and Umbakumba), Bickerton Island (Milyakburra), Yirrkala, Elcho Island (Galiwin'ku), Darwin, Ngukurr, Urapunga, Numbulwar, Papunya (near Alice Springs), Hermannsburg (Ntaria), Santa Teresa, Goulburn Island (Warruwi), Oenpelli (Gunbalunya) and North Queensland.

Spread of the disease to Arnhem Land had previously (before Feb 2012) been attributed to the 16th Century trading and exploration activities of Portuguese Sailors. Entry into the Australian population was thought to have been through trading relationships between the Aboriginal people of Arnhem Land and the Macassan people of Indonesia, who in turn traded with the Portuguese. However in February 2012, research was published which effectively rules out a Portuguese link, and instead points to a direct Asian link based on an international DNA Haplotyping study.

Although it is impossible to predict the number of Indigenous Australians who will develop MJD, there are currently over 550 people alive today that are 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)

MACHADO JOSEPH DISEASE HOW IT AFFECTS MY BODY



- Loss of balance
- Sad/depressed
- Slurred speech
- Sleep disturbance
- Blurry/shaky vision
- Swallowing difficulties
- Bowel/bladder problems
- Muscle cramping
- No strength
- Falling over

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



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This Chinese coin is dated between 1736 and 1795 and was recently found on a beach on Elcho Island – Source: ABC News

Mission Statement

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

Activities

The activities of the MJD Foundation are organised as follows:

- Research
- Education
- Equipment
- Advocacy
- Improved Services

Locations



The MJD Foundation commenced on Groote Eylandt and Bickerton Island, but has now rolled out programs and services to other communities in Australia where there are Indigenous Australians living with Machado Joseph Disease. We are currently focussing on Galiwin'ku (Elcho Island), Ngukkur/Urapunga and Darwin.

Full rollout of programs and services to all affected communities where there are Indigenous Australians living with MJD is dependent on future funding.





Steve Wurraramara at the official opening of the Angurugu Library ramp

Equipment

It was all hands on deck to get Angurugu Library wheelchair accessible when a 27 metre ramp was installed. The Aussie Ramp was funded by a donation from the GEMCO RMS team, along with MJDF sponsorship funds from BHP Billiton. The ramp was shipped to Groote Eylandt free of charge by Toll Marine Logistics and thanks to Betapave who donated the concrete to cyclone code the ramp. An afternoon BBQ was enjoyed by the community as the Library Ramp was officially opened by MJDF client and staff member Steve Wurraramara.

During 2013-2014 the MJDF purchased \$95,000 worth of new equipment, and spent \$19,000 on repairs and maintenance.

Some of our equipment purchases throughout the year were:

- Physiotherapy tilt table
- Apple iPads (thanks to the Telstra Foundation)
- Ramps and grab rails
- Washing machines and clothes dryers
- Shower Commodes
- Wheelchairs
- Exercise bike
- Beds/mattresses
- Wheelchair maintenance tools

In May 2014, the MJDF was able to experience the latest in assistive technology, mobility solutions, pressure care, employment support, accessible recreation/holiday ideas, modified motor vehicles and a lot more at the Melbourne **Daily Living Expo**. The Expo also provided two days of clinical education workshops. Director of Research and Community Services, Libby Massey said: *"I really enjoyed the Expo and seeing our team gain this new knowledge. In particular I enjoyed seeing our Groote Eylandt staff and client representative cruising around and being able to see first-hand the options available. Our Aboriginal Community Worker Brett is really keen to trial a new type of beach wheelchair that he saw."*

Our equipment for 2013-2014 was able to be purchased thanks to the Newman's Own Foundation (in Paul Newman's memory), Anindilyakwa Land Council, BHP Billiton, Telstra Foundation, Federal Government, Centrecorp and generous donations from our individual supporters.





MJDF client Melinda Lalara and staff member Brett Mamarika with Dr Angela Laird and Professor Thomas Becker in the Zebra fish laboratory at the Brain & Mind Research Institute in Sydney

Research

The MJD Foundation continues to fund and support research projects through a grant of \$1 million provided in 2009 by the Anindilyakwa Land Council (ALC) and Groote Eylandt Bickerton Island Enterprises (GEBIE).

MJD Treatment (Zebra fish project) – This MJD Foundation (and Anindilyakwa Land Council/GEBIE) funded project with the ANZAC Research Institute located at the Brain & Mind Institute in Sydney continues to progress extremely well. This year the project was successful in attracting competitive NHMRC funding in order to continue the project for several more years. The team, lead by Dr Angela Laird, has recently been measuring the swimming patterns of Zebra fish with MJD. These measurements are critical in order to determine whether drug treatments are having an effect on the fish. They have also expanded the team to have several different research streams running at the same time. The team will present their findings to date at the 2015 MJD International Research Conference.

MJD International Research Conference - On 28th/29th August 2015, the MJD Foundation is hosting the International MJD Research Conference. Leading researchers from around the world will come together to present their latest scientific findings. The conference will have a molecular/neurological (curative/treatment) stream and a functional (quality of life) stream. ABSTRACT submissions will open in February 2015.





Stephanie Nganjmirra teaches CDU/Flinders Uni medical students about MJD.

Education

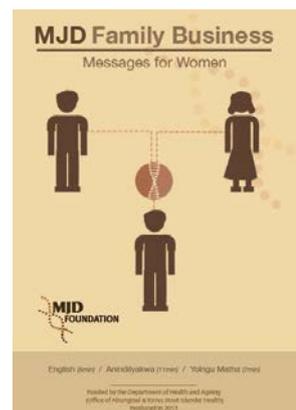
The MJD Foundation's education program has continued to expand throughout 2013-2014 with a strong focus on production of educational resources for families, careworkers and health professionals.

Genetic Education – the MJD Foundation has worked closely with Medical Geneticist Associate Professor John MacMillan since 2008 to provide genetic education to individuals and families living with MJD as well as to health clinics, schools, Aboriginal land councils and other community groups. The highlight of 2013-2014 was the production and launch of the DVD “MJD Family Business – Messages for Women” – an educational resource produced in 4 languages.

Health Professionals – the MJD Foundation staff and clients are conducting an annual two days of Machado Joseph Disease training to Medical students from Charles Darwin University and Flinders University. This is a great way to send 25 new graduate Doctors out into Australia having a better understanding of MJD.

Supporters of the MJDF Education program across 2013-2014 include: BHP Billiton, John T Reid Charitable Trusts, Federal Government Dept of Health, and the Rowan Nicks Russell Drysdale Fellowship.

The MJD Foundation continues to build on our education resources, and these are freely available on the resource tab of our website: www.mjd.org.au





Anna Lalara speaks with the NT News

Advocacy

As a charity, the MJD Foundation is reliant on funds from members of the public, corporate sponsorship, Aboriginal traditional owners, philanthropic organisations and government. In order to demonstrate the 'need' or to make a connection with people so that they understand where their money goes, we often ask our clients to go above and beyond where anyone with a disabling and terminal disease should have to go. To put themselves out there to the media, and have their story heard.

In doing this, we are constantly amazed at how gracious and beautiful our clients are in talking about their experiences. This year, when Minister Scullion overturned a previously Ministerially approved and publicly announced Aboriginals Benefit Account (ABA) grant of \$10 million, we saw a massive turnaround from our clients in their willingness to speak openly about what is happening for them, their families and the impact of MJD on their communities.



Groote Eylandters and Elcho Islanders unite.
Gayangwa Lalara, Julie Wunungmurra, Joyce Lalara, Steve Wurramara



Clockwise from top left: Carers' morning tea (Groote Eylandt); Kin Connect trip back to Groote Eylandt; Team Ngukurr; Holiday of a Lifetime to the Gold Coast.

Improved Services

MJD Therapy Program – “Staying Stronger for Longer”. In 2013-2014 we started to roll-out our therapy program to communities outside of Groote Eylandt especially focussing on Ngukurr, Elcho Island and Darwin. Thanks to BHP Billiton who continue to sponsor Physiotherapist Nick Kenny’s time. This adds to other formalised therapeutic activities such as hydrotherapy and speech therapy, and strategic on-country informal activities such as fishing and shopping, which all build upon the physical, social, mental and emotional health gains people experience when participating in their communities and lives.

Carer Support – In 2013-2014, the MJDF has focussed on carer support activities. People living with MJD in the severe stage require 24/7 care for all activities of daily living. The pressure on family carers is immeasurable, and the MJDF will continue to customise the support we provide to each family’s individual needs. Activities range from morning teas and social outings to supplementing government funded respite and transport assistance. The core principles of the program are: Recognition; Health and Wellbeing; Community Support Services; Education and Training.

Holiday of a Lifetime/Respite Support/Kin Connect Program – The MJDF continues to provide MJD clients from remote communities with social outings when on government funded respite in ‘town’, and Kin Connect trips home to community when they are no longer able to remain living in their community and have had to move to permanent residential care.

Neurological Assessments – the MJD Foundation (lead by Associate Professor John MacMillan) conducts formal neurological assessments of individuals with MJD (and at risk of having MJD) enabling the beginnings of baseline data collection and the capacity to track the progression of the disease in this population. In 2013-2014 an educational DVD was completed to demonstrate the SARA (Scale for Assessment and rating of Ataxia) to health professionals.



Our Clients – Joyce Lalara

Over the last few years, Joyce (who has moderate stage MJD) has been progressively relying on the use of her walking stick (“undawada”) or a 4 wheel walker for mobility, especially outside the home.

In 2013 Joyce commenced regular physiotherapy with Nick Kenny (Active Performance) on Groote Eylandt. Nick developed a physiotherapy program for Joyce with the goal of improving her balance, mobility and gait. The focus is on developing lower limb strength, core stability and gait exercises including using stairs. Balance improvement exercises and maintenance exercises for upper limb strength and gross and fine motor co-ordination are also done regularly.

Joyce has been very motivated with her program and she incorporates all the principles into her everyday routine. Joyce gets great satisfaction from making improvements with her physical functionality and she is determined to improve on her recordable outcome measures such as timed balance, stairs, walking speed and strength measures.

But a picture tells a thousand words – the photo above is Joyce in 2014 walking unassisted and without the use of her undawada or walker. Joyce proudly says *“They’ve been looking for that undawada some people! I’ve been doing my physio exercises and I’m stronger. I don’t need that undawada.”*

From Nick: *“I wish all of my clients were as dedicated as Joyce. She is a very strong and determined woman who absorbs everything we practice in therapy sessions. She makes a concerted effort to apply those learnings in to her everyday activities of daily living. Despite the realisation that MJD will continue to weaken her body as time goes by, Joyce is always positive and has not only maintained her functionality but she has improved on several physical markers, particularly balance and gait pattern. I am very proud of her progress and it is an honour to work with her.”*

Thanks to BHP Billiton who are funding the Physiotherapy program on Groote, and have now approved its rollout to our clients on Elcho Island and Ngukurr.



Thanks to TIO, a group of MJDF clients and their families enjoyed the AFL in Darwin.
 Pictured: MJDF Nadia Lindop and client Stephanie Nganmjirra.

Our Sponsors (2013-2014)

Thank you so much to our government, philanthropic and corporate sponsors for 2013-2014. Your contribution makes an enormous difference in allowing us to meet our objectives.





The MJDF and Motivation Australia partnered to deliver a wheelchair prescription workshop for allied health professionals. Pictured: Kaitleen Garrawurra with course attendees.

Our Partners (2013-2014)

Our partners are the organisations that work with the MJDF to allow us to directly achieve our objectives. We wish to thank the following organisations for their support during 2013-2014.





Top: Tina Hebblewhite, Julie Wunungmurra, Janine Ryan, Bryan Massey, Steve Wurraramara, Brett Mamarika, Nick Kenny, Nadia Lindop
 Bottom: Libby Massey, Gayangwa Lalara, Simone McGrath, Joyce Lalara, Ali Beckwith, Ros Kempton, Ellen Christian, Mark Kilpatrick

Board Members (2013-2014)

Chairperson	- Neil Westbury
Vice-Chairperson	- Gayangwa Lalara
Treasurer	- Janice Oake (incoming); Doug Talbert (outgoing)
Secretary	- Kathy Massey
ALC Representative	- Tony Wurramarrba
Family Representative	- Jennifer Baird
Ex-Officio	- Libby Massey
Ex-Officio	- Nadia Lindop

Staff (2013-2014)

Executive Officer	- Nadia Lindop
Director, Research and Community Services	- Libby Massey
Senior Cultural Advisor	- Gayangwa Lalara
Manager, Community Services	- Simone McGrath
Manager, Community Services	- Ellen Christian
Manager, Community Services	- Mark Kilpatrick
Manager, Community Services (acting)	- Bryan Massey
Project Manager	- Ali Beckwith
Travel/Respite Coordinator	- Kathy Massey
Manager, Education Resources	- Roslyn Kempton
Community Worker	- Joyce Lalara
Community Worker	- Steve Wurraramara
Community Worker	- Brett Mamarika
Community Worker	- Julie Gungunbuy Wunungmurra
Genealogist	- Janine Ryan
Procurement and Administrative Officer	- Tina Hebblewhite
Bookkeeper	- Zeng Jones

Patrons

Professor Garth Nicholson is a Patron of the MJD Foundation.

Volunteers (2013-2014)

Thanks so much to our wonderful volunteers for 2013-2014. Associate Professor John MacMillan, Michaela Jackson, Melinda Lalara, Desiree LaGrappe, Bryan Massey, Greg Creecy, Sally Lang, Nicola Rangeley, Lorna Brunton, Joyce Cox, Arthur Grogan.



MJDF client Sharon Thompson and project manager Ali Beckwith working on Sharon's iPad as part of the Telstra Foundation funded program.

Grants (2013-2014)

Telstra Foundation (Digital Inclusion iPad program), John T Reid Charitable Trusts (Genetic and carer education), Carers NT (Carers week event).

Donors (2013-2014)

Organisations

Groote Eylandt & Bickerton Island Enterprises (GEBIE), BHP Billiton, Groote Eylandt Aboriginal Trust (GEAT), Overgrove, NBC Consultants, Alyangula Cycling Club, The Friends School, Westfarmers employees, FaHCSIA social club, Day at the Races Event Committee (Groote Eylandt), Alyangula Kiosk and Newsagent.

Individuals

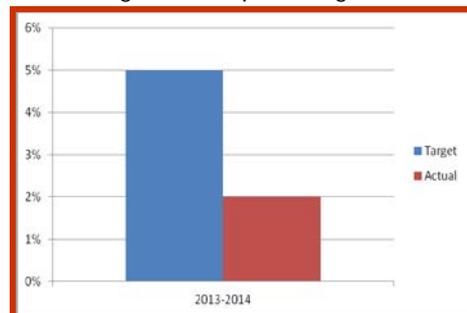
Col and Ali Lloyd, Professor Bart Currie, Suzanna Elliott, Averill Langrell, Jake Frazer, Elizabeth Milewicz-Tyson, Isobel Walker, Lorraine Richardson, Roger Layton, Margaret Wright, Matt Stormont, Sally and Michael Lang, John Payne, Jan and Max Boyley, Michelle Leonard, Leif Belton, Peter Milton, Jodie Weerakkody, Anne Horadam, Pam McGrath, Patrick and Sabine O'Doherty, Robert Martin, Michael Turbett, WR Hearn, Dr Tom and Dulcie Gavranic, Nicole Barry, Colin Hardy, Anna Petrozzino, Shenagh Gamble, Dr John Rowell, Georgina Whitehead, Lesley and John Zylstra, Dr Roger Livsey, Pascale Stendell, Anne Turnbull and the amazing Canberra women's running team.



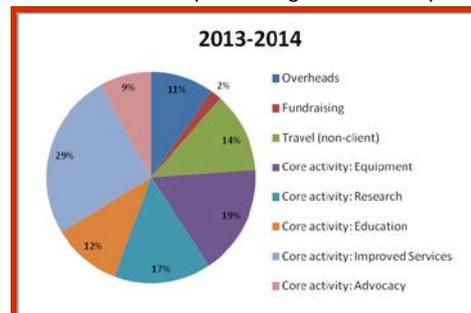
Financial Statements (2013-2014)

For a full copy of the MJD Foundation Annual Financial Report including all notes to the financial statements, visit www.mjd.org.au.

Fundraising cost as a percentage of revenue



Overall cost as a percentage of total expenditure



Balance Sheet (For the year ended 30 June 2014)

	2014 \$	2013 \$
Cash Assets – Operating		
Cash at Bank	255,612	286,020
NAB term deposits	1,421,381	1,447,386
Undeposited funds	9,815	0
Total Cash On Hand	1,686,809	1,733,406
Available-for-Sale Investments		
NAB term deposits	2,923,799	3,777,519
Fixed interest	1,951,714	1,000,814
Property funds	228,762	360,000
Domestic equity	539,924	779,865
International equity	390,000	240,000
NAB - CMF	40,881	187
NAB - 11am	127,907	160,831
Total Available-for-Sale Investments	6,202,987	6,319,215
Receivables		
Trade debtors	42,993	91,967
Accrued income	87,764	103,341
Current Tax Assets		
GST payable control account	(19)	0
Input tax credit control account	24,166	0
Total Current Assets	8,044,700	8,247,929
Non-Current Assets		
Property, Plant and Equipment		
Plant & equipment - at cost	85,832	81,247
Less: accumulated depreciation	(40,781)	(32,608)
Motor vehicles - at cost	116,992	109,719
Less: accumulated depreciation	(50,842)	(33,827)
Total Non-Current Assets	111,200	124,531
Total Assets	8,155,900	8,372,459
Current Liabilities		
Payables		
Trade creditors	26,112	37,130
Holiday pay liability	37,864	32,550
Other creditors	(422)	13,791
Current Tax Liabilities		
Amounts withheld from salary and wages	19,131	0
Total Liabilities	82,665	83,470
Net Assets	8,073,235	8,288,988

Financial Statements (2013-2014)

Profit and Loss Statement (for the year ended 30 June 2014)

	2014 \$	2013 \$
Income		
Grants	58,800	731,572
Donations	420,532	443,386
Bequests	0	15,353
Sponsorship	345,000	0
Merchandise sales	1,081	3,749
Other agency programs	13,653	0
Dividends	80,526	299,784
Interest received	319,259	177,602
Other income	21,818	17,141
Capital gain/loss	62,775	(184,760)
Rebates and refunds	950	2,510
Total income	1,324,394	1,506,335
Expenses		
Accountancy	900	900
Advertising and promotion	7,553	12,659
Bad debts	0	1,029
Bank fees and charges	837	399
Books and publications	434	0
Client carers (non salary)	108,557	75,916
Client meals	8,694	7,365
Computer software & others	3,556	1,485
Conference/seminar costs	5,031	12,364
Consultants fees	161,802	170,115
Delivery (freight)	10,271	2,313
Depreciation	23,808	25,930
Asset write-down	3,275	0
Equipment (<\$300)	12,795	7,941
Equipment (>\$300)	82,218	39,074
Filing fees	0	113
Gift	1,210	223
Insurance	13,533	12,399
Interest - Australia	1,302	0
Legal fees	3,000	0
Materials & supplies (merchandise)	0	4,627
Medical supplies	5,248	5,448
Medical research	220,000	216,000
Medical services	3,363	920
Medical resources (education)	8,221	14,558
Office consumables	5,347	8,977
Postage	3,454	5,613
Repairs & maintenance	18,297	20,891
Salaries - ordinary	438,036	342,918
Holiday pay provision	5,314	18,491
Employee fringe benefits	75,600	71,640
Rent / storage	1,912	236
Staff amenities	14	0
Staff training	3,396	4,502
Stamp duty	0	745
Subscriptions	3,074	4,288
Superannuation	39,219	30,140
Telephone/internet	12,136	11,430
Travel & accommodation	186,394	228,764
Travel - client respite/holidays	72,380	29,161
Total expenses	1,550,183	1,389,577
Profit from ordinary activities before income tax	(225,791)	116,758

Dedications

2013-2014 has been a year marked by some significant hurdles and sadly, it is also the first year when we have had to farewell more of our MJD family than can comfortably fit on one page of this annual report – a page that in many ways is the most important one in this document.

Johnny Djilipa Garrawara

15/08/1943 – 27/03/2014



Jane Wurramara

16/01/1969 – 10-01/2014



Rose Mirnyowan

10/09/1961 – 02/07/2014



Dedications

Johnny Djilipa Garrawara

15/08/1943 – 27/03/2014

The song 'My Island Home' may well have been written for this dignified old man. His enduring love for his home on Elcho Island and his deep commitment to his cultural responsibilities kept him firmly at Galiwin'ku despite very significant illness and limited community service support, right up until his death at the age of 71.

Like many families in the region Djilipa had seen his brothers and sisters die slowly, one by one of Machado Joseph Disease. He was the last of his generation in the family and will be missed by his wife children, grandchildren and great grandchildren. The commitment and care that they showed to him in life and their honour and mourning of him in death is a measure of the respect in which he was held.

You will be missed old man.

Jane Wurrarama

16/01/1969 – 10-01/2014

Jane's incredibly beautiful smile is still so easily brought to mind; the power and shy magnetism of that smile made her the 'poster girl' for so much of what the MJDF does. She was ever willing to allow her image to be used -to raise awareness and to participate in activities and outings to promote the care of her family.

Jane's devotion to her Naaman and his to her, despite the marathon they endured with MJD was legendary. Their joint love of being 'on country' and refusal to allow Jane's illness to limit them led to many many (sometimes funny) stories of escapades and drama's – who could forget the 'wheelchair dinghy' ride to Bickerton from Groote, or the time Naaman piggy backed Jane 5km's home after a flat tyre on a bush trip...

Jane was the inspiration for our current MJDF iPad program. Her ability to use the device to help us understand her world ensured that we will continue to try our hardest to unlock the worlds of others with MJD whose speech fails them.

We will miss her enthusiasm and precision (and some of us will miss our spelling being corrected by her!) but most of all, it will be Jane's grace, dignity and courage that we will miss. She lived her life with so much hope and love.

Rose Mirnyowan

10/09/1961 – 02/07/2014

Rose was the original 'warrior woman' she was fierce, proud, funny, and courageous. A real life legend – Rose was a person you met and could not forget. An incredibly hard lady to say no to, she had a way of fixing her gaze on you that let you know just exactly what she thought. And if that did not work there was always her tongue! We have many many treasured photos of Rose demonstrating her feisty attitude and irreverent humour. It is so hard to believe that she is not still here, knowing everything there is to be known about *everything* at Angurugu - and leaving no one wondering what she thought about it all!

Rose endured more than she should have and fought bravely to live her life with independence and dignity. She was truly one of a kind and will be missed by her husband Ernie, her sister and closest companion Roseanne, Gayangwa and all of her family on Groote.

Rose you will never be forgotten.

Auditor Statement (2013-2014)



MJD Foundation Limited ABN 65 159 208 867 Independent Auditor's Report

Report on the Financial Report

We have audited the accompanying financial report of the MJD Foundation Limited, which comprises the Statement by Directors of the Board, Profit and Loss Statement, Balance Sheet, notes comprising a summary of significant accounting policies and other explanatory notes for the financial year ended 30 June 2014.

Directors' Responsibility for the Financial Report

The Directors of the company are responsible for the preparation of the financial report that gives a true and fair view in accordance with Australian Accounting Standards and the *Australian Charities and Not-for-Profits Commission Act 2012* (ACNC Act) and for such internal control as the Directors determine is necessary to enable the preparation of the financial report that gives a true and fair view and is free from material mismanagement, whether due to fraud or error.

Auditor's Responsibility

Our responsibility is to express an opinion on the financial report based on our audit. We have conducted our audit in accordance with Australian Auditing Standards. Those Standards require that we comply with relevant ethical requirements relating to audit engagements and plan and perform the audit to obtain reasonable assurance whether the financial report is free from material misstatement.

An audit involves performing procedures to obtain audit evidence about the amounts and disclosures in the financial report. The procedures selected depend on the auditor's judgement, including the assessment of the risks of material misstatement of the financial report, whether due to fraud or error. In making those risk assessments, the auditor considers internal control relevant to the Company's preparation of the financial report that gives a true and fair view, in order to design audit procedures that are appropriate in the circumstances, but not for the purpose of expressing an opinion on the effectiveness of the Company's internal control. An audit also includes evaluating the appropriateness of accounting policies used and the reasonableness of accounting estimates made by the Board, as well as evaluating the overall presentation of the financial report.

We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our audit opinion.

Auditor's Opinion

In our opinion, the financial report of MJD Foundation Limited has been prepared in accordance with Division 60 of the *Australian Charities and Not-for-Profits Commission Act 2012*, including:

- a) Giving a true and fair view of the MJD Foundation's financial position as at 30 June 2014 and its financial performance and cash flows for the year ended on that date; and
- b) Complying with Australian Accounting Standards and Division 60 of the *Australian Charities and Not-for-Profits Regulation 2013*.

Signed on: 12th December 2014

A handwritten signature in black ink, appearing to read 'Nina De Luca', is written over a horizontal line.

Nina De Luca

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