

**MJD
Foundation
Annual
Report
2011/2012**

THE SMALL THINGS ARE SO IMPORTANT



The wonderful Josie Peerdeman presenting Nadia Lindop (MJDF) with crocheted rugs.



Nadia Lindop giving Jane Wuramarra her rug on Groote Eylandt.

MJD Foundation

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Cover Photos:

Sisters Melinda & Joyce Lalara

Steve Wurraramara & Hilroy Manngurra
(NTG Regional Arts Fund project "Our Story")

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Chairperson's Report 2011-2012

Working with the careful guidance and encouragement of Aboriginal people living with MJD across a number of communities in the Northern Territory, I am pleased to report that the MJDF has continued to meet increasing demands for its support and advocacy services and further enhance its educational role at the local, regional and national levels.

As a direct result of local community level engagement by MJDF, the identification of the number of people at risk of having the disease has drastically increased across the Territory. We are indeed on a steep learning curve as a result. This not only highlights the value and importance of the MJDF's work but also underlines the need to ensure the MJDF continues to work closely and strategically with all stakeholders in improving the well being of people living with MJD both now and into the future.

The increased numbers of people at risk also reflects the importance both the Board and staff have attached to raising awareness and educating remote communities, governments and the wider community regarding the implications for the provision of relevant disability and care services. The MJDF has also drawn these issues to Governments' attention (by direct representations in both Canberra and Darwin) in the context of the implementation of the proposed National Disability Insurance Scheme (NDIS) in remote communities. The MJDF has been successful in receiving NDIS funding to undertake a disability audit in selected remote communities which should assist in informing the design of more cost efficient and effective services relevant to the needs of local people, and which maximise local involvement and employment.

I also acknowledge the outstanding work by the staff effectively lead by Nadia Lindop and Libby Massey and the dedication and professionalism of all MJDF staff throughout the year in meeting the never ending challenges they face on a day to day basis. Special mention of Associate Professor John MacMillan is also warranted given his ongoing commitment to working in partnership with the MJDF and the critical contribution he is making at both the community level and more widely.

The importance of the continued support our loyal sponsors and donors cannot be overstated and I particularly want to thank our key sponsors, including the Anindilyakwa Land Council and GEBIE, the Aboriginals Benefit Account, Minister Macklin and FaHCSIA, Vincent Aviation, Dugong Beach Resort, Toll Marine Logistics, BHP Billiton and the Commonwealth Department of Health and Ageing.

I also want to thank the ongoing expert advice to the Board from the Research Advisory Committee and Finance Sub-Committees who provide outstanding expertise and support to the Board on a voluntary basis.

Notwithstanding a very productive twelve months the MJDF continues to face significant challenges which will feature prominently at our next planning day in February 2013. These include:

- Continued carefully targeted advocacy to ensure the establishment of a National Disability Insurance Scheme (NDIS) will result in the delivery of effective services for individuals and families who live with MJD; and
- The increased numbers of people at risk, especially in remote communities such as Galiwin'ku, Ngukurr and Yirrkala means that MJDF needs to raise significant monies to meet both growing demands and to support projects that contribute to improving individuals' and families' wellbeing.

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

Neil Westbury PSM

Staff Report 2011-2012

Finding a neat, precise way to sum up the previous twelve months for the MJD Foundation is becoming increasingly difficult – which is not such a terrible problem to have!

Reflecting on the reports written, activities conducted and general frenetic pace at which things have been progressing this year though, several themes are very clear.

*The first is that we are all on a very **steep learning curve**.*

We continue to learn about MJD as a disease, following and participating in frontline scientific research. Recently we have learnt that the MJD in our region is a particularly anticipation prone and aggressive form of the disease and therefore we will inevitably have younger and younger people experiencing the disease. Through our medical protocols project we are learning and documenting the best ways to assist people with MJD by medical and therapeutic means. We have learnt more about the geographical scope of MJD and the numbers of people affected in the NT and as a result of regular community visiting we are now aware of around 600 people alive today who are at risk of developing the disease.

We also continue to learn about how to conduct ourselves in the quickly expanding number of communities in which we work, being taught by those who know – those residents and families who have MJD.

As a result of this learning, we are able to modify and direct the way in which we operate. A significant change to our mission statement endorsed by our Board this year reiterates this – the word ‘sufferer’ has been removed replaced by ‘people living with’. The strength and graciousness of this group of people inspires and motivates us on a daily basis, and those ‘people living with’ MJD and their families continue to direct our community services. We have been fortunate to have been able to employ several community workers who are directly impacted by MJD this year through the generous support of organisations such as the Groote Eylandt Bickerton Island Enterprises (GEBIE) and the Aboriginals Benefit Account (ABA).

*Learning has resulted in the second theme for this year and it is its natural consequence – **education**.* What we learn we must pass on, and this year has been tremendous growth in our capacity to provide education across a range of scenarios – to the residential care worker, community service and professional health care sector and to families. We remain indebted to Assoc Professor John MacMillan for his ongoing voluntary contribution to this.

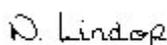
Our capacity to function in communities is determined by our funding and we have been successful in attracting government and philanthropic grant funding, we have a wonderful groups of corporate sponsors, and a growing group of individual donors to enable our continuing community engagement as well as to operate core programs such as ‘staying stronger for longer’ and ‘kin connect’.

It is clear that as an organisation the time is right to consolidate our learning, translating that into tangible directed support for families within all of the communities where people with MJD live. Our focus into 2013 will be on securing the funding to enable additional permanent positions in communities and to map needs and advocating for appropriate community based support services in those communities.

The road as they say is long... but we are privileged to travel it with a unique group of talented committed people (Board and staff) who have proven both their strength and their capacity to bend!



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.

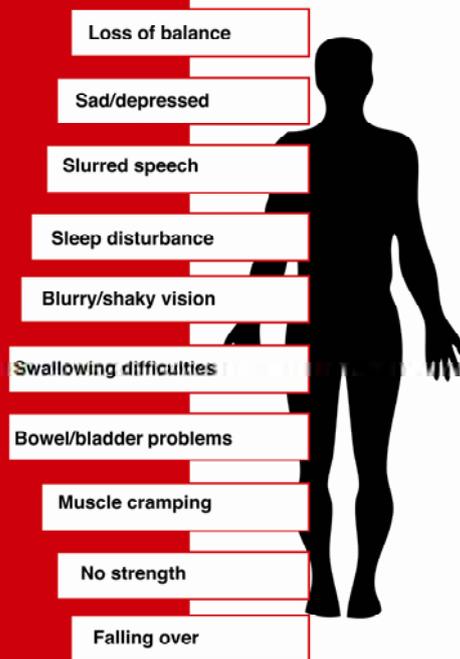
Following the discovery of the gene for MJD, "Groote Eylandt Syndrome" was confirmed as MJD in 1995 and there are people living with the disease on Groote Eylandt (Angurugu and Umbakumba), Bickerton Island (Milyakburra), Yirrkala, Elcho Island (Galiwin'ku), Darwin, Ngukurr, Urupunga, Birany Birany, Numbulwar,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

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.

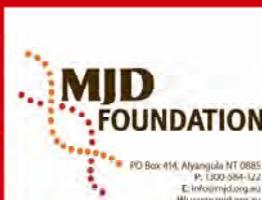
Although it is impossible to predict the number of Indigenous Australians who will develop MJD, there are currently around **550** (up 50 from our last annual report) people alive today that are thought to be "at risk" of developing the disease across the top end.

(At risk individuals are individuals alive today who are direct descendents of those with the disease.)

MACHADO JOSEPH DISEASE HOW IT AFFECTS MY BODY



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



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 continues to focus and pilot its activities on Groote Eylandt and Bickerton Island.

In addition, there is continued rollout of programs and services to other communities in Australia where there are Indigenous Australians living with Machado Joseph Disease.

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





Elcho Island aircraft wheelchair lift launch
Thanks to our sponsors for this project marked ** below
Feb 2012

Equipment

During 2011-2012 we continued to provide equipment to our clients and their families, along with a key focus on supplying equipment to strengthen infrastructure within communities.

Our equipment for 2011-2012 was able to be purchased thanks to the Newman's Own Foundation (in Paul Newman's memory), Anindilyakwa Land Council, BHP Billiton, NTG Regional Arts fund, TIO, Arnhem Land Progress Association (ALPA)**, Mercy Foundation**, Ross Divett Foundation**, Marion & EH Flack Trust**, Foundation for Rural and Regional Renewal**, Darwin International Airport Corporate Giving Fund**, Federal Government Employee Assistance Fund, Bunnings, Country Women's Association (Alyangula), Centrecorp and generous donations from our individual supporters.

During 2011-2012 we purchased \$110,000 worth of equipment, plus a new vehicle.

Some of our equipment purchases throughout the year were:

- Aircraft wheelchair lift for Elcho Island
- Electric beds (height and angle adjustable)
- Apple iPads as part of our improved communication and social & emotional wellbeing program
- Grab Rails
- Equipment for the Zebrafish research lab in Sydney
- Hoist scales
- Cooling vests
- Voice adapter
- Washing machines and clothes driers
- Shower chairs
- Electric Wheelchair
- Portable wheelchairs



A highlight for the year was being able to purchase a new Wheelchair accessible vehicle for Groote Eylandt thanks to BHP Billiton and TIO.



Joyce Lalara and Simone McGrath participate in Skype Telehealth therapy sessions with Professors Deb Theodoros and Liz Ward as part of the UQ Speech/Swallowing research.



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).

Speech/Swallowing – in partnership with the University of Queensland, the MJD Foundation has been looking at the difficulties around speech and swallowing for people with MJD. This ranges from determining therapeutic speech exercises to enable speech to be retained for longer, and current communication devices...all the way through to swallowing and food consistency guidelines.

MJD Treatment (Zebrafish project) – This MJD Foundation (and ALC) funded project with the ANZAC Research Institute in Sydney continues to progress well. In 2010, The Anzac Institute appointed Dr Angela Laird to lead the project reporting to Professor Garth Nicholson. Dr Angela Laird returned home to Australia in 2010 after working in Europe where she used Zebrafish to model other forms of neurodegenerative diseases.

Urinary Incontinence – work continues on this project which is expected to complete in late 2013. The project aims to determine the types and causes of bladder incontinence issues experienced by individuals with MJD, and develop best practice management protocols for these issues.

DNA Haplotyping - Australian medical researcher Professor Garth Nicholson (University of Sydney) and Portuguese Professor Jorge Sequeiros have been part of an international group of scientists who published their findings in Feb 2012 in the Archives of Neurology paper "*Mutational Origin of Machado-Joseph Disease in the Australian Aboriginal Communities of Groote Eylandt and Yirrkala*". The MJDF aided in facilitating this research in 2008. The research shows that the affected Aboriginal families of NE Arnhem Land share the more ancient "Joseph" strain of the disease with Asian affected families, and not the "Machado" strain of the disease found mostly in Portugal. This effectively rules out the prevailing hypothesis that the disease in Aboriginal Australians has a Portuguese ancestry (via the Macassan people of Indonesia). **The new prevailing hypothesis is now a direct Asian link.**





Associate Professor John MacMillan conducts a 'front verandah' genetic education session with the translation team at Galiwin'ku, Elcho Island.

Education

The MJD Foundation's education program has continued to expand throughout 2011-2012 with significant effort and resources put into existing and new components of the program.

Genetic Education – the MJD Foundation has for three years now partnered with Medical Geneticist Associate Professor John MacMillan to provide genetic education and counselling to individuals and families living with MJD as well as to health clinics, schools, Aboriginal land councils and other community groups. During 2011-2012 Associate Professor John MacMillan and the MJD Foundation's Libby Massey delivered these services to: Groote Eylandt, Darwin, Elcho Island, Ngukurr, Urapunga and Nhulunbuy. A highlight of the year was the MJD Foundation runner up award in the National Excellence in Indigenous Health awards.



Carer Education – This program was expanded in 2011-2012 targeting residential and respite care workers as well as family carers, all of whom are looking after people with MJD. As well as face to face training delivery, the MJDF has started developing a suite of education resources "Help Sheets". The objectives of the program are to:

1. Provide practical education around caring for someone with MJD.
2. Build empathy, confidence and resilience in the person caring for people with MJD.
3. Build a support network for people caring for individuals with MJD.

Wheelchair Prescription Workshop - In late May 2012, the MJD Foundation hosted a three-day wheelchair prescription workshop (run by Motivation Australia) for 22 Northern Territory allied health professionals. The workshop addressed an urgent need - how to prescribe a wheelchair for people with Machado Joseph Disease in remote Aboriginal communities.

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



Joyce Lalara attempting to depart from her house on
Groote Eylandt in the wet season

Advocacy

The MJD Foundation strives to be a strong voice for clients and families living with MJD whilst also maintaining strong positive partnerships with service providers be they government or non government organisations.

We advocate for a 'better deal for those (with MJD) in the bush' and refuse to accept the status quo. We have found that those we work with almost without exception share our view, and we want to thank those individuals we work with on the ground who are as passionate as we are and collaborate to get great outcomes.

Throughout 2011-2012 we have worked with organisations that have been open to hearing from us on how things can improve in the future. Thanks to:

- Federal Government's National Disability Insurance Scheme (NDIS) taskforce for allowing us to have a voice
- Federal Government's Strategic Indigenous Housing Infrastructure Program (SIHIP) for allowing us to prioritise our clients and work collaboratively to design appropriate home modifications
- First People's Disability Network for engaging with us and providing leadership training to people living with MJD
- Nicolas Rothwell for researching and writing "When Grief is a Family Legacy" published on 16 June 2012 in The Australian.

During this year we have also been delighted to initiate and participate in collaborative forums to facilitate information exchange and coordinated services within communities such as the Groote Supported Client Reference Group (GSCRG).



Backyard Blitz on Groote Eylandt

Improved Services

MJD Therapy Program – “Staying Stronger for Longer”. This program incorporates formalised therapeutic components such as hydrotherapy, but its strength is its “therapy by stealth” - the physical, social, mental and emotional health gains people experience through participation in informal or opportunistic activities provided in everyday living - such as... collecting firewood, moving furniture, carrying groceries.

Social and Emotional Wellbeing Program – Being accepted in your community; being able to communicate effectively; feeling empowered to make informed choices about your life and your body throughout the different stages of MJD are just some of the things that contribute to good social and emotional wellbeing. Some of our projects in 2011-2012 are:

- Apple iPads – this program is not only effective in improving communication, but has also created employment opportunities for some of our clients to film and tell their stories. Thanks to CWA Alyangula, Newman’s Own Foundation, NTG Regional Arts Fund.
- Hip Hop workshop – 20 Groote Eylandt kids from Angurugu who are facing the challenges of MJD in their families learnt how to make hip hop beats and raps from the award winning hip hop artist Nick Juan. Thanks to the Coca Cola Foundation.
- Backyard Blitz - The MJD Foundation, supported by BHP Billiton, Bunnings Warehouse Darwin, Toll Marine Logistics and Territory Alliance, sent a team into our clients’ new SIHIP homes to perform a garden makeover including wheelchair accessible raised garden beds.

Holiday of a Lifetime/Respite Support/Kin Connection Program – We have continued to provide MJD clients with social outings when on government funded respite, and Kin Connection 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 (with Associate Professor John MacMillan) continues to conduct 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.



Our Clients

Stephanie Thompson Nganjmirra

As part of 2012 International Women's Day, Stephanie received a prestigious 2012 Tribute to Northern Territory Women award for her commitment to cross cultural reconciliation and her contribution to economic and social outcomes for Indigenous people in the NT.

Stephanie was born in Darwin in 1964. Stephanie was the eldest of five children and completed her education to Year 10 in Darwin. Stephanie was also a basketball star, travelling overseas and interstate as a representative player. In 1985 Stephanie married the first Kunwinjku man to become a minister and together they started a soup kitchen in Gunbalunya, providing nutritious meals to the residents. During this time they provided counselling to those that needed it.

Stephanie was instrumental along with her husband and other Kunwinjku elders in starting a tourist venture in Arnhem Land. She taught others how to use computers, write and speak in English and put traditional owners and visitors at ease. She was instrumental in delivering a new style of training for Indigenous people in tourism, creating a model that built upon existing skills, knowledge and values and not treating them as "cultural curiosities".

Stephanie has overcome racism in all forms along with sexism, the premature death of her mother, and has assisted where family members had problems with alcohol. She is a strong Larrakia woman and quiet leader who has done her best to help her family and many others through good times and bad. A woman of vision she has worked tirelessly to improve the lives of many Aboriginal people and to build bridges with non-Aboriginal people.

Now wheelchair bound due to Machado-Joseph disease Stephanie is still working, she is currently assisting with a paper and video about Kunwinjku child-rearing that will be of benefit to Northern Territorians and wider Australian society.



Thanks to the Country Women's Association of Alyangula for funding the MJDF iPad project on Groote Eylandt

Our Sponsors (2011-2012)

Thank you so much to our sponsors for 2011-2012. Your contribution makes an enormous difference in allowing us to meet our objectives.





The MJD Foundation's Libby Massey and Ros Kempton, along with client Daniel Lalara conduct training for Healthscope's Alawa House team

Our Partners (2011-2012)

Our partners are the organisations that share resources and provide support in allowing us to directly achieve our objectives. We wish to thank the following organisations for their support during 2011-2012.



GEBIE
Groote Eylandt and
Bickerton Island Enterprises





Board Members (2011-2012)

Chairperson	- Neil Westbury
Vice-Chairperson	- Gayangwa Lalara
Treasurer	- Doug Talbert
Secretary	- Kathy Massey
ALC Representative	- Tony Wurramarra
Family Representative	- Jennifer Baird
Ex-Officio	- Libby Massey
Ex-Officio	- Nadia Lindop

Staff (2011-2012)

Executive Officer	- Nadia Lindop
Director, Research and Community Services	- Libby Massey
Senior Cultural Consultant	- Gayangwa Lalara
Manager, Community Services	- Simone McGrath
Project Manager	- Angela Jane
Travel/Respite Coordinator	- Kathy Massey
Manager, Education Resources	- Roslyn Kempton
Community Worker	- Joyce Lalara
Community Worker	- Steve Wurramara
Community Worker	- Brett Mamarika
Administrative Assistant	- Tina Hebblewhite
Bookkeeper	- Zeng Jones

Patrons

Professor Garth Nicholson is a Patron of the MJD Foundation.

Volunteers (2011-2012)

Thanks so much to our wonderful volunteers for 2011-2012.

Bryan Massey, Associate Professor John MacMillan, Sally Lang, Jen Watts, Deb Shannon, Arthur Grogan



Regional Arts
Funding



The Regional Arts Fund is an Australian Government initiative supporting the arts in regional, remote and very remote/isolated Australia. The program is delivered in partnership with the Northern Territory Government.

Steve Wuramarra making his movie "Making a Spear" as part of "Our Story" funded by the Regional Arts Fund

Grants (2011-2012)

Federal Department of Health and Ageing (Office of Aboriginal and Torres Strait Islander Health)

- (\$280,000 MJD Education resources; Family Planning workshops; Medical Protocols

Northern Territory Government/Australian Government - Regional Arts Fund

- \$16,000 Our Story

Sydney Myer Foundation

- \$10,000 Family Carer education workshops

Coca Cola (Australia) Foundation

- \$10,000 HipHop project

Marian and EH Flack Trust

- \$7,200 Towards the Elcho Island aircraft wheelchair lift

Max E Grants

- \$5,000 For a young girl on Elcho Island

Ross Divett Foundation (Centrelink)

- \$5,000 Towards the Elcho Island aircraft wheelchair lift

Mercy Foundation

- \$2,500 Towards the Elcho Island aircraft wheelchair (second installment)

Carers NT

- \$500 Carers Week event

Donors (2011-2012)

Organisations

GEIE, Westbury Smith and Associates, Fitzos Boutique, Overgrove, Alyangula Cycling Club, Toll Marine Logistics.

Individuals

Neil Westbury & Diane Smith, Jake & Jane Frazer, Alice & Colin Lloyd, Professor Bart Currie, Suzanne Elliot, W R Hearn, Lloyd Chidlow, Margaret Wright, Janice Oake, Emma Cadogan, Professor Deb Theodoros, Assoc Professor Liz Ward, Bishop Ken Mason, Carolyn Anderson, Catherine Mellors, Andrea Shanley, Anne Cotton, Chris Lloyd, Dr Tom and Dulcie Gavranic, Elizabeth Milewicz-Tyson, Emily Carroll, Georgina Whitehead, Giuseppina Petrozzino, Hugh Hartigan, Janice Boddice, Karen Mohr, Kylie McKay, Lavina Faneva, Marj Robinson, Matthew Keene, Pascale Stendell, Patrick & Sabine O'Doherty, Robert Martin, Sally & Michael Lang, Shivali Grover, Stuart McLaren, Vanessa Dayeh, Shirley Williams.



In memory of the late Andrew Shaw
Used with permission from his family.

Bequests (2011-2012)

We are honoured to have received two (2) bequests this year from:

- the Estate of the late Rex Croker
- the Estate of the late Andrew Shaw

Andrew Shaw was very passionate about everything in his life, and this included the work that he did with severely disabled people in Melbourne, together with, a number of years ago, acting as advocate for disabled Aboriginals in the Northern Territory. When Andrew moved from Victoria to the NT he soon began work as a Tour Guide, taking international tourists into the remote bush. This work had him sharing his knowledge, passion and love for the region and its Indigenous people with groups from all around the world. Knowing Andrew, and judging by the numerous letters of thanks that his family have seen since his death, he was truly unique in his ability to express this love and inflame the passion in the people around him.

Andrew was also quite a gifted musician. He would always have his guitar with him, and never needed a second request to pull it out and commence playing. This not only provided entertainment for the company that he was with at the time, it was a comfort for himself when he was alone, or, during the latter years of his life as his health deteriorated.

Finally, but most importantly, Andrew was a most loved son, brother, uncle, friend and partner to Caroline.

Rex Croker was well liked and known on Groote Eylandt as a "nice old guy", and during his time with the Anindilyakwa Land Council on Groote Eylandt, always showed a keen interest in the MJD patients and was particularly fond of Jock.

When he died his family generously donated many of his personal effects to Anglicare which helped fund some much needed medical equipment.

His bequest has been directly used to purchase a new wheelchair for Jock who now lives in permanent care in Darwin.

Financial Statements (2011-2012)

INCOME AND EXPENDITURE STATEMENT

	2012	2011
Income		
Membership fees		145
Grants	310,150	6,900,126
Donation	130,075	148,114
Bequests	10,500	
Sponsorship	20,227	2,000
Merchandise sales	1,734	965
Income from MFCo Investment	128,796	
Interest received	441,811	285,271
Other income	32,200	6,229
Total income	1,075,493	7,342,851
Expenses		
Accountancy	900	
Advertising and promotion	19,231	18,066
Bad Debts	800	
Bank Fees And Charges	9,041	8,513
Books and publications	361	585
Client carers(Non Salary)	39,780	23,649
Client meals	2,281	901
Computer software & others	922	2,014
Conference/seminar costs	12,541	5,305
Consultants fees	120,632	80,240
Delivery	1,839	9,757
Depreciation	24,010	11,653
Write-down to recoverable amount NPP	590	
Equipment (<\$300)	15,148	6,813
Equipment (>\$300)	86,504	50,834
Gift	2,092	1,068
Insurance	7,749	4,178
Interest - Australia	476	637
Materials & supplies		12,079
Medical Supplies & research	73,389	96,371
Office consumable	5,355	5,962
Postage	1,939	3,119
Repairs & maintenance	7,302	3,847
Salaries - ordinary	259,539	237,134
Holiday Pay Provision	5,329	7,541
Employee fringe benefits	55,155	19,845
Staff training	636	4,836
Stamp duty	457	413
Subscriptions	3,243	3,338
Superannuation	23,035	21,342
Telephone/Internet	9,025	9,105
Travel – Board, Staff, Researchers, Specialists	140,373	95,369
Travel – Client Holidays, Respite Support, Kin Connect	32,039	46,500
Total expenses	961,712	791,012
Profit from ordinary activities before income tax	113,782	6,551,839

Financial Statements (2011-2012)

BALANCE SHEET (AS AT 30th JUNE 2012)

	2012	2011
Current Assets		
Cash Assets		
Cash At Bank	374,342	55,384
TCU Saving account		200,000
NAB - Myer Family CMF	1,102	
NAB - Myer Cash	76,112	
NAB Term deposits	1,395,819	1,498,475
NAB Trustee account		6,001,355
NAB Operating account	19,756	38,916
Undeposited funds	7,090	1,774
MFCo Investment	6,068,805	
	7,943,025	7,795,903
Receivables		
Trade debtors	79,402	86,449
Accrued income	77,120	131,478
	156,522	217,926
Total Current Assets	8,099,547	8,013,830
Non-Current Assets		
Property, Plant and Equipment		
Plant & equipment - at cost	76,901	67,284
Less: Accumulated depreciation	(22,043)	(12,242)
Motor vehicles - at cost	92,272	18,200
Less: Accumulated depreciation	(17,132)	(3,663)
	129,998	69,579
Total Non-Current Assets	129,998	69,579
Total Assets	8,229,545	8,083,409
Current Liabilities		
Payables		
Trade creditors	41,976	10,539
Holiday pay liability	14,058	8,729
Other creditors	1,678	6,090
Total Current Liabilities	57,713	25,359
Total Liabilities	57,713	25,359
Net Assets	8,171,832	8,058,050
Members' Funds		
Accumulated surplus (deficit)	8,171,832	8,058,050
Total Funds	8,171,832	8,058,050

Auditor Statement (2011-2012)



Report on the Financial Report

We have audited the accompanying financial report, being a special purpose financial report, of MJD Foundation Incorporated (the association), which comprises the Statement by Members of the Committee, Income and Expenditure Statement, Balance Sheet, notes comprising a summary of significant accounting policies and other explanatory notes for the financial year ended 30 June 2012.

Committee's Responsibility for the Financial Report

The committee of MJD Foundation Incorporated are responsible for the preparation of the financial report and have determined that the basis of preparation described in Note 1, is appropriate to meet the requirements of the Associations Incorporation Act and is appropriate to meet the needs of the members. The committee's responsibilities also includes such internal control as the committee determine is necessary to enable the preparation of a financial report that is free from material misstatement, 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 association'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 association's internal control. An audit also includes evaluating the appropriateness of accounting policies used and the reasonableness of accounting estimates made by the committee, 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 presents fairly, in all material respects, the financial position of MJD Foundation Incorporated as at 30 June 2012 and its financial performance for the year then ended in accordance with the accounting policies described in Note 1 to the financial statements, and the Associations Incorporation Act .

Basis of Accounting

Without modifying our opinion, we draw attention to Note 1 to the financial report, which describes the basis of accounting. The financial report has been prepared to assist MJD Foundation Incorporated to meet the requirements of the Associations Incorporation Act . As a result, the financial report may not be suitable for another purpose.

Signed on: 14 September 2012

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

Nina De Luca

For a Beautiful Mother and Daughter

Gabriella Helmhout 16/01/1989 – 05/10/2012
Robyn Yunupingu 15/08/1968 – 22/11/2012



It might seem strange to refer to someone who never in her life weighed more than 40kg's as strong, but that is what Gabby was. She was strong in the truest sense of the word. Her body may have been fragile, broken, and wasted - but never her spirit.

Everyone who knew Gabby could vouch for the fact that she was one of the most feisty, determined and positive young ladies to ever grace our world.

She needed that strength. There is no doubt that Gabby was given more than her fair share of burdens in life - and we will never know why.

What we do know, is that she shouldered them with strength and with dignity. And in the struggles that came her way she was in every sense a trailblazer.

Gabby's mother was Robyn. When Robyn became sick, her young daughter became her carer, and Robyn suffered the pain of seeing her own daughter develop this disease. When we think of Robyn, we can't help but smile. She had a wicked sense of humour and determination that she obviously passed onto her daughter. She loved a smoke and was determined to stay in this world for her daughter. In true Robyn style she made it home for her daughter's funeral and then joined her. As in life, she took control of her passing. This is a testament to the fact that this disease takes so much away in terms of physical abilities, but does not alter the spirit.

Gabby and Robyn have left a legacy- their path through their illness has informed those of us who try to provide care of many things – but the most significant of them is the knowledge that an illness or disability can never determine a person.

Gabby and Robyn were never their illness – it was an inconvenient, frustrating barrier to their living, but it was not THEM...and may we never forget that!



Photos used with the permission of the ladies' family

