



**MJD
Foundation
Annual
Report
2012/2013**

A YEAR OF PROUD ACHIEVEMENT

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MJD Foundation client and staff member Steve Wurramara received a local government award of excellence in Canberra celebrating the work he does for the Angurugu community (Groote Eylandt) with iPads.

Steve spends most days at Angurugu Library where he supports other community members, and also makes movies about his community that can be seen on the MJDF YouTube channel.



The MJD Foundation was a finalist in the 2012 National Disability Awards. Nadia Lindop (Executive Officer) and Joyce Lalara (Aboriginal Community Worker) travelled to Canberra for the awards ceremony.

The MJDF was nominated in recognition of its work to improve the quality of life for Indigenous Australians and their families living with MJD in Arnhem Land and beyond.



Associate Professor John MacMillan received the prestigious Rowan Nicks Russell Drysdale Fellowship to fund his travel for 12 months to Arnhem Land.

This travel will enable Assoc. Prof MacMillan to continue his important work in providing Machado Joseph Disease genetic education to health professionals, communities and Indigenous Australian families affected by the disease.



MJD Foundation Board Member and Anindilyakwa Land Council Chairperson Tony Wurramarrba was awarded an AO for distinguished service to the Indigenous community of the Groote Eylandt Archipelago through leadership and advocacy for improved services and infrastructure.

MJD Foundation

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Cover Photos:

Ros Kempton and Melinda Lalara at the MJD Women's Camp on Groote (Photo: Ange Jane)

Jane Wurramara
(Photo: Belinda Mason)



Chairperson's Report 2012-2013

For all Australians with disabilities (and their families), 2013 was a historic turning point in the nation's history. Both the successful passage of the *National Disability Insurance Scheme Act* through the National Parliament and the commencement of trials of the resultant new scheme in various locations across Australia, represent an unprecedented opportunity to ensure much needed disability services which will be fully rolled out to remote Australia by 2019.

MJDF is playing a positive and constructive role in providing expert advice to governments about how the NDIS can be effectively implemented in remote communities. In practical terms, this resulted in MJDF successfully tendering to undertake a comprehensive 'Disability Audit' in six (6) East Arnhem and NT Gulf Aboriginal townships. The resultant report has been widely welcomed as making a timely contribution to providing a sound evidence base upon which to inform what challenges are involved in designing NDIS for remote communities.

This work should also 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 congratulate all those staff involved in producing this comprehensive report, and particularly the efforts of both Nadia Lindop and Libby Massey in bringing the audit report to fruition. Libby also sits on the National Disability Strategy Indigenous Working Group (NDSIWG) which is advising the Government directly on disability issues for Aboriginal peoples.

MJDF has also taken the opportunity before the federal election to meet and brief the incoming Commonwealth Minister with responsibility for the roll out of NDIS, Senator Mitch Fifield on the work of MJDF and the findings of the Disability Audit. We are looking forward to continuing to work constructively with the Commonwealth and State and Territory Governments on these issues.

On a more general note, MJDF has seen a successful year on a range of fronts. One overall theme for the past year has been to focus on consolidating our existing activities and strategic positioning of the organisation that ensures it can continue to deliver its support and services effectively into the future.

As Nadia and Libby's report highlights, this has been reflected by the fact that over the past year MJDF has quietly increased the scope, quality and quantity of the support that we offer to people with MJD and their families - in terms of capacity, range of services and geography.

This has included further extending our existing relationships with families at Ngukurr, Urapunga, Galiwin'ku and Yirrkala in the Top End of the Northern Territory, as well as in Central Australia at Papunya, Hermannsburg and Santa Teresa. In this context we have been lucky in being able to engage Ellen Christian (Manager, Community Services – Ngukurr, Darwin and Oenpelli) who has been a very welcome addition to the team.

As Nadia and Libby's staff report also highlights, MJDF continues to work closely and strategically with all stakeholders in improving the care and wellbeing of people living with MJD both now and into the future, whilst being particularly mindful of the increased numbers of people at risk.

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 is also made of Simone McGrath who left full time employment with MJDF after three years based on Groote Eylandt where she (and her partner Tim) made a fantastic contribution to the work of MJDF.

Our thanks and acknowledgement of the fantastic support MJDF received from our loyal sponsors and donors is particularly gratifying.

I would particularly like to thank our principal sponsors, including the Anindilyakwa Land Council and GEBIE, the Aboriginals Benefit Account, Minister Jenny Macklin and FaHCSIA, BHP Billiton, Vincent Aviation, Telstra Foundation, Toll Marine Logistics, Groote Eylandt Aboriginal Trust, Newman's Own Foundation, Centrecorp, JT Reid Charitable Trusts, McCullough Robertson and the Commonwealth Department of Health and Ageing.

This year also saw high profile visitors come to Groote Eylandt to view the work of MJDF, including the Governor General Her Excellency Ms Quentin Bryce AC AO who kindly launched educational videos produced in Anindilyakwa, Yolgnu Matha, Kriol and English languages.

Telstra Chairperson, Catherine Livingstone AO, Telstra CEO, David Thodey and other senior Telstra executives visited Groote Eylandt and announced a major sponsorship over three years to assist in the rollout of electronic communications technology and software for people living with MJD.

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

Significant challenges which will feature prominently at our next planning day in February 2014 include:

- In recognition of the fact that both the identification of the number of people at risk of developing MJD has drastically increased across the Territory and the importance attached to the work of the MJDF, MJDF was formally advised by Minister Macklin in July this year that we had been successful in securing a further \$10m from the Aboriginals Benefit Account. These monies are conditional on being invested in perpetuity, with the investment earnings helping underwrite the operational costs of the MJDF. We are hopeful that the new Government will agree to proceed with the grant;
- As highlighted in the Disability Audit report, most remote communities currently lack the necessary services infrastructure in place for people to benefit from the NDIS when the scheme is eventually implemented. This will require MJDF to continue to carefully target its advocacy and encourage government, non-government and corporate stakeholders to explore and adopt creative options to provide the critically required infrastructure to cope with the ever increasing numbers of individuals and families living with MJD; and
- The continued emerging evidence of the aggressive nature and prevalence of MJD and increased numbers of people at risk, especially in remote communities such as Galiwinku, Ngukurr and Yirrkala, means the MJDF needs to continue to raise significant monies to meet both growing demands and to support projects that contribute to improving individuals' and families' wellbeing.

Last, but not least I need to pay tribute to my Vice-Chair Gayangwa Lalara for the tireless efforts, leadership and inspiration she has, and continues to provide, to all of us involved in fighting this terrible disease. As part recognition of her life-long work and commitment, Gayangwa was ordained as a Deacon of the Church of England earlier this year.



Neil Westbury PSM
Chairperson



Staff Report 2012-2013

Internationally, 2012 and 2013 have been variously dedicated the years of the farmer, dragon, reading, student, statistics, snake and are even the official United Nations (UN) years of water co-operation and quinoa! Little wonder 12 months has passed at such breakneck speed – there has been much to celebrate and venerate!

For the MJD Foundation, it has been the year of the catch up! It's been a time of consolidation and positioning to meet current and future needs.

2011-2012 was characterised by emerging evidence of the aggressive nature and spread of MJD in our region and this necessitated careful and strategic consideration of the placement and implementation of our services.

Over the 2012-2013 period, we have increased the scope, quality and quantity of the support that we offer to people with MJD and their families - in terms of capacity, range of services and geography.

The employment of an additional Manager, Community Services for Ngukurr has meant that we have begun to provide the level of real tangible support needed for people there. Ellen Christian is an experienced Occupational Therapist, whose previous 3 years working in Ngukurr has placed her exceptionally well to work with the Ngukurr/Urapunga families with MJD. As always, we aim to listen to those with MJD and their families and tailor services to meet their expressed needs.

Ongoing sponsorship from BHP Billiton has enabled our clients and their carers on Groote Eylandt to receive hands on, weekly therapeutic physiotherapy for the first time, and the service has been enthusiastically taken up by many clients. The employment of a local driver/community worker on Groote Eylandt has also vastly increased the practical assistance that can be offered and Brett Mamarika, his wife Melinda and the trusty MJD bus are kept very busy assisting people to access community services and facilities.

We also embarked on a mammoth 5 month project through the National Disability Insurance Scheme (NDIS) in early 2013, mapping the number of people with a disability, their needs and the current range of services in six (6) of the communities that the MJDF works in. The quantifying of this information will be invaluable when the changed model of disability care rolls out in the region and has positioned the MJDF well to understand how the needs profile will change in remote communities and how best to meet them. Central to this has been the updating and maintenance of family information and we are fortunate to have employed Janine Ryan as our Genealogy manager.

Developing a library of culturally appropriate educational resources has continued this year and we have been pleased to have produced Careworker education (including a DVD and workbook) and a series of women's and kid's DVDs in local languages explaining the genetic transmission and features of MJD.

Of course in order to increase services there is always significant work to be done behind the scenes. The transition from NT Association to Public Company limited by Guarantee was completed and there have also been several major grants received, including: Telstra Foundation, Centrecorp, Newman's Own Foundation, Rowan Nicks Russell Drysdale Fellowship, John T Reid Charitable Trusts, Federal Government, NAB, Groote Eylandt Bickerton Island Enterprises and Groote Eylandt Aboriginal Trust.

Growing as an organisation has been a privilege and a pleasure. Our team (staff, contractors, board and volunteers) has been very busy; our families have been ever more able to express their needs and the ways they believe they should be met.

There is no doubt the next 12 months will bring yet more challenges and we look forward to meeting them from increasingly secure foundations.

Libby Massey
Director, Research & Community Services

Nadia Lindop
Executive Officer

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



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 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.)

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.





This is Angel looking very guilty next to a chewed power assist wheelchair cord.

Equipment

Given the MJDF is now 5 years old, it is hardly a surprise that 'repairs and maintenance' has now become a key theme for our equipment expenditure, and an essential item of expenditure to ensure longevity for the financial investment made to improve equipment and infrastructure in the communities in which we work.

Our equipment for 2012-2013 was able to be purchased thanks to the Newman's Own Foundation (in Paul Newman's memory), Anindilyakwa Land Council, BHP Billiton, NT Library, Federal Government, Country Women's Association (Alyangula), Centrecorp and generous donations from our individual supporters.

During 2012-2013 we purchased \$66,000 worth of new equipment, and spent \$20,000 on repairs and maintenance.

Some of our equipment purchases throughout the year were:

- Kitchen trolleys
- Apple iPads
- Ramps
- Washing machines and clothes dryers
- Shower Commodes
- Aircraft aisle Wheelchair
- Wheelchairs
- Anatomical model





MJDF client and staff member Joyce Lalara with Dr Angela Laird in the Zebra fish laboratory 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 in Sydney continues to progress extremely well. This year the research team, lead by Dr Angela Laird have been successful in giving the Zebra fish Machado Joseph Disease, and being able to breed the Zebra fish to have them pass the defective gene onto their offspring. Of importance, the research team have been able to measure that the sick Zebra fish exhibit slower and more wobbly swimming patterns. These measurements are critical in order to determine whether drug treatments are having an effect on the fish.

Disability Audit – In the latter half of 2012-2013, the MJDF conducted federal government funded research which examined the prevalence of all disability (not just MJD) and service provision in six very remote Indigenous communities (Angurugu, Umbakumba, Milyakburra, Ngukurr, Urapunga and Galiwin'ku). The project (with ethics approval from Menzies School of Health Research and the NT Government) will inform the design of the National Disability Insurance Scheme for remote communities around Australia.





In early 2013, the MJDF commenced training in safe lifting/transfers and wheelchair handling with Vincent Aviation

Education

The MJDF Foundation's education program has continued to expand throughout 2012-2013 with significant effort and resources put into existing and new components of the program.

Genetic Education – the MJDF Foundation continues to partner 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 2012-2013 there was a focus on designing culturally appropriate educational resources around family planning.

Corporate Education – in early 2013, the MJDF commenced training workshops for Vincent Aviation's pilots, crew and ground handlers in the safe lifting and transferring of wheelchair using passengers, as well as the safe storage of wheelchairs. The MJDF will now run 3-4 training workshops per year.

Carer Education – This program was strengthened in 2012-2013 through the development of the DVD "Saltwater & Smiles: Carers' Perspectives on MJD" which was launched in April 2013 and is available free of charge. This resource was funded by the Federal Government, and provides insights into caring for people with MJD.

The MJDF continued to provide workshop training for residential and respite care workers as well as family carers, all of whom are looking after people with MJD. 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.

Supporters of the MJDF Education program across 2012-2013 include: John T Reid Charitable Trusts, Federal Government Dept of Health and Ageing, Rowan Nicks Russell Drysdale Fellowship.

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