



**MJD  
Foundation  
Annual  
Report  
2010/2011**

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Riley (on the right) is 11 years old and lives in the USA. Her grandmother died from Machado Joseph Disease, as well as her great aunts and uncles, and many of her aunts and uncles. Riley is blessed with good health, yet the experience of her family and its impact on her life prompted her to write this story below. Her mother (pictured) shared this story with us after seeing the MJD Foundation's website, and feeling a sense of family with those affected in Australia.

## THE GIFT

It was a crisp autumn morning when I decided who I would give the gift to. I had decided that along with giving gifts to my friends and family, I would give a gift to a person in need. After thinking and thinking, I finally came up with it. I would give the people with MJD the gift of a disease free life. MJD is a disease that affects a person's ability to walk, talk, eat, or even move and it eventually kills that person.

I would give this gift not only to take the disease out of the world, but because it has affected my family. The main reason for me to give this gift is because my grandmother, many of my great aunts, many of my great uncles, and a lot of my mom's cousins died of this disease because it runs in the family. Even though all of my family members that had it died, I still want the other people who have it to live and the people who have the risk of getting it not to get it. Even though I could never give this gift, I wish I could.

### **MJD Foundation**

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### **Cover Photos:**

Simone McGrath & Rose Mirniyowan  
Hydrotherapy

Steve Wurramara  
Umbakumba to Naked Pools Xtreme Bike  
Challenge



## Chairperson's Report

2010-2011 has been another challenging yet successful year for the MJD Foundation, with a number of highlights, including:

- The continued critical support, encouragement and guidance of the work of the MJD Foundation from Aboriginal people living with MJD, their families and the community;
- Aply lead by Libby Massey and Nadia Lindop, the dedication and professionalism of all MJD Foundation staff whose level of commitment and passion for the work of the MJD Foundation is widely recognised and acknowledged;
- Securing significant funding approved by Minister Jenny Macklin from the Aboriginals Benefit Account (conditional on it being invested in perpetuity), with resultant income being applied towards meeting the future operational costs of the MJD Foundation;
- Successful applications to various philanthropic and corporate bodies for a number of individual projects and continued strong support from our sponsors;
- Continued progress of the medical protocols and social & emotional wellbeing projects;
- Successful introduction of the MJD therapy program ("Staying Stronger for Longer");
- Delivery of training and educational workshops on MJD to professional health personnel, carers and community members, and continued promotion of improved education and understanding of the needs of people living with MJD both at the local community level and via attendance at various workshops and conferences;
- Further strengthening of the partnership with Associate Professor John MacMillan reflected in joint collaboration in the delivery of genetic counselling and education on the ground in a number of communities and "Genetics in General Practice" workshops;
- Further day trips and holidays through our Holiday, Respite Support, Kin Connection program;
- The successful trial of Apple iPads to improve communication and social and emotional wellbeing;
- Presentation to the Chronic Diseases Network Conference making the case for MJD to be recognised as an Indigenous chronic disease;
- The continued active engagement with a range of partners through the MJD Foundation research program
- MJD Foundation facilitating enhanced collaboration between relevant service providers on Groote Eylandt supporting better quality of life outcomes for people living with MJD including suitably designed housing;
- Enhanced MJD Foundation outreach into a number of Northern Territory remote communities;
- Continued engagement with NT Department of Health in securing agreement of a joint implementation plan for addressing key issues consistent with the MOU;
- Conduct of a successful governance workshop for Board members to directly inform the development of a revised constitution under Commonwealth legislation and Board endorsement of its own five year Governance Development Plan;
- Successful conduct of a joint staff planning day, to now be conducted annually; and
- Ongoing expert advice to the Board from the Research Advisory Committee, Finance and Governance Sub-Committees.

## Future and Outstanding Challenges

Notwithstanding a very productive twelve months the MJD Foundation continues to face significant challenges which will no doubt feature prominently at our next planning day in February 2012. These include:

- While the Federal Government's decision to move towards the establishment of a National Disability Insurance Scheme (NDIS) should have significant potential benefits for individuals and families who live with MJD, the current reality is that in most remote communities the necessary services infrastructure is not in place for people to benefit when the scheme is implemented. This issue and those related to gaining Indigenous chronic disease recognition will require some carefully targeted advocacy and wider community education by the MJD Foundation;
- Notwithstanding the MJD Foundation's success in working towards securing its financial position, it still needs to raise significant monies to meet both growing demands and to support projects that contribute to improving individuals' and families' wellbeing. Further enhancing our fundraising capacity will remain an ongoing challenge, and in 2012 we will also be exploring the means of accessing of some form of ongoing government support;
- Continued challenges in some areas of the NT Department of Health to accepting the current number of individuals with MJD, and the projected number of people at risk is being progressively tackled by the joint efforts of Libby Massey and Associate Professor John MacMillan. Resolution of this issue will be critical to the MJD Foundation's ability to build its case for greater recognition and funding and service delivery support, and we will continue to work in a positive and collaborative manner with the NT Government.
- The provision of Aged/Disability Care and Respite services continues to raise its head as an issue with community feedback highlighting the need to explore other potential models for managing delivery. Further careful consideration of this issue and potential options for a way forward in remote locations, in a rapidly changing funding environment will need to be explored.
- Finally I would like again to acknowledge all our many generous sponsors and donors who provide fantastic support to the MJD Foundation. Without their support the MJD Foundation could not continue to carry out its critical work. I also thank all our wonderful seemingly tireless committed staff and fellow voluntary Board members for their ongoing support and commitment.



Neil Westbury  
Chairperson

## What is Machado Joseph Disease?

Machado Joseph Disease (MJD) is an hereditary 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.

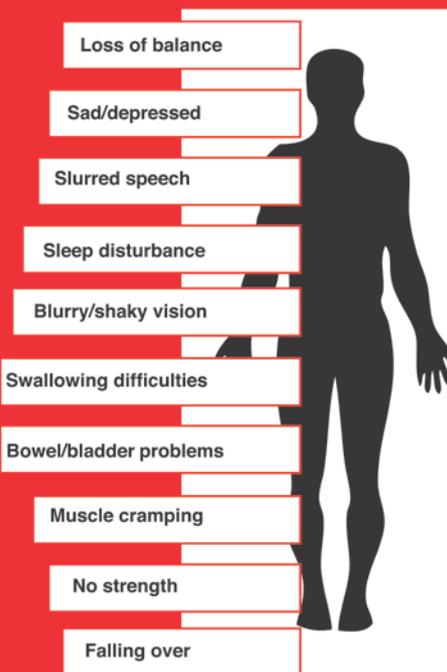
Following the discovery of the gene for MJD, "Groote Eylandt Syndrome" was confirmed as MJD in 1995 and there are people living with the disease on Groote Eylandt (Angurugu and Umbakumba), Bickerton Island (Milyakburra), Yirrkala, Elcho Island (Galiwin'ku), Darwin, Ngukurr, Urapunga, Birany Birany, Numbulwar,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

Spread of the disease to Arnhem Land is hypothesised as being attributed to the 16th Century trading and exploration activities of Portuguese Sailors. Entry into the Australian population is thought to have been through trading relationships between the Aboriginal people of Arnhem Land and the Makassar people of Indonesia, who in turn traded with the Portuguese and Chinese. However further research and genetic analysis is being undertaken to definitively confirm this.

Although it is impossible to predict the number of Indigenous Australians who will develop MJD, there are currently around **500** 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



- 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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## 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

## Location



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

In addition we provide some of our 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.



## Staff Report

It is incredible to think that we have been operating now for 3 years. We hope that we have made a difference to Indigenous Australians and families living with Machado Joseph Disease in Arnhem Land and beyond, but we also know that we have only scratched the surface in terms of the enormous and complex needs.

We also hope that we have put in place some solid structures that will ensure the stability of the MJD Foundation into the future, so that work can continue for many years to come.

In our first year of operation (2008-2009), we basically responded to critical and urgent needs and operated as "firefighters". We were also able to forge some solid and long term partnerships with families, communities and our valuable sponsors who have been very loyal to us to this day.

In our second year (2009-2010) we were able to also put effort into policies, procedures and formal partnerships, and define sound structures in terms of our priorities, our staff and our partners. We also focused on ensuring the long-term financial sustainability of the MJD Foundation.

In this year (2010-2011), we have been able to analyse our activities, structure these into defined programs and prioritise these for the future. We have been able to look closely at not only our severe clients, but those emerging clients who are just starting to get sick. We are increasingly focusing on early intervention and have begun implementing programs for clients to "*stay stronger for longer*". Hand in hand with this focus is our determination to develop programs and opportunities to enrich the social and emotional wellbeing of those with MJD and their families.

This year we have also worked on ensuring we have strong governance, and above all else, we have ensured we keep our clients and communities first in all that we do.

Looking forward we will be further gathering numbers of clients in other communities, developing appropriate relationships in those communities and continuing to structure, prioritise and seek long term funding for our Programs.

Thank you to our wonderful and supportive Board who continue to sustain, and provide invaluable advice to the MJD Foundation on a voluntary basis.

We would also like to thank our small team of enormously dedicated staff members for all the extra things they do!

Libby Massey  
Director, Research & Community Services

Nadia Lindop  
Executive Officer



Jock using his Apple iPad and Proloquo2Go communication app at the Speech Pathology Australia national conference in Darwin



Melinda participating in the Umbakumba to Naked Pools Xtreme Bike Challenge on Groote Eylandt

## Equipment

During 2010-2011 we continued to provide equipment to our clients and their families, focussing on those items that are not provided under the NT Government's Territory Independent Mobility Equipment Scheme (TIMES).

Most of our equipment for 2010-2011 was able to be purchased thanks to the Newman's Own Foundation (in Paul Newman's memory), BHP Billiton, Arnhem Land Progress Association (ALPA), the St George Foundation, Country Women's Association (Alyangula) and Centrecorp. In addition, a small grant from the federal Department of Health and Ageing made it possible for us to provide small equipment grants to non-Indigenous Australians with MJD.

**During 2010-2011 we purchased \$70,000 worth of equipment.**

Some of our equipment purchases throughout the year were:

- Three wheeler bikes to improve community access for our mild clients
- Electric beds (height and angle adjustable)
- Apple iPads as part of our improved communication and social & emotional wellbeing program
- Portable ramps for improved house and community access
- Washing machines and clothes driers
- Shower chairs
- Electric Wheelchair
- Portable wheelchairs
- Bath Chair

A highlight for the year is our successful trial of the Apple iPad using the disability communication software Proloquo2Go to improve our clients' ability to communicate, as well as improve their social and emotional wellbeing. We plan to publish our trial next year.



Dr Angela Laird explains the Zebrafish research to MJD Foundation Vice-Chairperson Gayangwa Lalara

## 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).

The MJD Foundation defines research in two categories:

1. Quality of Life research that focuses on practical and functional solutions to improving quality of life for people living with MJD.
2. Treatment/Curative research that focuses on treating and/or curing Machado Joseph Disease.

**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 three year MJD Foundation (and ALC) funded project with the ANZAC Research Institute in Sydney is progressing 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.

In July 2011, the MJD Foundation brought a group of Groote Eylandters to Sydney for a tour of the laboratory which is housed at the Brain and Mind Institute. Groote Eylandter and MJD Foundation Vice-Chairperson Gayangwa Lalara said "The lab was very interesting and Angela explained things well to me. I understand more now about the work she is doing and I feel proud that we are part of this research".

**Urinary Incontinence** – the MJD Foundation approved this study last year, and the project is well underway. 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.





Gayangwa Lalara and Ros Kempton conduct a carer education workshop on Groote Eylandt

## Education

The MJD Foundation's education program has been a major priority 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 2010-2011 Associate Professor John MacMillan and the MJD Foundation's Libby Massey delivered these services to: Groote Eylandt, Darwin, Elcho Island, Ngukurr, Urapunga and Nhulunbuy.

**Inservices** – the MJD Foundation continues to provide inservices to raise awareness of MJD and provide information to other organisations as is relevant to that organisation. Some examples of sessions conducted throughout 2010-2011 are: Centrelink Darwin and Angurugu, Royal Darwin Hospital Allied Health team, Northern Rehabilitation Network, Darwin Aged and Disability Program, Dental and Oral Health Darwin, Angurugu Public School (Ngakwurra Langwa College), Carpentaria Disability Services, Aged Care Network Central Australia.

**Carer Education** – The MJD Foundation kicked off its Carer Education Program in May 2011. The program targets 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.

The MJD Foundation continues to build on our education resources, and these are freely available on our website: [www.mjd.org.au](http://www.mjd.org.au)

# MJD FOUNDATION WHAT DO WE DO?

Equipment



Education

Improved Services

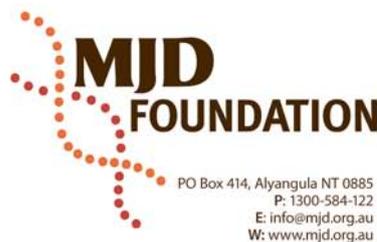


Research

Advocacy



Improving the lives of Indigenous Australians with Machado Joseph Disease in Arnhem Land and beyond



## Advocacy

Achieving the balance between providing support for clients and families and maintaining strong positive partnerships with service providers be they government or non government organisations has been a strong theme throughout this year.

The need to be a critical assessing voice for those whose voices have for too long been diminished by distance, disease and the day to day drain of caring will always be forefront in the actions of the MJD Foundation. We are all too painfully aware however, that service providers themselves, are also subject to the harsh realities of cross cultural work in remote locations - looming large among these, social and infrastructure deficits and high costs.

We unapologetically 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.

We believe there is a need for a rethink around service models currently in practice such as 'Fly in Fly out' services which we know lead to a lack of 'local knowledge' - the vital awareness of local community make up, the interaction between communities and family groups and cultural barriers to the sharing of information.

They are models that without a doubt, stem from funding constraints, however they in turn lead to extraordinarily high turnover of staff and consequently a lack of adequate support structures (whether they be funding structures, or organisational structures) for both those working in the area and those who require services. During this year there have been many occasions when the teamwork between NT Dept of Health Aged & Disability Program staff and MJD Foundation staff have enhanced the quality of care options available for our clients.

During this year there have also been unprecedented opportunities for long-term advocacy and real change for clients through one off programs such as the Federal Government's

Strategic Indigenous Housing Infrastructure Program (SIHIP). We have been privileged to work alongside families, government and non government organisations to map out needs and ensure appropriate fit for purpose accommodation provision in several communities for the foreseeable future.

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).



Simone McGrath and Joyce Lalara run the MJD Therapy Program on Groote Eylandt

## Improved Services

**MJD Therapy Program** – “Staying Stronger for Longer”. This program has been running on Groote Eylandt for 12 months now. Whilst it incorporates formalised therapeutic components such as hydrotherapy, 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** – There are many aspects to social and emotional wellbeing. 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 the projects the MJD Foundation has focussed on in 2010-2011 are:

- Young Men’s fishing trip – which followed on from the Young Men’s camp of 2009.
- Apple iPads – the Proloquo2Go communication application has been trialled to improve or return communication for those people who can no longer communicate effectively due to their MJD.
- Psychological counselling – integrating counselling into activities in an informal manner has proven to be an effective way of engaging with individuals living with MJD.

**Holiday of a Lifetime/Respite Support/Kin Connection Program** – These programs form part of our Social and Emotional Wellbeing program and consistently provide us with the most conclusive evidence that “laughter is the best medicine”. 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. This program is at risk of ending in March 2012 when our current funding runs out.

**Medical Protocols** – The MJD Foundation is compiling a set of protocols to gather current evidence based practice and develop best practice guidelines around treatments and interventions for managing symptoms of MJD throughout the disease’s degeneration.

**Neurological Assessments** – In 2011 the MJD Foundation (with Associate Professor John MacMillan) commenced formal neurological assessments of individuals with MJD. Regular assessments will not only provide valuable data for the health practitioner, but also to the MJD Foundation’s Medical Protocols Project.

## Our Clients

### Movement Cometh and Movement Taken Away

By Roseanne Mirniyowan  
(with assistance from Simone McGrath)

We've got this sickness  
But we don't want this  
We don't know where it came from  
Or how to get rid of it.

It's passed down in the genes  
And now we know what it means  
They call it this "MJD" -  
This Machado Joseph Disease.

We used to hunt  
And collect bush tucker  
We were fast and accurate  
But now, none of that.

This MJD makes our muscles weak  
We get all wobbly on our feet  
Eventually we can walk no more  
We're stuck in wheelchairs, or on the floor.

We used to sing -  
Dancing, ceremonies, everything  
Now our voice gets weak  
Until we can no longer speak.

Our eyes get shaky  
We see two of things  
It's worse at night  
We fall and cause fright.

We get real skinny  
'Cos it's hard to swallow  
We cough and choke  
It's not a joke.

Our bladder gets mixed up  
And causes embarrassment  
Sometimes we lose control  
And want to crawl into a hole.

And our bowel - it does too  
Sometimes we can't... you know...  
We get pain in our tummy  
It hurts - it's not funny.

We have trouble sleeping  
And get this REM Behaviour Disorder  
Our legs they are restless  
Trust us - we don't want this.



We need help to shower  
To dress and to shave  
We need help to shop  
Go to the bank - the lot.

This MJD - it's in our family  
Mothers, fathers, brothers, sisters  
Sons, daughters; it keeps going on  
The road ahead is going to be long.

It's a burden on our loved ones  
And the people in our communities  
But we try to stay positive  
There's more to life than this.

We love to be active  
But the disease holds us captive  
Our mind and brains are strong  
It's our muscles and movements that are  
wrong.

We go fishing when we can  
Boy, girl, woman or man  
They lift us into the Troopy  
People watching think we're loopy!

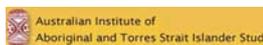
So if you see me in the street  
Even though I might not speak  
Please come and say hello  
I'm still a person you know.



Thanks to BHP Billiton, the MJD Foundation purchased three wheeler bikes for the Umbakumba to Naked Pools Xtreme Bike Challenge

## Our Sponsors (2010-2011)

Thank you so much to our sponsors for 2010-2011. Your contribution makes an enormous difference in allowing us to meet our objectives.





The MJD Foundation's Simone McGrath and NT Department of Health's Keren Shanley with Natalya

## Our Partners (2010-2011)

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 2010-2011.



**GEBIE**  
Groote Eylandt and  
Bickerton Island Enterprises





Left to Right: Jennifer Baird, Tony Wurrumarrba, Gayangwa Lalara, Doug Talbert, Kathy Massey, Neil Westbury, Libby Massey, Nadia Lindop  
Photo: Francine Chinn

## Our Board Members (2010-2011)

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

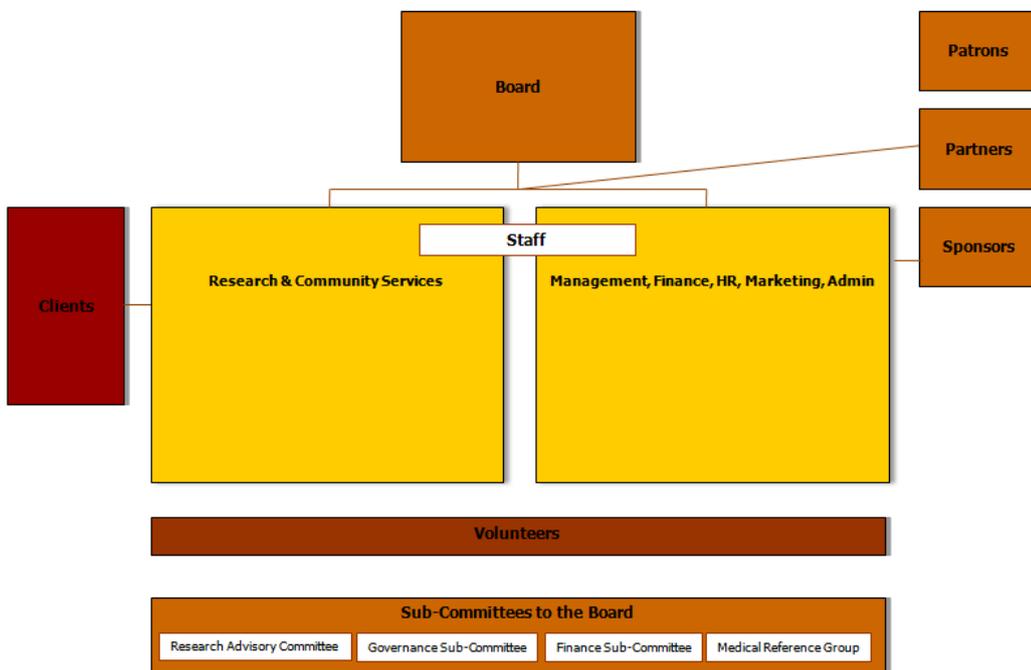


Photo: Kate Freestone Photography

## Patrons

Professor Garth Nicholson is a Patron of the MJD Foundation.

## Governance and Organisational Structure





### Our Staff (2010-2011)

- Executive Officer
- Director, Research and Community Services
- Senior Cultural Consultant
- Manager, Community Services
- Project Manager
- Community Worker
- Travel/Respite Coordinator
- Manager, Education Resources
- Manager, Augmentative and Alternative Communication
- Administrative Assistant
- Bookkeeper

- Nadia Lindop
- Libby Massey
- Gayangwa Lalara
- Simone McGrath
- Angela Chesters
- Joyce Lalara
- Kathy Massey
- Roslyn Kempton
- Sheri Lochner
- Tina Hebblewhite
- Zeng Jones

### Our Volunteers (2010-2011)



Thanks so much to our wonderful volunteers for 2010-2011.

Bryan Massey, Associate Professor John MacMillan, Sam Morgan and Sally Lang.





## Grants (2010-2011)

### Aboriginals Benefit Account

- \$850,000 second instalment of the 2008 awarded grant
- \$6,000,000 to be invested in perpetuity with the resultant income earned being applied towards meeting future operational costs

### Department of Families, Housing, Community Services and Indigenous Affairs

- \$3,650 volunteer grant to support the activities of volunteers

### Newman's Own Foundation

- \$40,000 for rollout of services and equipment provision across the Northern Territory

### Mercy Foundation

- \$5,000 towards the Elcho Island aircraft wheelchair lift project launching Feb 2012

### Foundation for Rural and Regional Renewal

- \$5,000 towards the Elcho Island aircraft wheelchair lift project launching Feb 2012

### Darwin International Airport Corporate Giving Fund

- \$2,000 towards the Elcho Island aircraft wheelchair lift project launching Feb 2012

## Donors (2010-2011)

### Organisations

GEBIE, Darwin Airport Resort, Westbury, Smith and Associates, Fitzos Boutique, Overgrove, Alyangula Cycling Club, Manunda Terrace Primary School, Bundanoon Good Yarn.

### Individuals

Neil Westbury & Diane Smith, Jake Fraser, Gretel Shanahan, Roger Layton, Lucienne Layton, Fran Edis, Prof Bart Currie, Alice & Colin Lloyd, Janice Oake, Matthew Keene, Matt Stormont, Hugh Hartigan, Elizabeth Milewicz-Tyson, Tom Gavranic, Santana Khurana, Georgina Whitehead, Emma Cadogan, Michael Turbett, Ian & Bev Millar, Hannah Middleton-Baker, Erica Bleakley, Lavina Faneva, Stuart McLaren, Sarah Coles, Barrie and Margaret Spalding, Emma Wood, Kimberley Booth, Sergio Avelleda, Michael Michie, Shivali Grover, Nicole Barry, Jan & Max Boyley, Judy Wolff (Calvert), Janice Boddice, Pascale Stendell, Leslie & John Zylstra, Rohanna Mohr, Ken Mason.

## Financial Statements – Income Statement (2010-2011)

<b>Income</b>	<b>2011</b>	<b>2010</b>
Membership fees	145	418
Grants	6,900,126	96,921
Donation	148,114	122,923
Sponsorship	2,000	3,951
Merchandise sales	965	4,776
Interest received	285,271	81,300
Other income	6,229	22,269
Rebates and refunds		2,130
<b>Total income</b>	<b>7,342,851</b>	<b>334,688</b>
<b>Expenses</b>		
Accountancy		700
Advertising and promotion	18,066	32,837
Bad Debts		34
Bank Fees and Charges	8,513	804
Books and publications	585	
Client carers (Non Salary)	23,649	6,867
Client meals	901	522
Computer software & others	2,014	735
Conference/seminar costs	5,305	2,405
Consultants fees	80,240	80,000
Delivery	9,757	4,296
Depreciation	11,653	3,803
Equipment (<\$300)	6,813	2,030
Equipment (>\$300)	50,834	57,027
Gift	1,068	1,356
Insurance	4,178	7,511
Interest - Australia	637	563
Materials & supplies (Merchandise)	12,079	2,722
Medical Supplies & research	96,371	167,180
Office consumable	5,962	911
Postage	3,119	2,036
Rent on land & buildings		600
Repairs & maintenance	3,847	1,744
Salaries - ordinary	237,134	124,376
Holiday Pay Provision	7,541	1,188
Employee fringe benefits	19,845	
Staff training	4,836	
Stamp duty	413	121
Subscriptions	3,338	194
Superannuation	21,342	11,194
Telephone	9,105	4,407
Travel	95,369	67,422
Travel - Client Respite/Holidays/Kin Connection	46,500	49,929
<b>Total expenses</b>	<b>791,012</b>	<b>635,514</b>
<b>Surplus for the year</b>	<b>6,551,839</b>	<b>(300,826)</b>

## Financial Statements – Balance Sheet (2010-2011)

	2011	2010
<b>Current Assets</b>		
<b>Cash Assets</b>		
Cash At Bank	55,384	115,409
TCU Saving account	200,000	
Term Deposits	1,498,475	1,290,000
NAB Trustee account	6,001,355	
NAB Operating account	38,916	
Undeposited funds	1,774	1,300
	<b>7,795,903</b>	<b>1,406,709</b>
<b>Receivables</b>		
Trade debtors	86,449	17,354
Accrued income	131,478	24,781
	217,926	42,135
<b>Total Current Assets</b>	<b>8,013,830</b>	<b>1,448,844</b>
<b>Non-Current Assets</b>		
<b>Property, Plant and Equipment</b>		
Plant & equipment - at cost	67,284	51,052
Less: Accumulated depreciation	(12,265)	(3,972)
Motor vehicles - at cost	18,200	18,200
Less: Accumulated depreciation	(3,640)	(280)
	69,579	65,000
<b>Total Non-Current Assets</b>	<b>69,579</b>	<b>65,000</b>
<b>Total Assets</b>	<b>8,083,409</b>	<b>1,513,844</b>
<b>Current Liabilities</b>		
<b>Payables</b>		
Trade creditors	10,539	10,806
Holiday pay liability	8,729	1,188
Other creditors	6,090	8,804
	<b>25,359</b>	<b>20,798</b>
<b>Current Tax Liabilities</b>		
ATO Liabilities		(13,165)
		(13,165)
<b>Total Current Liabilities</b>	<b>25,359</b>	<b>7,633</b>
<b>Total Liabilities</b>	<b>25,359</b>	<b>7,633</b>
<b>Net Assets</b>	<b>8,058,050</b>	<b>1,506,211</b>
<b>Members' Funds</b>		
Accumulated surplus (deficit)	8,058,050	1,506,211
<b>Total Members' Funds</b>	<b>8,058,050</b>	<b>1,506,211</b>

Note: Please email [nadia.lindop@mjd.org.au](mailto:nadia.lindop@mjd.org.au) for a copy of the full Financial Statements with Notes.



MJD Foundation Incorporated ABN 85 714 539 093

**Independent Auditor's Report to the Members**

**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 2011.

**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 2, 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 2011 and its financial performance for the year then ended in accordance with the accounting policies described in Note 2 to the financial statements, and the Associations Incorporation Act .

**Basis of Accounting**

Without modifying our opinion, we draw attention to Note 2 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 : 24<sup>th</sup> Nov 2011

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

Nina Deluca

# MJD Money Business



## \$6 Million Injection into the Balance Sheet

In 2010-2011 the MJD Foundation was awarded with a \$6 million Aboriginals Benefit Account (ABA) grant.

The ABA is an account established under law to receive and distribute royalty equivalent monies generated from mining on Aboriginal land in the Northern Territory. An Advisory Committee made up from representatives from NT Aboriginal Land Councils makes recommendations to the Minister for Families, Housing, Community Services and Indigenous Affairs on how to direct funding for the benefit of Aboriginal people living in the Northern Territory.

The purpose of this \$6 million grant to the MJD Foundation is for the funds to be invested in perpetuity with the resultant income earned being applied towards meeting future operational costs. The result is that this injection into the MJD Foundation balance sheet this year cannot be spent, and instead, the earnings (estimated to be around \$350,000 per annum) will help keep the MJD Foundation operational for many years to come.

## Why Are Travel Costs So High?

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



Some examples of the costs and necessity for travel are:

- A small single engine air charter from Groote Eylandt to Elcho Island (return) costs \$2,500
- A small single engine air charter from Groote Eylandt to Bickerton Island (return) costs \$520 (This is a 10 minute flight)
- For many months of the year communities are cut off because of the wet season, therefore accessing communities (such as Ngukurr) is only viable by chartered aircraft
- Many communities are islands or very remote and do not have a regular passenger service therefore the only option to access the community is by charter
- More of our clients are moving into residential care in Darwin which necessitates travel to Darwin and the associated accommodation costs
- Commercial flights from Gove to Darwin (return) can be up to \$600 (for a 1 hour flight)
- To take a client who lives permanently in residential care in Darwin back to their community for a Kin Connection trip costs up to \$4,000
- We conduct education and research in communities, and therefore bring specialists into communities

What are some of the things we do to reduce travel costs?

- All MJD Foundation Board, staff, medical specialists, researchers and clients always fly economy class
- The travel allowance for Board, staff and volunteers is well below the ATO recommended allowances
- The MJD Foundation aims to borrow vehicles in communities where possible rather than hire
- Coordination of charter requirements with other organisations to share costs
- The MJD Foundation has some wonderful sponsors who assist to keep our costs down:
  - Vincent Aviation provides us with discounted flights, and in 2010-2011 saved us \$15,000 in flight costs
  - Dugong Beach Resort provides us with free accommodation on Groote Eylandt and in 2010-2011 saved us \$30,000 in accommodation
- Clients are registered with a QANTAS carer concession card to receive discounted flights
- Board meetings are scheduled where possible at non-peak travel times

For a beautiful lady

# Gwenda Lalara

03/05/1951 – 24/06/2011



Dedication





Dedication

