



# OUR JOURNEY TOGETHER

Annual Report 2016-2017





Bakala insisting that Jen (PhD student) increases her speed



**MJD Foundation**

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“

MJD Foundation is a grassroots organisation, which is driven by the clients. MJD Foundation adopts a holistic person-centred or family-centred approach that puts the needs of the client firmly at the centre of the process and is based on their views and wishes. MJD Foundation staff discovers and act on what is important to a person. For

them it is a process of patient continual listening and learning, focusing on what is important now to the person and what is important for their future. Actions are taken in alliance with the person, their family and their community. The outcome is a strengths based practice which emphasises people's self-determination and strengths. This

practice within this organisation is definitely client led.”

NDIS Quality & Safeguards Assessment - March 2017





p.5 Barbara enjoys her holiday of a lifetime with family at the Cold Coast

p.4 Melinda runs along the beach with Nick and Simon; Paulette fishing at Gunbalanya; Barbara and Elah at the MJDF Communication Group

## THE MJD FOUNDATION

**The MJD Foundation works in partnership with Aboriginal<sup>1</sup> Australians, their families and communities living with Machado-Joseph Disease to provide comprehensive supports and engage in research providing hope for the future.**

Initially established in 2008 across the Groote Archipelago (Angurugu, Umbakumba, Milyakburra), the activities of the MJD Foundation have now been established in Darwin, Alice Springs, Gove (Nhulunbuy) Peninsular, Elcho Island (Galiwin'ku), Ngukurr, Urapunga, Numbulwar, Papunya, Hermannsburg, Santa Teresa, Oenpelli (Gunbalanya) and North Queensland.

The MJD Foundation is a charity with deductible gift recipient status. It prides itself on strong community and family connections, and always works from a grassroots perspective to listen to the needs and desires of families

affected by MJD.

The activities of the MJD Foundation are broad and ambitious for a small organisation. The scope of education delivery, equipment provision and communities services are more broad than the supports under the National Disability Insurance Scheme (NDIS), and clients are acknowledged and supported at a much earlier stage in their MJD journey than the NDIS recognises them, as are their families and children. Research is a strategic priority for the MJD Foundation, as is advocacy at a government policy level for improved outcomes for families.

1. The MJDF uses the term Aboriginal in preference to Aboriginal and Torres Strait Islander in recognition that Aboriginal people are the original inhabitants of Arnhem Land. Aboriginal and Torres Strait Islander is referred to in the national context. No disrespect is intended to our Torres Strait Islander families and communities. The MJDF acknowledges the inclusion of Torres Strait Islanders who may be affected by MJD.



“

I am pleased to report that the MJD Foundation can again report a year of solid outcomes and achievements.

”

## CHAIRPERSON'S REPORT

Neil Westbury PSM

### NDIS Quality and Safeguards Framework Assessment

A major highlight this year was the results of an independent Quality and Safeguards Framework Assessment of MJD Foundation commissioned by the Northern Territory Government, consistent with meeting the requirements to become a registered support provider under the National Disability Insurance Scheme (NDIS). This exhaustive and independent assessment (conducted by HDAA and observed by KPMG) provided an unprecedented and glowing report on MJD Foundation's capabilities against a number of strict criteria. It is also testament to the skills and commitment of our people throughout the organisation, its sound policies and procedures, good governance and financial management, workplace planning and delivery and relationship with its

clients and various stakeholders. Of particular note the assessment concluded that:

*“Clients, their families and their kin willingly engage with the organisation, and make decisions based on cultural and social needs. Family, extended kin networks, and community members are involved in support delivery. Clients interviewed were open, direct, confident and engaging about their experiences with MJD and how the Foundation was helping them and their families.”*

### Roll out of the NDIS

Without government support and at considerable cost, the Board has over the last several years committed resources towards ensuring MJD Foundation's clients can be best placed to maximise the opportunities and benefits that flow from the implementation of the NDIS. This work has involved the provision of ongoing expert advice to the Board, detailed submissions to parliamentary inquiries and standing committees, the NDIA and the Productivity Commission highlighting critical issues that ought be addressed in the design and implementation of the NDIS.

This work has been further supplemented by a comprehensive unit costing study completed by our CEO

Nadia Lindop identifying the actual costs of delivering MJD Foundation's services in remote Australia (independently reviewed by Deloitte Access Economics) that formed the basis for a submission to McKinsey and Company. The Board is pleased to report that the Productivity Commission took up a number of our recommendations in our submission to its inquiry in its final report and we keenly await the Commonwealth's response.

MJD Foundation has also sought to ensure individual clients and their families are aware of the implications and opportunities flowing from the NDIS. This approach has also been reflected in the tireless efforts of our staff to work in close collaboration with the NDIA and other relevant locally based organisations to ensure individual plans under the NDIS reflect the actual needs and wishes of MJD Foundation clients. The differentials in the quality and level of resources approved under those plans with MJD Foundation direct involvement versus those without have again highlighted the value MJD Foundation and its people add to the planning process for individual clients.

## Research

Thanks to additional support, in particular from the Traditional Owners of Groote Eylandt, MJDF has been able to significantly enhance and broaden the Research program in a number of important areas, both internationally and here in Australia, as set out in the CEOs report. Of particular significance is the increased focus on MJD Foundation's Aboriginal workforce being co-researchers.

## Governance Review and Implementation

The past year has seen considerable progress in the implementation of the findings of the independent governance review kindly undertaken by Beth Fiedler on a pro bono basis. These include rationalising management across the organisation via a stand alone CEO, establishment of Research and Education, and Community Services as stand alone programs to reflect the priority our clients attach to these functions and their heavy workloads, appointment of a Chief Financial Officer and two new appointments of highly qualified and skilled Aboriginal people to the Board. We have also established an independently chaired Risk Management sub-committee to assess and report regularly to the Board on the risks and opportunities facing MJD Foundation. These and a number of other changes have materially strengthened the organisation as a whole.

## Victory for Justice

MJD Foundation secured a major victory in its long running battle for justice when Minister Scullion's appeal against Justice Flick's previous Federal Court judgment overturning the Minister's 2013 decision to overturn a previously

approved and publicly announced \$10m Aboriginals Benefit Account grant to MJD Foundation was rejected by a majority decision of the full bench of the Federal Court on 3rd March 2017. MJD Foundation is particularly grateful to our legal advisers Gilbert + Tobin and Barrister Stephen Free who acted pro-bono on the MJD Foundation's behalf.

## The People who make our work possible

I would like to take this opportunity to thank and acknowledge my fellow Board and subcommittee members, and all the staff of MJD Foundation for their tremendous work, support and continued commitment. I would also like to particularly thank Nadia for her outstanding contribution and Libby for her critical role in both helping make MJD Foundation what it is today.

In particular I want to acknowledge our clients without whose trust and support MJD Foundation would never have achieved so much in such a short time. As our co-founder and courageous Vice Chair Gayangwa Lalara recently reminded us 'we are all family and we are here because we love one another'.

Both Gayangwa and Tony Wurramarrba have taught us as an organisation that relationships and respect for family and culture are at the heart of successful work for people with disabilities. The MJD Foundation is only able to do the work it does with its Aboriginal clients because it puts the client, family and community needs at the centre of its working culture. A key challenge is therefore never to lose sight of this first order principle.

I would also again take this opportunity also sincerely thank and acknowledge our many partners, sponsors, funders and volunteers for their past and continued critical assistance in ensuring MJD Foundation can continue its work. This continued support remains critical into the future. As the CEO's report attests, the NDIS will remain only a small portion of the overall work of the Foundation. MJD Foundation supports clients well before they reach a point they become eligible for assistance under NDIS and many of the activities and programs conducted by the MJD Foundation will not be funded under the NDIS. It therefore remains essential that MJD Foundation's broad funding base can be expanded to enable us to meet our strategic goals.



Neil Westbury PSM



Physio in the water, part of the 'On Country' program on Groote Eylandt

## THE YEAR: HIGHLIGHTS 2016-17

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- **RAHC eLearning Module** - All health professionals now have access to CPD-approved online clinical information about working with a patient with MJD. This training module is designed for remote area work and was made possible through a collaboration with Remote Area Health Corp (RAHC) (<https://www.rahc.com.au/elearning>).
- **Genetics Roadshow** - The MJD Foundation in collaboration with VIC Clinical Genetics Services toured six locations in five days to deliver nine genetic education workshops on MJD to 119 health professionals. Funded by the federal Dept of Health, the team visited: Elcho Island, Nhulunbuy, Groote Eylandt, Katherine, Ngukurr and Darwin.
- **NDIS Rollout** - after years of preparation, the National Disability Insurance Scheme (NDIS) commenced its rollout to MJD Foundation clients across the NT. The MJD Foundation is working hard to ensure our clients get the best possible plans.
- **Quality & Safeguards Assessment** - The MJD Foundation was assessed by independent assessors to ensure compliance with the NDIS Quality & Safeguards Framework. We are proud that we were given excellent feedback.
- **Bakala the Film** - Anindilyakwa man 'Bakala', facing the crippling effects of a neuro-degenerative disorder is searching for a cure in the traditional medicines from the land. As his body deteriorates, Bakala's inner strength grows as he fights against black magic and looks to his Ancestors for the answer ([www.bakalathefilm.com](http://www.bakalathefilm.com)).
- **Zebrafish Findings** - People living with MJD are a little closer to treatment after Macquarie University researchers working with zebrafish identified a substance they think could help the body clear itself of toxic disease-causing proteins.



# OUR IMPACT

## EDUCATION



- Collaborated with Remote Area Health Corp to create an MJD eLearning module for Health professionals
- Conducted a Genetics Roadshow bringing Genetics expertise to remote communities to train health professionals
- Educated careworkers across the NT and QLD
- Began publishing medical protocols through peer reviewed process

## RESEARCH



- Expanded our research focus through the recruitment of Aboriginal Co-Researcher to work alongside our PhD students
- Celebrated the publication of the Zebrafish research paper in the 'Journal of Neuroscience' showing it may be possible to slow the effects of MJD
- Supported PhD projects across communication; zebra fish; physical exercise
- Participated in the BIG (Better Indigenous Genomics) project to evaluation our Genetics program

## EQUIPMENT



- Delivered 120 pieces of equipment to clients across NT and QLD
- Funded \$80,000 worth of equipment
- Renovated an important family outstation house to be accessible

## ADVOCACY



- Launched "Bakala" the film to raise awareness of MJD and raise funds for research. [www.bakalathefilm.com](http://www.bakalathefilm.com)
- Wrote submissions to the Productivity Commission and the Parliamentary Joint Standing Committee around the NDIS transition, especially focussed on pricing and remote communities
- Raised over \$20k (thanks to the Alyangula Golf Club) annual Fundraiser on Groote Eyland

## COMMUNITY SERVICES

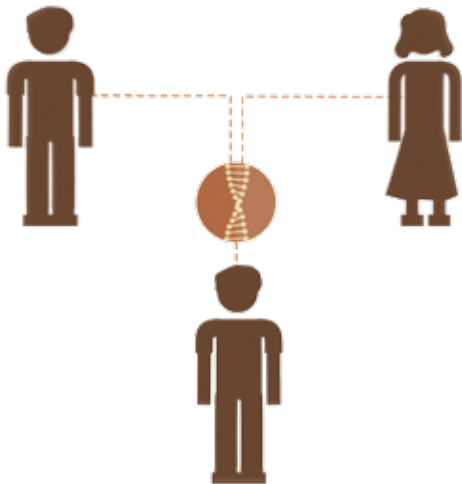


- Conducted 4 Kin Connect trips taking clients back to their home community
- Provided 2 Holidays of a lifetime to clients and their families
- Worked with the NDIA alongside our first 7 clients to get NDIS plans (at 30th June)

# WHAT IS MACHADO JOSEPH DISEASE?

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

MJD is an inherited, autosomal dominant disorder, meaning that each child of a person who carries the defective gene has a 50% chance of developing the disease. In addition the mutation is typically expanded (worsened) when it is



## HOW MJD AFFECTS THE BODY

### SYMPTOMS

- Muscle weakness and falls
- Slurred speech
- Loss of balance and muscle cramping
- Blurry or shaky vision
- Sleep disturbances
- Bowel and bladder problems
- Swallowing difficulties
- Mental health issues including sadness and depression

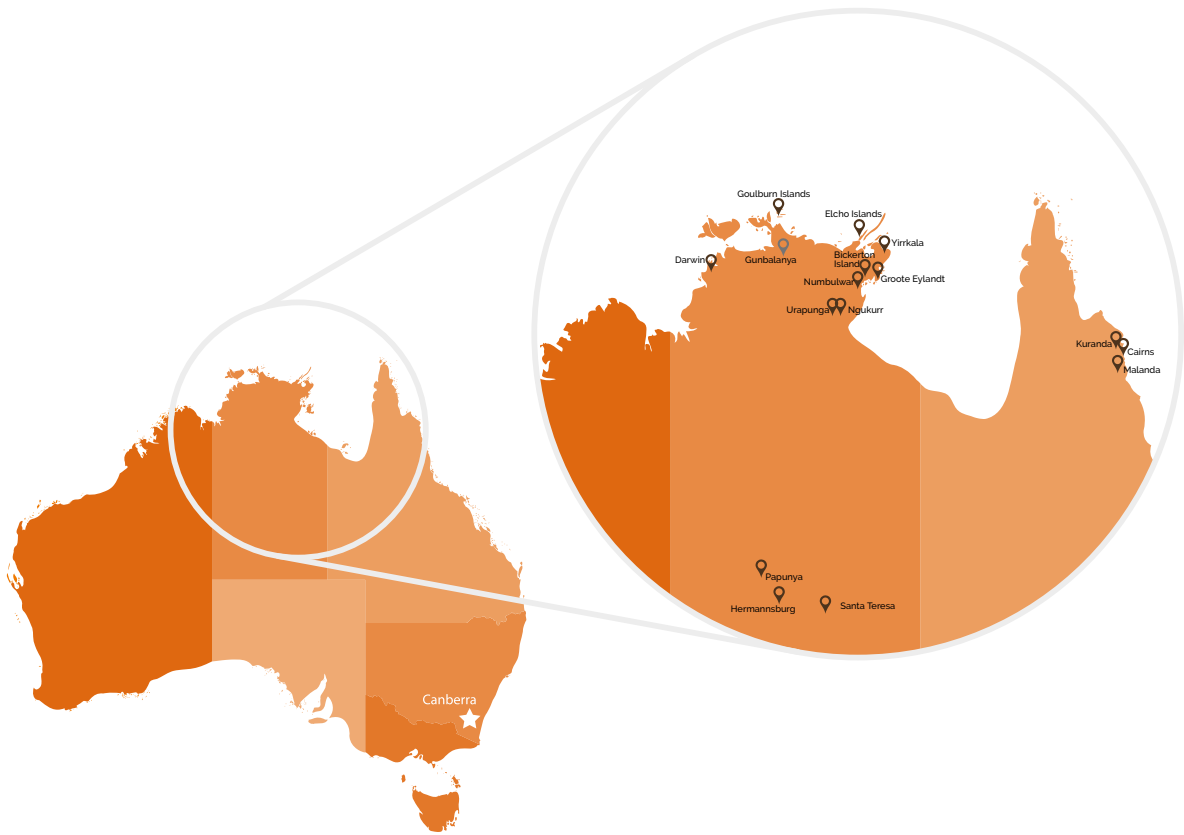
passed to the next generation (known as an 'anticipation effect'). This means that symptoms of the disease can sometimes appear around 8 to 10 years earlier each generation and are more severe.

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

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



Sharon's Kin Connect trip back to Cunbalanya with Desirée, Paulette and young Japeth



## MJD IN ARNHEM LAND AND BEYOND

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

Although it is impossible to predict the number of Aboriginal Australians who will develop MJD, there are currently over 650 Aboriginal Australians thought to be “at risk” of developing the disease across the top end.

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

# STAND WITH US



Senior Management team: Jen Telfer, Mel Fajerman, Libby Massey, Morag MacLennan, Nadia Lindop

This year can definitely be marked as a year dominated by the National Disability Insurance Scheme (NDIS). Whilst we've prepared for four years now, I don't think anyone knew how much work it would be when it actually hit us. The rollout across the NT commenced in January 2017, with our Arnhem clients and for clients living in Darwin supported accommodation was first off the blocks.

In parallel with the efforts to walk through the process alongside our clients, was the process of the MJD Foundation becoming an approved NDIS registered support provider.

And even before clients have their plans bedded down and supports in place, there is now a wave of consultants coming out to conduct 'reviews' of the rollout. As always, our clients have shown enormous graciousness and patience, and I want to especially thank our wonderful MJD Foundation team who, despite countless challenges, have kept our key goal (of ensuring our clients get the best NDIS plans that they can possibly get) in their sights.

However, NDIS will remain only a small portion of the overall work of the

MJD Foundation. MJD Foundation clients are eligible for MJD Foundation supports well before they reach the stage of MJD that sees them living with a severe or profound disability. The MJD Foundation supports clients and their families throughout their whole journey with MJD. And many of the activities and programs conducted by the MJD Foundation will never be activities that are funded under the NDIS. For example: genetic education/counselling; research, and much of our education and advocacy streams. It therefore remains essential that MJD Foundation maintains a broad funding base to enable us to meet our strategic goals.

## Workforce

We continue to grow our capacity especially respecting our two-way working model of having our Aboriginal and non-Aboriginal staff working alongside each other across everything we do.

In 2016/2017 our team of dedicated staff rose from 19 to 27, with an increase in Aboriginal Staff from 6 to 11.

## Community Services

The ability to access ones community with family remains a priority for our clients, whether they are still living in their remote/very remote community, or whether they now live in Darwin, Alice Springs or Cairns due to needing supports that are not available remotely. Our 'Kin Connect' trips continue to support our clients to travel home each year to spend precious time with their families and on country. The heart-warming smiles of our clients as they arrive back home, and their tears as they once again leave reminds us each time of how important this program is.

Our 'Staying stronger for longer' program now incorporates traditional therapeutic interventions with culturally appropriate approaches which are now embedded in our Groote Eylandt 'On Country' days, and is planned for commencement in Darwin in the 2017/18 financial year. We have also commenced a Communication group in Darwin which provides clients/families with skills to use communication aids, plus supports those clients who are losing their ability to verbally communicate.

## Education

This year we were proud to launch an e-Learning resource partnering with Remote Area Health Corps. Our VCGS genetic education and counselling service continues to strengthen with VCGS visiting most of the communities we work in more than once across the year.

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

We have continued to provide face to face educational opportunities to people caring for those with MJD, and also to primary and allied health care practitioners with a Genetics Roadshow to 119 people across 6 locations in 5 days which was very well received.

## Research

A clear strategic focus of the MJD Foundation this year was to expand our Research program by having dedicated research staff; increase collaboration with Australian and International MJD (and other relevant) researchers; increase support for PhD projects focussing on areas that are priorities to our MJD families; and to increase the publication of papers adding to the international literature

around MJD. In particular, we have focussed on increasing our Aboriginal workforce as Co-researchers to ensure our two-way model of working in communities with our clients/families is carried into all research activities as well.

## Highlights

After a long battle in the Federal Court, the MJD Foundation finally received the \$10 million Aboriginals Benefit Account grant in May 2017. This funding will be invested, and the earnings used to deliver critical MJD Foundation programs to clients into the future. We are enormously grateful to Gilbert+Tobin for taking on this challenge with us.

One of the highlights of the year was the filming and screening of "Bakala" the film. Being able to share in Bakala's joy and pride of attending the first international screening at Telstra's head office in Melbourne was certainly a notable highlight. We hope to continue to raise awareness of Bakala's journey to raise awareness and funds for research over the coming years ([www.bakalathefilm.com](http://www.bakalathefilm.com)).

## Thank You

We are extremely appreciative of the support from our 2016-2017 collaborators, funders and partners:

Anindilyakwa Land Council, South32/ GEMCO, Telstra Foundation, GEBIE, Federal Dept of Health, Federal Dept of Prime Minister & Cabinet, Groote Eylandt Lodge, Seaswift, Youngcare, Airthorn, GEAT, Gilbert + Tobin, McCullough Robertson, Bridge Toyota Darwin, U-Store-it, CWA Alyangula, Accor Darwin, Workpac, McQueens Solicitors, Blackcat Civil, Alyangula Golf Club, Adaptalift, Kate Freestone Photography, Katherine Aviation, Skinny Fish, TCU, and all who enable us to extend our services, participate in research, educate others, and provide equipment to our clients.

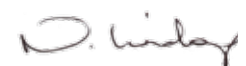
## The Year Ahead

The year ahead will continue to see us focus on the NDIS with the transition across the NT continuing and the QLD transition commencing for our clients.

We will launch our new three year Strategic plan (2018-2021).

And watch out for our birthday celebrations in 2018, as the MJD Foundation turns 10!

Nadia Lindop, CEO



Bakala visits the zebrafish lab; Kaitleen using her iPad; Colleen, Joyce and Melinda baking cakes

## OUR WORK

**Navigating the National Disability Insurance Scheme (NDIS) rollout has been a major focus this year. How to best prepare our clients and families for the new scheme, how to ensure our clients get the best possible plans, and ensuring the MJD Foundation is positioned well to enable continued and sustainable supports to clients, families and their communities.**



Aboriginal Co-Researcher Joyce studying for her Lowitja conference presentation

## RESEARCH

**Central to all the research conducted by the MJD Foundation is the principle of involving those who have the disease, and their families. We take this direction and channel it to researchers and build the capacity of individuals, family carers, health professionals and co-researchers.**

Building on the firm foundations afforded by the generous Anindilyakwa Land Council (ALC) donation to the MJD Foundation research program, there has been both steady progress and exciting new opportunities during this year.

We have developed a strategic plan for the research program, articulating the goals and key desired outcomes.

### Strategic Plan – Research

**1. Strategic scientific endeavor**, oriented to finding a cure for MJD.

**2. Community ‘people’ based projects**, working together with families who have MJD to find better ways to deal with the symptoms of the disease

**3. ‘Big picture’ research**, designed to consider and improve the systems and processes that provide care and information.

Collaborations established with the University of Melbourne, James Cook University, Charles Darwin University and Macquarie University ensure that there is strong academic support for the research projects.

Three talented PhD students and a growing team of Aboriginal co-researchers have become important members of the MJD Foundation family

and have developed strong links with the dedicated community service team, ensuring that the research being conducted on the ground enhances and reflects the values and principles of the MJD Foundation.

Moving into the next year we plan to grow a focus on international partnerships and alliances, bringing the experiences of Aboriginal Australians with MJD and their opportunities, in line with those around the world.



Maxinne Watchon with Bakala, Jacob and Dr Angela Laird; Jen Carr checking out the trike on Groote; Rebecca Amery and little-one on Elcho Island



**Maxinne Watchon** is in the final year of her PhD studies at the University of Sydney. Her PhD has used MJD zebrafish to test different drug compounds in the hope of finding a potential treatment for MJD

Her findings have been presented at both international and national conferences including the International Conference of Neurology (Portugal, March 2016), International MJD conference (Cairns, Australia, 2015) and the Australian Neuroscience Society Conferences (Hobart, 2016 and Sydney, 2017). Findings from her studies have also been published in the prestigious Journal of Neuroscience (August, 2017) and she aims to publish additional findings in the near future.

Maxine completed her Bachelor of Medical Science followed by a Graduate Diploma project studying MJD using zebrafish. She has worked in MJD research since 2012.

Maxinne's PhD study is supported by an industry scholarship from the MJD Foundation, funded by the Anindilyakwa Land Council.

**Jen Carr** is a PhD student working together with families with MJD from Groote Eylandt and the MJD Foundation to help find the best ways to keep people with MJD 'walking and moving' and 'living a good life'.

Jen completed a Bachelor of Physiotherapy at James Cook University (JCU) in Townsville in 2009 and a Graduate Diploma in Neurological Rehabilitation in 2014. Jen has spent most of her career working in Neurological Rehabilitation, and currently holds a position as Senior Physiotherapist in Rehabilitation in the Gold Coast. Jen has also worked in remote Aboriginal and Torres Strait Islander communities in Cape York, to develop and evaluate a rehabilitation service for stroke survivors in 2014.

Jen has been involved in research throughout her career and published research on community participation following spinal cord injury in 2016. Jen was awarded a full time PhD scholarship from JCU in 2017 to undertake this research alongside families with MJD on Groote Eylandt. Jen and the research team recently secured \$99,760 from the Lowitja Institute for this research.

**Rebecca Amery** is a speech pathologist and PhD student at Charles Darwin University (CDU). Rebecca is 12 months through her PhD research, 'Understanding and Supporting the Communication Needs of Yolŋu with MJD'

Rebecca grew up in Yirrkala and remembers spending school holidays at Galiwin'ku, Elcho Island in northeast Arnhem Land.

She graduated in 2011 from the University of Newcastle with a Bachelor of Speech Pathology, Honours Class 1. Over the last 6 years Rebecca has worked and volunteered as a speech pathologist in Darwin, Melbourne, Vietnam and Indonesia with children and adolescents with complex communication needs and multiple disabilities.

Rebecca is concurrently enrolled in a Graduate Certificate of Yolŋu Studies at CDU. Rebecca is currently enjoying analysing research data with Yolŋu co-researchers from the MJD Darwin office. Rebecca's Industry scholarship from the MJD Foundation is funded by the Telstra Foundation.

## EDUCATION

The Genetic education program is fundamental to the MJD Foundation's work and represents our 'two way' model of practice. The relationships and knowledge growing in this space have resulted in more genetic testing and the development of emerging experiential protocols. Our partnership with Victorian Clinical Genetics Services provides an enduring platform for this work.

Translation of best practice information into comprehensive literature reviews and then accessible current documents is an amalgam of the research and education programs. Our 'Medical Protocols' (funded by the Federal Dept of Health and the NAB) have been slowly developing and now comprehensively cover the issues of most concern in MJD (<http://mjd.org.au/125-medical-protocols>).

[html](#)). Help sheets which provide the key information in simple formats for family and carers have also been developed.

In 2016-17 the evidence based best practice information in these protocols is disseminated along with general MJD awareness and knowledge to the community through:

- **Health Sector education** - 8 education in-services conducted across the NT and Nth Qld.
- **Medical Student Training** - to Flinders University Medical Students conducted annually.
- **Family and Carer workshops** - 9 education in-services conducted across the NT and Nth Qld.
- **Community Organisation education** (schools, land councils, etc) - 3 education in-

services conducted across NT and Nth Qld.

- **Remote Area Health Corps** (RAHC) launched a free e-learning module for health professionals. (<https://www.rahc.com.au/elearning>)

We also have a growing Publication and Presentations portfolio.

During 2016-2017 there have been presentation at the National Indigenous Health (Lowitja) Conference; The Australian Disease Management Association (ADMA)/ Chronic Diseases Network NT Conference and the CRANApus Remote Area Nursing Conference.

Two peer reviewed journal articles have been published in The Journal of Neuroscience and the Australian and New Zealand Continence Journal.



All providing Careworker training to the TCASS team in Darwin



## EQUIPMENT



A highlight for the year was the Men's Camp at Nalawan Homeland near the Roper River with a team of clients, family, staff and volunteers performing a home modification and renovation project. As well as installing a huge Aussie ramp, and grabrails, the team decorated the home with AFL themed colours much to the delight of the client, their family and the whole community.

Bryan Massey, Brett Mamarika and Simon Mead (top)  
Brian Daniels (bottom)





A beautiful fishing spot near Gunbalanya for a Kin Connect trip

## COMMUNITY SERVICES

After a significant year of growth and change, our clients and families are now supported by a highly-skilled multidisciplinary team of Aboriginal Health and Community Workers, Occupational Therapists, Physiotherapists, Social Workers and a Family Support Worker.

The Community Services team work, in partnership with families living with MJD using a holistic person-centered practice that values and respects a cross-cultural or, 'two-way' approach.

The advent of the National Disability Insurance Scheme (NDIS) has meant profound changes for the way that people with disability receive their services. MJD Foundation has worked in partnership with our clients to align their needs and rights with sector changes.

This preparation has resulted in strategic and formalised planning processes, ahead of meeting with NDIA representatives. Throughout this process MJD Foundation's clients continue to be empowered to articulate their own priorities and advocate for their needs and goals. At the end of the 2017 financial year, 7 of our clients had active (or established)

NDIS plans. MJD Foundation's programming continues to grow to better meet the needs of our clients and families. Programs support clients living away from home to maintain cultural connection and return to country, and provide experiences for clients to improve wellbeing and participation.

This year MJD Foundation delivered four (4) **Kin Connect trips** to Groote Eylandt and Gunbalanya. The **Staying Stronger for Longer program** continues to provide best practice therapeutic intervention across sites, and the 'On Country' model engages experts from both cultures, combining traditional knowledge and priorities with best practice therapy, including speech, occupational therapy and physiotherapy.

MJD Foundation's **Holiday of a Lifetime** program has supported three (3) families to attend adventures on the Gold Coast. The heartfelt smiles we witnessed during these experiences demonstrated the intangible value that these programs offer to our clients and families.

Next year provides the MJD Foundation's Community Services

team an opportunity to improve meaningful community programming, strengthen staff support and ensure our clients continue to advocate for best practice and culturally sensitive service delivery through the NDIS roll-out.

## ADVOCACY - BAKALA THE FILM

**By telling his story, Bakala is hoping to raise funds for the MJD Foundation's Research Program to continue to search for a treatment for Machado Joseph Disease. Of funds raised through the film, 100% will go directly to research with no overhead costs.**

In 2016-2017, we had the opportunity to share a powerful story. Groote Eylandt is an ancient and spectacular land, but one that also harbours a tragic secret. A dark secret that Steve 'Bakala' Wurramara travelled some 4304km to reveal to the world.

Steve 'Bakala' Wurramara comes from an island in the Gulf of Carpentaria, called Groote Eylandt. To get there from Darwin, you must first fly 1.5 hours across the striking landscape and deep red earth of the Northern Territory, with the final 20 minutes over captivating cerulean blue waters.

It's a remote island in North East Arnhem Land and the traditional country of the Anindilyakwa people, Bakala's people. It's an ancient and beautiful land, but it protects a tragic, once secret story.

It was a secret of shame and blame. And it remains the story of the struggle of this proud and ancient people with an old and deadly foe, a fatal inherited

disease called Machado-Joseph Disease (MJD).

Bakala lives on Groote Eylandt amongst a population of around 1,100 Aboriginal Australians.

First experiencing symptoms of MJD in his late teens, Bakala has lived with the progressive onset of this insidious and debilitating neuro-degenerative disease his entire adult life.

While working on an MJD Foundation clinical education project in 2015, a filmmaker from Zakpage spent much of his time on Bakala's traditional country. In a serene swimming hole, Bakala revealed to him a somewhat whimsical, though heartfelt desire. He wanted to find a cure for MJD somewhere there, out on country, from the land itself.

Maybe from a plant or a balm or even a ceremony, or a practice. Magic, and the belief in its presence and power, is still strong among the Anindilyakwa people. Talk of curses and sorcery are never far from local conversation.

As that day ended, Bakala, backlit by the golden remains of the day, stood in the river, a vision as old as time, and thanked his ancestors for giving him this life and this country.

An idea started to foment in the recesses of the filmmaker's imagination, and 'Bakala' the film was born.

Bakala was also well known to Telstra. What started in 2010 as a tiny seed grant from the local Country Women's

Association to purchase a few iPads, caught the Telstra Foundation's attention. And in 2013, the Telstra Foundation partnered with the MJD Foundation to fund a communication program incorporating a research component to explore the use of digital technology to help people living with MJD.

It's this partnership that led to Telstra rolling out the red carpet at its headquarters in Melbourne to welcome Bakala who flew 4304km to premier his film. Telstra employees from across the organisation came together as part of NAIDOC Week to welcome Bakala to Melbourne and hear his story.

MJD is a cruel and complex disease, robbing those who have it of their independence and dignity.

It occurs in families, with each child of an affected person at a 50% risk of developing the disease themselves, almost always at an earlier age than their parent.

Although it's a rare disease, the incidence of MJD in these communities is the highest in the world, and is now known to have entered the North East Arnhem families through Chinese traders many centuries ago.

Visit [www.bakalathefilm.com](http://www.bakalathefilm.com) for more information on how you can help Bakala on his journey and to see the film's preview.

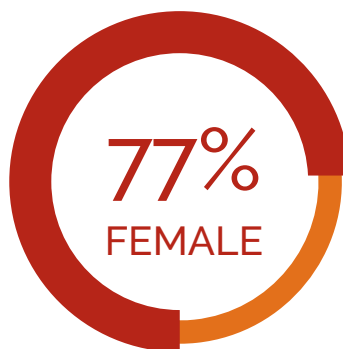




## BOARD/STAFF



**5/30**  
Proportion of people with disabilities (PWD)



**23/30**  
Female gender representation



**13/30**  
Proportion of aboriginal people

# COMMUNITY

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## The people who make it possible.

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

## STAFF/CONTRACTORS

Chief Executive Officer	Nadia Lindop	Community Worker	Tommy Weetra
Director, Research and Education	Libby Massey	Community Worker	Steve Wurrarama
Director, Community Services	Melinda Fajerman	Community Worker	Brett Mamarika
Senior Cultural Advisor	Gayangwa Lalara	Community Worker	Loretta George
Operations Manager	Morag Maclennan	Community Worker	Bronwyn Daniels
Chief Financial Officer	Jennifer Telfer	Community Worker	Julie Wunungmurra
Manager, Community Services	Ali Beckwith	Community Worker	Elah Yunupingu
Manager, Community Services	Ali Grootendorst	Co-Researcher	Joyce Lalara
Manager, Community Services	Kate Pope	Co-Researcher	Rachel Baker
Manager, Community Services	Nick Kenny	Genealogist	Janine Ryan
Research Officer	Desireé LaGrappe	NDIS Consultant	Mandy Doherty
Special Projects Officer	Kathy Massey	Physiotherapist	Nick Kenny
Accounts	Zeng Jones	Physiotherapist	Josh Mallett
Procurement Officer	Tina Hebblewhite	Physiotherapist	Simon Morris
		Physiotherapist	Simon Mead



Jennifer Baird, Gayangwa Lalara, Janice Oake, Jennifer Cullen, Neil Westbury, Nadia Lindop, Tony Wurramarrba (absent: Olga Havnen)

## BOARD MEMBERS

Chairperson	Neil Westbury
V-Chairperson	Gayangwa Lalara
Treasurer	Janice Oake
Director	Tony Wurramarrba
Director	Jennifer Baird
Director	Olga Havnen
Director	Jennifer Cullen
Ex-Officio	Nadia Lindop

## GRANTS/FUNDING

Department of Prime Minister and Cabinet, Federal Department of Health, Youngcare, NT Government, CentreCorp, National Disability Insurance Scheme

## PATRONS

Professor Garth Nicholson  
Bryan & Kathy Massey

## VOLUNTEERS

As well as our Board members and Subcommittee members who are all volunteers we want to thank the following people: Nicola Rangeley, Chris Kenny, Bryan Massey, Sally Lang, Nan Jamieson, Ben Ngwele, Melinda Simmons, Philip Meadors, Chris Lloyd, Brendan Kenny, Jen Carr, Karen Munro, Rebecca Verbeek, Samantha Wainright, Romy Tielman

## SPONSOR/DONOR ORGANISATIONS

South32 (GEMCO), Groote Eylandt & Bickerton Island Enterprises, Centrecorp, Anindilyakwa Land Council, Groote Eylandt Aboriginal Trust, Telstra Foundation, Overgrove P/L, CWA Alyangula, Blackcat Civil, Seaswift, Groote Eylandt Lodge, Gilbert + Tobin, McCullough Robertson, Bridge Toyota, U-Store-It, Airnorth, Traditional Credit Union, Workpac, Eylandt Automotive, Adaptalift GSE

OUR PARTNERS



Our partners are the organisations that work directly with the MJD Foundation, to allow us to directly achieve our objectives. We wish to thank our partners and government, philanthropic and corporate sponsors for helping us achieve our objectives in 2016-2017. Your contribution makes an enormous difference.

OUR SPONSORS



Eylandt Automotive





## TEN SUMMITS CHALLENGE

Faced with her own diagnosis of Machado-Joseph Disease, Bec Lyons has bravely decided to put her skills and talent to work and raise critical funds for MJD research. Here's her story...

Bec is 24 years old. She lives in Wallan, Victoria and grew up in Corryong and Seymour. Bec's a nurse in a busy emergency department, a volunteer firefighter with the CFA, and she plays the guitar, enjoys hiking, riding and swimming. She'll give anything that's outdoorsy a go. At the end of February 2017 she found out that she inherited MJD. Bec's Mum has MJD, as do two of her Mum's siblings and their Mum. Bec's younger sister has also recently had genetic testing done and they both have the defective gene.

**Bec wants to give hope to people going through a similar situation. It doesn't have to be MJD, but all people who have hereditary genes in their family, people that have watched a loved one suffer and may face the same suffering themselves.**

Bec's passionate about pushing for the awareness of people with disabilities. She has witnessed firsthand people being discriminated and judged because of their disability. "A early symptom of MJD is ataxia, which is an unsteady gait and looks like a drunken walk. This then leads to people being mislabelled a drunk. As part of MJD you lose coordination and speech skills but remain intellectually intact. But people misread this decline in function and communicate with suffers on a lower level. People often misunderstand people with any disability. It's not just about creating awareness for MJD for me, it's about empowering people who have been misjudged and mislabelled, and supporting those who care for other





people. It's about helping people understand that a disability doesn't define who someone is, it doesn't make them any less of a person. If you know of someone with a disability, know of someone who cares for someone else, especially a parent who cares for the other parent; cook them a meal, go mow the lawns for them, offer to drive their kids to school on rainy days, find a way to help. And for those families, allow people to help you out."

The Challenge is to climb the ten highest peaks in Australia over five days with some of Australia's most experienced Mountain Guides from K7 Adventures. Bec and a bunch of her amazing friends are doing this to raise awareness for MJD and people with disabilities; and to raise funds for research and support programs.

The top ten peaks in Australia are located in the southern end of the Kosciuszko National Park, NSW.

The combined height of all ten peaks is 21,788 metres. Although they won't actually ascend that height, it is about 75km in distance they will cover while hiking. On their biggest day they will summit four of the peaks.

The ten summit challenge will run from 19-23rd March 2018.

Please sponsor a hiker! Giving options could be \$1 per peak (\$10), or \$1 per kilometres hiked (\$75), or 1 cent per metre of the combined height of the peaks (\$217.88). Give what you can (<http://www.tensummitschallenge.com/>).

## 10 SUMMITS – 10 DAYS

1. Mt Kosciuszko, 2228 m
2. Mt Townsend, 2209 m
3. Mt Twynam, 2195 m
4. Rams Head, 2190 m
5. Etheridge Ridge Peak, 2180m
6. Rams Head North, 2177 m
7. Alice Rawson, 2160 m
8. Abbot peak, 2159 m
9. Abbot Peak East, 2145 m
10. Carruthers Peak, 2145 m

# OUR FINANCIAL STORY

## STATEMENT OF PROFIT OR LOSS

FOR THE YEAR ENDED 30 JUNE 2017

	Note	2017 \$	2016 \$
<b>REVENUE</b>	7	12,431,121	2,206,697
Administration Fees		(23,587)	(24,715)
Advertising & Marketing		(21,193)	(17,277)
Bank Charges		(1,702)	(1,345)
Computers & Office Supplies		(23,336)	(16,175)
Clients Care & Support		(428,862)	(399,764)
Depreciation Expenses	8	(61,670)	(51,358)
Employment Expenses		(956,411)	(824,311)
Freight, Postage		(6,815)	(9,089)
Insurance		(9,916)	(2,766)
Interest		(235)	-
Legal & Accounting		(7,816)	(6,900)
Assets written Off			(1,293)
Medical Research & Resources		(310,843)	(2,000)
Motor Vehicle Expenses		(24,599)	(21,788)
Office Building Expenses		(9,698)	(9,045)
Rent & Storage		(7,126)	(10,813)
Repairs & Maintenance		(13,461)	(12,910)
Travel		(277,015)	(323,086)
Other Expenses		(99,579)	(114,237)
Total Expenses		<u>(2,283,864)</u>	<u>(1,848,173)</u>
Profit/(Loss) for the year		10,147,257	357,824
Other Comprehensive income for the year			-
<b>Total comprehensive income for the year</b>		<u>10,147,257</u>	<u>357,824</u>
<b>Total comprehensive income attributable to the entity</b>		<u>10,147,257</u>	<u>357,824</u>

## STATEMENT OF FINANCIAL POSITION

AS AT 30 JUNE 2017

	Note	2017 \$	2016 \$
<b>CURRENT ASSETS</b>			
Cash & Cash Equivalents	15(a)	261,373	325,846
Receivables	9	165,556	229,255
Other Assets	10	15,475	11,921
Investments	11	19,387,331	8,087,915
<b>TOTAL CURRENT ASSETS</b>		19,829,735	8,654,937
<b>NON-CURRENT ASSETS</b>			
Property, Plant and Equipment	12	623,444	673,676
<b>TOTAL NON-CURRENT ASSETS</b>		623,444	673,676
<b>TOTAL ASSETS</b>		20,453,179	9,328,613
<b>CURRENT LIABILITIES</b>			
Payables	13	1,079,065	130,118
Provisions	14	68,238	48,955
<b>TOTAL CURRENT LIABILITIES</b>		1,147,303	179,073
<b>NON-CURRENT LIABILITIES</b>			
Provisions	14	41,129	32,050
<b>TOTAL NON-CURRENT LIABILITIES</b>		41,129	32,050
<b>TOTAL LIABILITIES</b>		1,188,432	211,123
<b>NET ASSETS</b>		19,264,747	9,117,490
<b>EQUITY</b>			
Retained Earnings		19,264,747	9,117,490
<b>TOTAL EQUITY</b>		19,264,747	9,117,490

# OUR FINANCIAL STORY

## STATEMENT OF CASH FLOWS

FOR THE YEAR ENDED 30 JUNE 2017

	2017	2016
	\$	\$
<b>Cash Flows from Operating Activities</b>		
Grants, sponsorships and donations received	13,082,520	1,779,139
Receipts from operations	137,882	(1,864)
Payments to suppliers and employees	(2,339,701)	(1,785,228)
Interest received	126,496	182,575
Dividends received	205,918	256,428
<b>Net cash provided by (used in) operating activities</b>	<b>11,213,115</b>	<b>431,050</b>
<b>Cash Flow from Investing Activities</b>		
Proceeds from sale of property, plant and equipment	-	-
Payment for property, plant and equipment	(6,980)	(509,373)
Proceeds from sale of investments	3,394,524	5,794,592
Payment for purchase of investments	(14,665,131)	(5,807,930)
<b>Net cash provided by (used in) investing activities</b>	<b>(11,277,587)</b>	<b>(522,711)</b>
<b>Net increase (decrease) in cash held</b>	<b>(64,473)</b>	<b>(91,661)</b>
<b>Cash at beginning of the year</b>	<b>325,846</b>	<b>417,507</b>
<b>Cash at end of the year</b>	<b>261,373</b>	<b>325,846</b>

For a full set of Financial Statements and accompanying notes, see [www.mjd.org.au](http://www.mjd.org.au).

# INDEPENDENT AUDITOR'S REPORT

MJD Foundation Limited

ABN 65 159 208 867

We have audited the financial report of MJD Foundation Limited which comprises the statement of financial position as at 30 June 2017, the statement of profit or loss and other comprehensive income, the statement of changes in equity and the statement of cash flows for the year then ended, notes comprising a summary of significant accounting policies and other explanatory information, and the director's declaration.

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

1. giving a true and fair view of the company's financial position as at 30 June 2017 an of its performance and cash flows for the year ended on that date; and
2. complying with Australian Accounting Standards to the extent described in Note 2, and Division 60 of the Australian Charities and Not-for-profits Commission Regulation 2013.

HILL ROGERS ASSURANCE PARTNERS



Brett Hanger

hillrogers



Lindsay Tuer and Ravi Savarirayan from VCCS, Danila Dilba staff member, Libby Massey

## GENETICS ROAD SHOW

In May 2017, the MJD Foundation in collaboration with VIC Clinical Genetics Services toured six locations in five days to deliver nine genetic education workshops on Machado Joseph Disease to 119 health professionals. Funded by the federal Department of Health, the team visited: Elcho Island, Nhulunbuy, Groote Eylandt, Katherine, Ngukurr and Darwin.

MJD is a rare, very disabling genetic condition occurring at high rates across remote communities in the NT. Detection and management of the condition may require referral to a range of primary health specialists including, genetics, neurology, respiratory, internal medicine, rehabilitation and ophthalmology during the patient's lifespan. Continuity of primary health care is a perennial issue for these patients, as MJD

is not well known outside of the region. Adding further complexity, an outpatient model of specialist service provision dominates in the NT, generally requiring the patient to travel to Darwin or Alice Springs.

Short term staffing, segregated provision of Primary Health Care services (Aboriginal Medical services or NT Government clinics) and limited opportunities for continuing Professional development (CPD), mean that health care professionals working in remote NT clinics often require additional support to know when referral is necessary, and stay abreast of appropriate management strategies. In the case of genetic conditions with high transfer rates such as MJD it is vital that health professionals are well informed and able to support patients.

The workshops were exceptionally well

received with participants scoring a very high level of satisfaction with the sessions.

# THE CHALLENGES OF THE NDIS

Transition to the National Disability Insurance Scheme (NDIS) has had its challenges. It's taken a significant amount of work collaboratively with the NDIA to get on top of the transition to the NDIS, whilst ensuring the plans developed for our clients are the best possible.

MJD Foundation clients are only eligible to enter the NDIS around the moderate stage of the disease. However, the MJD Foundation provides support throughout the entire life's journey with MJD. The organisational challenge is aiming to secure the best possible NDIS plan for our clients, while recognising that the NDIS does not provide an income stream for the work the MJD Foundation does across all of our clients.

The complexities of the transition have been extensive, including:

1. The NDIS is complex to understand, the systems are not yet mature, and rules are applied inconsistently;
2. NDIS staff are mostly new and they often don't have experience working with Aboriginal people, people with disabilities or working in remote communities. They often don't have an understanding of what is culturally

important to people, and what is at the centre of their lives.

The MJDF has been trying to disaggregate what those frustrating transition issues are, as opposed to what are the longer-term policy issues that will impact people's lives.

A key longer term issue is that the NDIS pricing is not high enough to cover the costs of delivering supports in remote and very remote communities.

For the MJD Foundation, we will not only have to fill the gaps in pricing, but we'll need to continually seek a broader funding base to deliver our full range of programs to our clients living with MJD, along with their families and communities.

Despite these complexities, challenges and frustrations the MJD Foundation has developed a positive working relationship with the NDIS. We're encouraged that the NDIA are open to suggestions and willing to innovate. It's important to innovate and think outside the square. We've pooled clients' funds on Groote Eylandt and the NDIS has been happy to work with us on implementing this.

Kin Connect trip for Stephanie, with Paulette and volunteer Nicola





## DEDICATIONS

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### ANNABELLE DANIELS

01/01/1959 – 10/09/2017

“When someone like Aunty passes on and there are lots of people sad at the funeral, it shows how loved she was. But she wouldn't want us to be sad. At the end she said 'I don't want anyone crying for me at my funeral. You will all be together and should be happy.' She said I will cry at my funeral because I miss you all.” Nick Kenny

Annabelle Daniels was strong and cheeky by nature, but small in frame. Generous, loving, funny and strong she was well loved within the community. She looked after everyone. Even when the MJD made her slower and weaker, she kept trying to cook and clean and care for everyone else, when she was the one who needed to be cared for. Many people stayed with her and cared for her, visiting her and making her food, giving her medicine and bush tucker. Everyone wanted to help her in the end because she had spent her

whole life helping everyone else.

The boys she grew up – Keifer, Mark, Dawson, Jackson and Ernest Junior had lots of happy memories of growing up. They recall a time she found out the boys were smoking some Ganja and she said to them “you better get that out of my house – flush it down the toilet now.” They begged her no, “no just let us finish the last bit, then no more”. So she called the police and said “I have 5 boys here with Ganja at my house – can you come around here now and arrest them. I didn't raise up criminals to live in my house!” Even though she became mad at the boys sometimes to teach them lessons, she always did it with a cheeky grin and she never stayed mad at them. She taught them that to follow the law is important. She also enforced the importance of obtaining





“When someone like Aunty passes on and there are lots of people sad at the funeral it shows how loved she was. But she wouldn't want us to be sad. At the end she said 'I don't want anyone crying for me at my funeral. You will all be together and should be happy.' She said I will cry at my funeral because I miss you all.”

Nick Kenny

a good education with equal velocity.

She taught them about growing up and how to be a good man too. She used to talk to the boys about their worries and she used to say to them “every good man has to know how to cook, clean up and look after your family. No matter where you go or who you marry a good man is a tidy man and he takes care of his family.” That is how she looked after her boys, and that's how she raised her boys and that's the way they are now. She did a good job raising those boys in to respectable men today.

Everything she had she gave to the boys.

She was hardworking and smart. She became a teacher and used to teach all the kids and grandkids with Blue. While the old man was chosen to be the leader of the community Blue Sea and Aunty would teach all the children. She studied at Nungalinya for her teaching and when she met her husband Paul Hicks she moved to Perth and Sydney with Ron and lived away from Ngukurr for 15 years raising Ron and teaching in schools. When she came back with Ron she moved in to the caravan near the bottom shed and when Ron moved out and got married and had Mark she took him in and began raising Mark and the other 4 boys with her second husband Ziggy. She taught them to work hard and provide for your family.

When Ziggy left she moved in to single men's quarters and kept looking after the boys until they were teenagers. She worked as a cleaner at Roper Shire and CDP until her MJD started getting worse and she knew it was too hard to look after the boys. The boys then started to look after themselves. The boys loved her like their own mother and even after they moved out they all kept on checking on her and caring for her right up to the end.

Aunty loved playing cards and she would push that walker all over Ngukurr every afternoon to find a card game to play. The Health Centre Staff loved her too. Whenever she would come in to see them they would say “Here comes trouble with a Capital A!” Aunty was always grateful for any help she got from the Clinic and she would always say thank you.




Alison, Bakala and Neil at the Telstra screening of Bakala the film

# THANK YOU

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

**Gayangwa Lalara**  
**Vice Chairperson**



**THANK YOU TO EVERYONE WHO HAS SUPPORTED THE MJD FOUNDATION TO ENABLE US TO CONTINUE MAKING A POSITIVE IMPACT ON THE LIVES OF PEOPLE LIVING WITH MACHADO-JOSEPH DISEASE.**



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



Front cover: Steve (Bakala), Mabel (South32/GEMCO), and young Danielle (Groote Eylandt)

Back Cover: South32 visitors attend an MJDF ‘On Country’ day on Groote Eylandt; Nick, Bronwyn and Hilroy in Ngukurr; the Groote team; Sharon’s Kin connect trip;

