



**Jane Gayinduba
Wurramara**
1969 — 2014



Gwenda Lalara
1951 — 2011



**Harry
Nangkwiylilya Lalara**
1939 — 2007

**Natalya
Genise Lalara**
1993 — 2014



**Murabuda
Wurramarra**
1934 — 2015



**Jock
Nanayanbayinga
Lalara**
1957 — 2013



**Ernie
Nanjirrilila Lalara**
1947 — 2002



**Fredrick
"Digger" Lalara**
1971 — 2009



**Kevin Kangkibana
(Gangubena) Lalara**
1940 — 1991



**Rose Labanbayi
Mirnyowan**
1961 — 2014



Warren Lalara
1954 — 2010



Ngeniyerriya

The story of Machado-Joseph Disease
on Groote Eylandt

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Foreword

This story is about my people who have gone away, died, to remember them, as they lived here with us. The reason why is so people when they see this, we can all remember them as family and friends — other people, the MJD Foundation staff and us as family can remember them. They have already gone before us.

Gayangwa Lalara OAM



Map of Groote Eylandt and surrounding islands

Image from: Hammil, Mary, 1987. 'Research on Manganese and Metabolism — Groote Eylandt, Northern Territory'. University of Queensland.

Note from the Project Manager

Our family went to Groote Eylandt in May 1970, after first spending three months at Gunbalanya (Oenpelli).

We are now honoured to call the Groote Eylandt Aboriginal people, Warnumamalya, our family.

It was sad to leave in 2008 after 38 years, and we are thankful to have had the opportunity to return on many occasions.

The reasons the MJD Foundation asked me to write this history are in themselves historical. The Board of the Foundation recognised that it is important to record the history and activities of the Foundation from its very inception, so as to reflect on the lived experiences of Aboriginal people affected by Machado-Joseph Disease (MJD), both prior to, and after its establishment. An important part of this is capturing the stories of Groote Eylandt loved ones that have passed away. This publication is not a history of the MJD Foundation, nor does it refer to the many current clients supported by the Foundation. It is also not a medical or scientific look at Machado-Joseph Disease. Rather, it is the life stories of those in the past who lived with the disease on Groote Eylandt.

It has been an honour, and I value the help and wise advice of Tony Wurramarra, Gayangwa Lalara, Jennifer Baird, Elizabeth Massey and Nadia

Lindop. I also want to thank Rebecca McCue for helping pull everything together.

Personally, the past three years have been hard. In 2019, during the process of compiling this publication and reviewing our time with the unique group of MJD families and carers who have passed away, we cared for and experienced the death of our terminally ill daughter. Her fight with cancer at times sapped our inner strength. This tribute is therefore about three years late. I wish to thank the MJD Foundation Board for their patience during this time.

I am proud of our family, and the contribution they have made to enable me to finish this project. Over many years, and before any money or services were available, they built ramps, fixed wheelchairs, cared for clients in respite, became taxi drivers, and researched with the aim for a cure, as well as supporting me emotionally.

To my mate of 55 years, Bryan, I say thanks and ponder how this project could have come to completion without your love and support — this is way beyond my understanding.




For those reading this story, I urge you to support the MJD Foundation, either practically or financially. It truly is a unique organisation, developing from its grassroots beginnings into the organisation it is today.

Kathryn Massey OAM

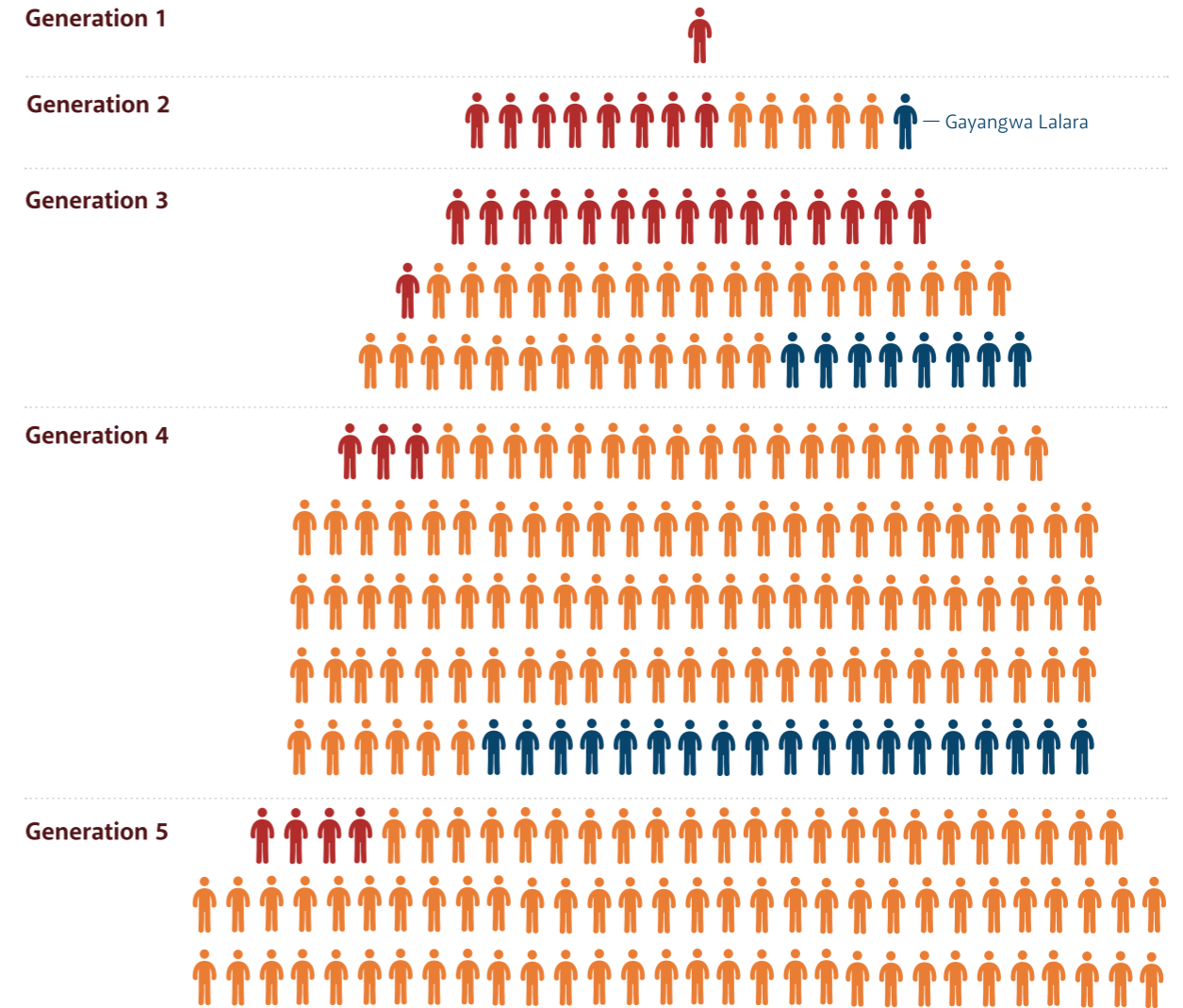
Lalara Family MJD story

The prevalence of MJD over five generations on Groote Eylandt



 MJD
  At risk of MJD*
  No MJD

* At risk individuals are direct descendants of those with the disease, or are those that have passed away but their MJD status was not determined.

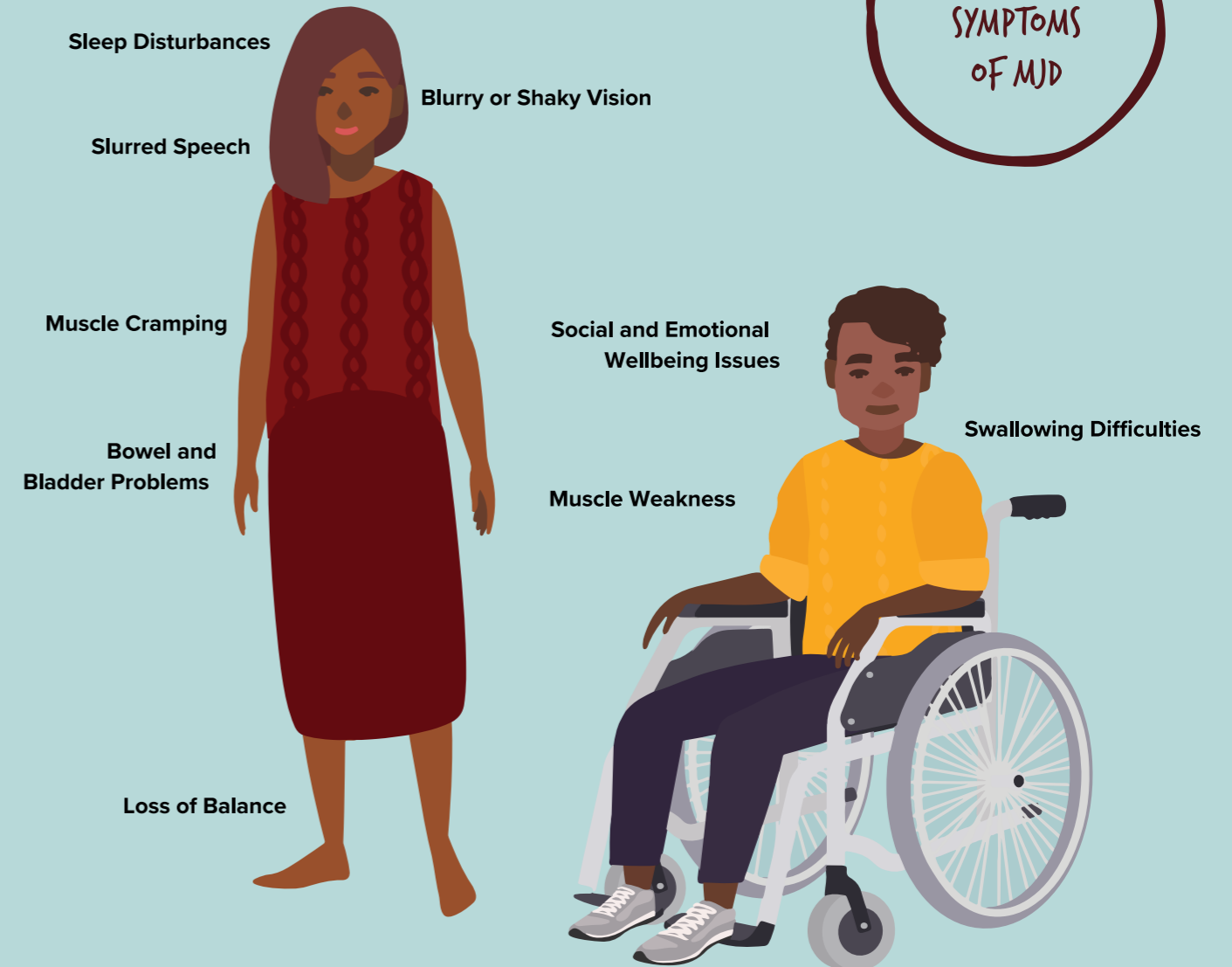


Signs and symptoms of Machado-Joseph Disease

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 700 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 descendants 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).

SIGNS AND SYMPTOMS OF MJD





Introduction — Angurugu, from 1970 to 2008

Groote Eylandt was quite a different place to live prior to when the MJD Foundation was launched in 2008.

Called the 'Mission', and referred to by many as 'the Village', Angurugu was a place of learning and interaction with the Traditional Owners, the Warnumamalya. This is where we had lived from 1970, brought up our family, and where we learnt from our Aboriginal family and friends.

Within the boundaries of the Village, and further beyond at Umbakumba (also on Groote Eylandt), there were many families who were, as Murabuda Wurraramarra used to say, 'old, sick, tired and damaged'. At first, we didn't understand, and as we became familiar with families, we were introduced to what for many was a heavy burden — all was not okay. As the years progressed, our work became more intensely involved with this group of families and individual people that were hurting.

There was a disease common to this group, and it spread over a particular clan group. There were strong feelings of shame and blame for affected families.

My particular interest and concern was for family carers, and their daily struggle with personal care support and mobility issues. Some family carers were dealing with the burden of caring for multiple family members affected by MJD. This group of people, some with other chronic diseases in their own lives, were and continue to be an awesome group of dedicated and resilient carers.

As hard as they worked, the challenges were enormous and we never became used to the stark reality of so little available help for people encountering such significant disability. We visited people in their homes, and despite our advocating for more help, it became obvious that the government departments didn't want to acknowledge the issues. Many promises were made, but very few dollars to translate into practical aid. Being isolated in such a remote community didn't help. It made us angry that an 'out of sight and out of mind' mentality was at play.

On many occasions, we saw people sitting on their rugs in the corner of their verandas with no walking frames, walking sticks or wheelchairs, and most importantly, no ramps to enable them to access their homes. Most houses were built with five or more steps. Some wheelchairs became available over time, but the ramps took longer!

We fought long and hard for a wheelchair-accessible bus to provide transport. Ironically, we first received funding for the bus wheelchair lift, but NOT the bus for it to go into. Frustrations were high. We took a photograph of a client sitting on a chair in the driveway with a cardboard-box bus cut out and asked the question of the funding bodies: 'Thanks for the lifter, but where is our bus?' Eventually we received our bus.

When the MJD Foundation commenced in 2008, the lives of those living with MJD on Groote Eylandt (and beyond) were changed. There was a lot of

activity happening for a few months before the actual launch in August 2008. It brought a strong feeling of anticipation within the MJD family, and there was finally hope for the future. There was something infectious about the changes going on — smiles were broader (if that was possible), and living with shame and blame was not the first thing on their minds every day. It seemed as if clients and carers had just joined an army, supported by people who knew their situation, that offered help and an alternative to merely living with the awful effects of this disease.

This brave group of people living with MJD was still isolated geographically, but was no longer alone.

MJD Foundation at a glance

The MJD Foundation is different.

In contrast to mainstream government and non-government disability services, the organisation evolved to meet the very specific needs created by Machado-Joseph Disease (MJD), a highly disabling genetic condition, clustered in small communities in remote Northern Australia.

Geographical isolation and cultural preferences for large, closely tied families has resulted in disproportionately high numbers of people living with this neurodegenerative condition, also known as Spinocerebellar Ataxia Type 3 (SCA3), in the very remote communities of northeast Arnhem Land.

The disease is currently incurable, creating incremental levels of disability over many years. Machado-Joseph Disease ultimately culminates in complete dependence on others for all activities of daily living, due to profound physical disability and complex medical requirements. The unprecedented impact of such a high burden of disability in small, isolated communities has created unsustainable pressure on fragile health and community-service infrastructure.

From the late 1990s, significant disability and community service gaps were obvious, and this, coupled with a paucity of information about the disease within affected communities, resulted in a catastrophic breakdown of care for those living with Machado-Joseph Disease.

At the time that the MJD Foundation was established in 2008, access to preventative therapeutic and allied health interventions in remote Northern Australia was minimal and substandard. Resource impoverishment forced the adoption of a minimalist service-delivery model by local service providers, the Northern Territory (NT) Department of Health (Aged and Disability Services — now Office of Disability) and others. High caseloads and issues with staff retention meant that service delivery was limited and clients with the highest needs were prioritised.

People with MJD were dying early of largely preventable complications within their communities. Sometimes, when their needs became too great, people with the disease were sent away to residential facilities in urban centres, such as Darwin or Gove.

It became clear that both increased numbers of people, and the younger generations, were becoming affected. In some families, three generations were manifesting the disease concurrently, with some carers also experiencing early symptoms. This created growing anxiety at a community level and an ethos of 'shame and blame' evolved, further reducing people's quality of life as people struggled to understand the disease's devastating impacts.

Working together with families to address needs in this context has required close communication, courage and innovation. In its journey to meet service-need gaps and to tailor support, the MJD Foundation has learnt it is fundamental to listen carefully to families and to direct its endeavours accordingly. To assist, the MJD Foundation provides genetic education and counselling, alongside

more traditional disability supports, interventional therapeutic activities and the conducting of research. Carers are prioritised alongside clients, and the organisation places a premium on conducting all activities within the cultural expectations and norms of local communities.

At its core, the MJD Foundation seeks to partner with families and to build local capacity. In this sense, the MJD Foundation breaks from traditional disability service models, which are based on individual care only, and provides a lifelong, mixed-mode and family-oriented service that honours a relationship-based holistic approach aligned with Aboriginal community expectations.

In the beginning

During the late 1960s and 70s, a family on Groote Eylandt began to experience a mysterious illness referred to by local people (Warnumamalya) as the 'Drunken Walking Sickness'. Those affected were sometimes referred to as 'Bird People', and their weakness attributed to being 'cursed' — believed to be the result of a broken cultural law. The disease was elsewhere referred to as the 'Groote Eylandt Syndrome'.

Sporadic investigations by medical professionals over the next two decades were unable to diagnose the cause of the illness, despite increasing numbers of people being affected on Groote Eylandt, as well as the identification of cases in mainland communities. Clinically, the condition was noted to mainly affect adults and to be of a neurological nature, typified by muscle weakness that resulted in an ataxic gait, and by difficulties with speaking, swallowing and vision.

Early theories linked the disease to the manganese mine on Groote Eylandt, but it was not until 1995 that the genetic nature of the disease was confirmed — the disease was identified to be Machado-Joseph Disease (MJD), or Spinocerebellar Ataxia type 3 (SCA3). Around the same time, other families with MJD were identified in nearby Yirrkala, on the mainland.

The introduction of the gene into the Aboriginal families residing in northeast Arnhem Land was initially thought to have been made through a historical trepang (sea cucumber) trade between the Makassan (or Macassan) people of Indonesia and northeast Arnhem Land. Later research published in 2012 supported an Asian origin of the gene, and work is ongoing to determine a more accurate estimation.

In 2004, the Northern Territory (NT) Department of Health funded Anglicare NT, a faith-based community service organisation, to develop a report detailing the impacts of Machado-Joseph Disease. The report also identified local care details and the extent of interventions needed. However, despite detecting a significant need for increased support and care for those living with MJD, the NT Department of Health and Community Services was unable to dedicate ongoing funding. At the time, preventable chronic disease mitigation strategies dominated healthcare resource allocation across the NT, resulting in a systemic reluctance to resource such a cohort-specific issue. This was reinforced by a lack of visibility of the issue within a centralised, primary healthcare dominated system. Disability funding was scarce and minimal support was available to those with MJD over 50 years of age, which was generally funded by federal Aged Care programs.

During the early 2000s, the Federal Government funded a pilot remote Aged Care program, building a number of small residential Aged Care facilities in remote communities. Angurugu was selected as a site and after extensive consultation, led by Murabuda Wurramarrba, a twelve-bed facility was constructed on the site of the old mission gardens. Murabuda was intensely aware of the issues faced by people living with MJD in his community and the facility was carefully designed to be inclusive of all 'old, tired and damaged ones'. Always intended to care for all those who needed it in the community, the building was designed to represent an important totem — the sawfish or Yukwurrindangwa — and it made careful concessions to kinship rules, incorporating two doorways in every room and being oriented to the nearby river to maximise the prevailing breezes.

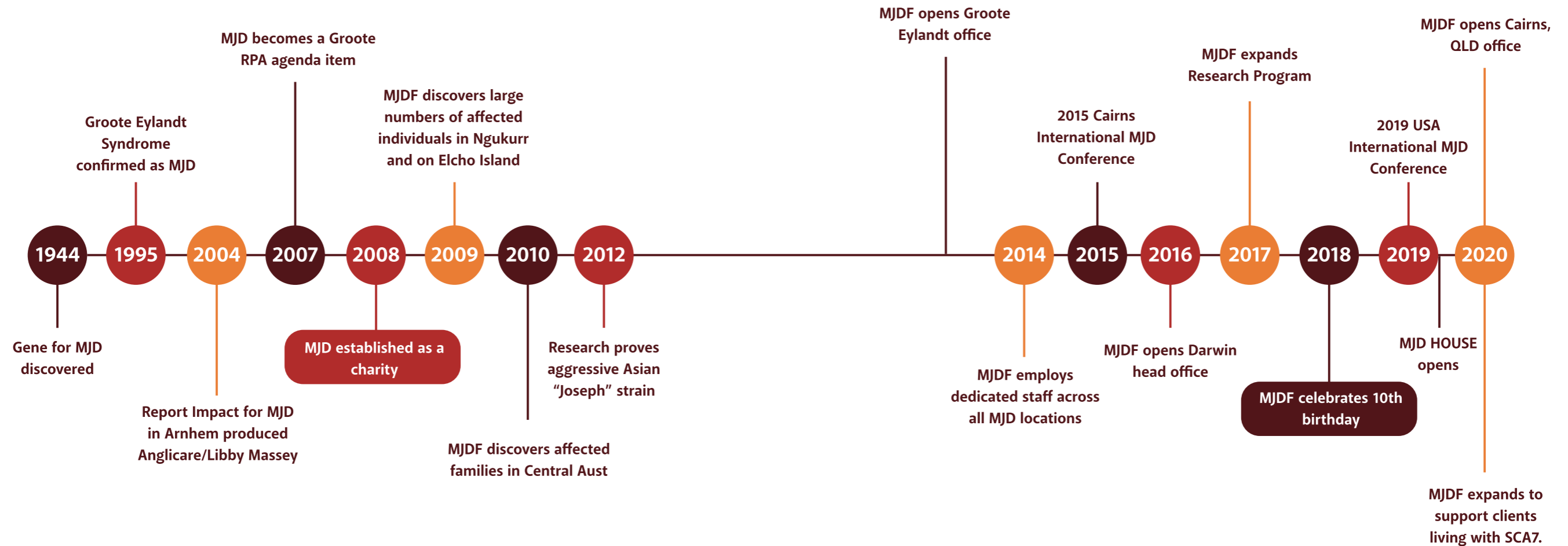
The lack of support for those living with MJD continued to generate local attention, and despite some resistance from the NT Government, in 2008 the issue was tabled as an agenda item by the Anindilyakwa Land Council (ALC) in the Regional Partnership Agreement (RPA) negotiations for Groote Eylandt. The RPA provided the political tool that led to the Federal Government allocating \$100,000 of funding to the investigation of MJD on Groote Eylandt, which was matched by the Anindilyakwa Land Council (ALC) (Groote Eylandt) — leading to the establishment of the MJD Foundation in May 2008. In 2009, the ALC donated a further \$1,000,000 to launch the Foundation's research program.

The MJD Foundation's initial consultations with families established the urgent need for ongoing sustained support, in addition to research. As the Foundation's funding strategy was largely independent of the cyclic and externally driven outcomes typical of government programs, the Foundation was able to directly respond to needs with a nimble and flexible service model. This approach has only been able to be sustained by virtue of critical grants from both the ALC and the Aboriginal Benefits Account (derived from equivalent mining royalties on Aboriginal owned land) — the latter only successfully secured following a drawn-out, three-year court battle with the then Federal Minister, Senator Scullion. The ongoing investment of these monies in perpetuity, for current and future generations of families living with MJD, produces earnings critical to underwriting the Foundation's operational costs.

The outputs of the MJD Foundation's service model are driven by the wants and needs of Aboriginal people living with MJD and their families — not externally decided. Importantly, this diversified funding structure has facilitated flexibility within the organisation, allowing for the delivery of genuine personal and family-centred supports, as well as the option to adapt services and tailor the workforce, as needed, in response to family-driven program changes. The supports provided by the MJD Foundation directly respond to the requirements expressed by the Foundation's clients and families, in contrast to those organisations bound by restrictions posed by standard, predetermined government funding programs, or by complex organisational culture.



The history of the MJD Foundation



MJD Foundation launch (2008)



1 The MJD Foundation was launched on the grounds of the Angurugu Aged Care Facility, Groote Eylandt, in August 2008. It was a grand occasion and many clients, carers, stakeholders and visitors attended.



2 Gayangwa Lalara, co-founder, Vice Chairperson and Senior Cultural Advisor of the MJD Foundation. It is Gayangwa's family that is most affected by MJD on Groote Eylandt. Her promise to her people that day was to continue to support them; and for herself, she was happy that she was no longer isolated and alone.



3 Under the shade of a large mango tree, clients and carers listened to news of hope for a cure, and promises of continued services that delivered positive outcomes.



4 MJD Foundation co-founders, Elizabeth Massey (Director, Research and Education) and Nadia Lindop (Chief Executive Officer). Along with Gayangwa Lalara, it was their vision and hard work that made the MJD Foundation a reality.



5 There was a sense that this was a very special occasion.

'People were listening, learning and knowing about MJD. The community didn't know anything about MJD before this day.' — Gayangwa Lalara



6 The Late Associate Professor John MacMillan (left), a Brisbane-based genealogist and founder of the MJD Foundation genetics program, listening to Tony Wurramarrba, Chairperson of the Anindilyakwa Land Council (ALC), alongside Kathy and Bryan Massey and Professor Nicholson.



7 Pictured centre: MJD Foundation Patron, neurogeneticist and researcher, Professor Garth Nicholson.



8 Gayangwa Lalara, and Kathy and Bryan Massey. This day was also Kathy and Bryan's last on Groote Eylandt, after 38 years living and working.



9 Tony Wurramarrba, Chairperson of the ALC, addresses those present and commits funding for the ongoing work of the MJD Foundation.



10 A dancing ceremony to farewell Bryan and Kathy Massey.



11 Paintings, baskets, ceremony sticks, and other gifts were presented to the Masseys by the community elders, through ceremony and dance.

Dedications — those that have gone before us

"It's important to always remember those that have finished up. Those that had this MJD, and they are the reason the MJD Foundation is here today."

GAYANGWA LALARA OAM

● Angurugu cemetery,
MJDF team remembering
family – Angurugu,
Groote Eylandt



Harry Nangkwiilyia Lalara

1 July 1939 — 2007 (68 years)

By Bryan Massey

Harry Lalara was married to Darribyanimanja ('Dambayana') Margaret Mamarika, and they had eight children together. Harry, Dambayana and family lived a great deal of their young lives at Umbakumba. During this time, Harry worked in the building team at Umbakumba.

I started to get to know Harry in the years before the Angurugu Aged Care Facility was built.

As a part of their Year 12 Biology studies, my daughters, Libby and Shelly, did some tests with Harry to see if he had issues with coordination and balance whilst walking in a straight line and when throwing a ball. Harry loved to help and was very patient.

Harry and Dambayana came to live at Angurugu with their family, and it was then that our friendship grew. Harry and all of his family, alongside his brother Johnny Lalara, Murabuda Wurramarra, Kathy (my wife) and I were all instrumental in helping Libby set up plans for the Mungkadinamanja Aged Care Facility in Angurugu.



1 Harry Lalara and his grandson. Harry was a family man, and any opportunity he had to see his grandchildren and children was special.

'Harry was a strong, hardworking man. He was a carpenter when he was young, working at Umbakumba.' — Gayangwa Lalara (c. 2005)

Harry did not want to become just someone living with MJD and tried everything he could to fight the disease. In the days before the MJD Foundation was operating, there were very few options for 'Staying Stronger for Longer' and visits from Allied Health professionals from Gove, a nearby community on the mainland, were limited to every six to eight weeks.

Harry was a great believer in traditional medicine and pursued this interest, but sadly, to no avail.

His family, many of them carers, split up, broken by carer burnout and the stress of caring for him with no other assistance.

Harry was a highly intelligent man and gifted with the wonderful Lalara smile. He was a good friend.

By Joyce Lalara

My name is Joyce Lalara [Harry's daughter], and I've got this disease called Machado-Joseph disease, but that sickness I didn't know for a long time. I didn't know that this disease was jumped to me. That disease got my father, and he jumped that disease to me and Melinda, only. I didn't know, but when we go for a walk, me and my friends, my friends they been look at me, and I was going zig-zag like a snake — wobbling! They been said to me 'Joyce, you be walking like a snake! You walk straight!', but when I look at myself, I been walking straight! But I didn't know it was starting. I didn't know that disease jump to me.

I knew my dad when he was strong. I don't forget — he been chase me with the thongs, because I been doing silly things!

Then, when my dad been have this disease, he didn't walk properly. He was wobbling, he didn't sit down properly, he was leaning on us, he fall down on us. When he was falling down on us, we all feel sorry. We thought that disease, sickness, someone was doing something with him, black magic way, but we didn't know this disease.

When he was still here, he was getting help from all his daughters. My last sister, younger sister Alvina Lalara, I been help with her to make a shower, cooking his food. What he want to tell us, then we been cook it. We feed him fish, turtle or dugong, we cut it into pieces, and we been feed him. We help him shower, and when Aged Care is on, we put him clothes in the bag, give it to Aged Care people, to make his shower there, and to have brekkie, giving us rest.

I only found caring really hard with food or drink, when it made him cough. I was a bit worried. He was worse coughing. His strong coughing would make us upset.

He was keep on asking with Gayangwa for help for a cure with this disease, and he said to Gayangwa, 'you try and fight for a cure'. Gayangwa, when she was starting new, she was pushing herself to make this happen with Bryan, Kathy and Libby. Then, when they been all pass away, Gayangwa's brothers and sisters and my father pass away, their children have this disease ... then she got strong! Now, because of her, we have everything. And there we go — we are here! We still fighting with that disease, with the exercise, and we still here, staying happy!

2 Harry Lalara, outside the Angurugu Council Office. Harry was a strong man, and he found it difficult when MJD made his body weak. He worked hard at finding ways to stay strong, but at the time, there was not much support from allied health professionals available. When he noticed he started feeling weak, he stopped work and stayed at home. (c. 1990)



My dad, he used to work at Groote Eylandt Mining Company (GEMCO) in security. Him and the boys from here [Angurugu] too worked there. They were happy men. One day he was taking me with the motorbike. Him and me, when he was a strong man. He was talking me and showing me, about how he was working there. That was a long time ago. Then, we been go back home again, and I spread the news with my sisters that our dad been taking me to where he been working, that I was riding with him, with the motorbike, and they been all jealous! My dad, he was sitting in the chair there laughing.

But my story about him is really make me happy is when he was telling my aunty Gayangwa about the cure — that's the one. I love his story: he was fighting for a cure. When I had this disease, I was getting worse first, but with Nick working at Aged Care, he took us there for physio and exercise and going slow down this disease. I been knew, 'maybe this exercise make this disease going slower?' I said myself: 'What I've been doing to get strong? What I've been doing to get strong?' ... and it was mostly exercise — that's the one!

When I moved to Bickerton Island, I didn't know my dad been pass away. Next day, council mob, they send me plane. Then I went from there to here [Angurugu], then I stay here for a while until everything finish, then I went back to Bickerton. That was a sad time.

By Melinda Lalara and Brett Mamarika

Harry lived with us in Angurugu. When his wife went to Darwin, we looked after him. We liked looking after him.

Melinda, Alvina, Joyce, Leonie and sisters, we all looked after him. Sometimes there was no men working down there, so I [Brett] would help with shower and toileting. It was good: I like caring for people. When me and that old man was at home, and they went shopping, I would take care of him.

Every morning we woke early, at 6 o'clock, to him shouting out 'Melinda!', 'Melinda!' to give him a shower. In the morning, he was always ready for the bus. He was outside waiting for the Aged Care bus, for pick up. Sometimes they give him a shower at the Aged Care, but he always needed morning shower at home. He would go to Aged Care for breakfast and lunch, resting there. Afternoon they brought him back home. When they brought him back they would say 'here is that old man!'

He was funny! When he was talking about his wife, when he was young, telling stories, little bit of one story. Sometimes he was angry — when he wanted a smoke!

He used to sit at the back at night, facing that way to Darwin. Every morning, every night, we would see a star that way, and he thought it was a plane! He thought that was a plane with his wife on it, and he would say, 'a plane is coming!', and we would say 'It's a star!' 'No, it's a plane coming!', he would say. It was funny!

He was talking to us, and he needed to go near Alice Springs, to Santa Teresa. He wanted to go that way where there is healing water around there, but no one could help. Maybe, if he was alive today, when we start the MJD Foundation, maybe we could help him.

When he got worse, he wasn't doing exercise. He was resting at the Aged Care, and they brought him back home, and he was only sitting on the wheelchair and laying on the bed and doing nothing. He was a builder and a strong man. He used to work at the mine, when he was strong. It was a bit hard for him ...

We went to Umbakumba, and he stayed with Joyce, Alvina and Dianne. I [Melinda] was working at Umbakumba Aged Care, and I was getting wobbly, and I knew it was MJD. I was wobbly and feeling myself, and I knew I had this MJD. I was working all day at the house, cleaning the house, doing gardens and cooking, and was doing all the work at home. I was skinny and couldn't put on weight, I was working so much! My father was happy and proud that he got his own daughter off working this better way ... even though I have this MJD.

His wife was still in Darwin when he passed away. He was very weak. That day, we went to Six-Mile Beach, and we didn't know, but our car got bogged. That old man passed away, and our car got bogged, and we thought 'maybe something is wrong?' When we got the car out, and we arrived at home, Brett's brother's son, he told us. We drove straight there to Angurugu.

When he passed away, I [Melinda] was so sad.

By Steve 'Bakala' Wurramara

When I was young, growing up to be a man, I remember my uncle, Harry Lalara and Gula Lalara. It was 1978. They had this ceremony at Yenbakwa, and there were mens only. I was only a kid, but my uncle showed me ceremony. They showed me everything about ceremony, and I now have the knowledge to remember what the ceremony about — dances and everything. Ceremony from when the old people were still alive.

I was fourteen years old that time, and I went to school up here at Angurugu. I wanted to learn about the western world, which is to have more education. Up at school, a local man were there in school. His name was Jambana Lalara. He used to drive us to where all the men and the old people was. They took us in, and they taught us traditional song. There I learnt traditional dance. It was my job when someone passed away to dance. I danced for the two moieties. That time I didn't have MJD, but then when I turned fifteen, I realised that I've got this disease.

● Harry started going to the Angurugu Aged Care Facility when he needed more help. Easter time at the Aged Care Facility was always special, and Harry enjoyed getting his Easter basket each year. (c. 2001)



Kevin Kangkibana (Gangubena) Lalara

1 December 1940 — 31 August 1991 (51 years)

By Jenny Baird (with input from Kathryn Massey)

Kevin was born at Angurugu, Groote Eylandt. His father was Mandaka Lalara and his mother was Diyandajirirra ('Dagunda') Mamarika. Kevin was his mother's forth son and his father's seventh son. His mother and father had seven children, and his father previously had seven children with his first wife. Kevin was married to Lois Wurramarrba and had six children.

Kevin was always a hard worker who believed in supporting his family. He was a man who had a gentle and peaceful nature, and this endeared him to all who met him. The goodness of Kevin's soul was evident by the way he lived his life and cared for his family. The impact of his upbringing and his extended family was evident in the importance he placed on living the 'right way' and valuing family above all. It was these values that led to Kevin taking different directions with his working life, and making the most of any opportunities that presented to him.

He worked in many different roles, one being with GEMCO for a number of years. When GEMCO arrived on Groote Eylandt, they relied on Aboriginal people as a labour force and set about training many in the areas of plant operation, road construction

and environmental rehabilitation (such as seed collection, storage and regeneration). In 1987, while with GEMCO, a drawing of Kevin holding a lump of manganese was on the front page of the Aboriginal Health Worker magazine. Kevin enjoyed working for GEMCO, and he developed meaningful relationships with non-Aboriginal personnel over the years. One being Alan Wright, who was with the company from the outset of exploration and mining, and for many years thereafter. Alan fondly remembers Kevin as being 'one of life's treasures' and expressed that he was privileged for having met him.

With the development of the mine and the associated Angurugu community going ahead, Kevin saw the need to advance his own education and travelled to Adelaide, South Australia, where he undertook studies in the 'Aboriginal Task Force' program. He took all of his family to Adelaide with him, and Lois (Kevin's wife) remembers that Kevin was insistent that all of the children attend the local school to continue their education.

Kevin returned afterwards to Angurugu and became the Works Manager for the newly established Angurugu Community Government Council — Kevin was the first Aboriginal person to hold this position. Kevin worked closely with the President, Jambana

● In 1987, while he was working with GEMCO, a drawing of Kevin Lalara holding a lump of manganese featured on the front page of the Aboriginal Health Worker magazine.

Image from: Hammil, Mary, 1987. 'Research on Manganese and Metabolism — Groote Eylandt, Northern Territory'. University of Queensland.



Lalara, and Town Clerk, Lance Tremlett, and together they saw the development of this new council. The role of the council was to liaise with Government departments on the expansion of the community, and to develop a local Aboriginal workforce, such as a housing team, a parks and gardens maintenance team, a mechanical workshop, and a shop that facilitated the training and employment of local staff.

Towards the late 1970s, Kevin developed signs of MJD; however, he continued to work until he could no longer walk. Jambana and Lance took on a protective role of Kevin and supported him wherever they could in the workplace so that he

could continue to work for as long as possible. Finally, when MJD made it too difficult for Kevin to work, he retired.

Lois and the children took care of him the best way that they could. As there were no disability support services at the time, the sole responsibility of caring for Kevin rested with the family. In the end it became too much, especially for Lois; she could not cope and left the family and went to Darwin. This was a very sad time for everyone, and it highlighted the plight of people who were disabled or old, and the lack of support for families who were left to do everything for themselves.

Fortunately, there had been some research undertaken on MJD on Groote Eylandt by a team of researchers, namely Dr Charles Kilburn and Dr Tim Burt. At this time, MJD was known as 'Groote Eylandt Syndrome'. Dr Tim Burt's wife, Josephine Gwynn, was living on Groote Eylandt and was an occupational therapist (OT). She recognised Kevin's needs and sought funding for Home Care support, such as personal hygiene care, five mornings a week; the family were able to therefore continue with the other supports needed. Kevin's family network of support included his extended family, and each school morning Abel Lalara and his wives, Donna and Freda Wurramarra (Lois's sisters), would come and visit the household and wake everyone up to ensure the children were going to school and that everyone was okay. It always brought a smile to Kevin's face when he heard Abel call out in a loud voice, 'wakey, wakey everyone — it's time to get up!'

Part of Dr Tim Burt's work was liaising with people who had MJD, and it was in his conversations with Kevin that Kevin was made aware of the disease and how it was in other parts of the world. This newfound information led Kevin to decide that, upon his death, he would allow for a brain autopsy so that researchers could determine whether he had MJD or something else. Kevin was a forward thinker and knew the importance of this decision, and how it would help other members of his family, who also had this illness, by helping to find a cure. Kevin's wishes were put in writing. It is important to acknowledge that an autopsy was traditionally considered 'foreign' to the people of Groote Eylandt, and typically everything was done to prevent one from happening. His family (including his brothers) knew of Kevin's request and respected his wishes.

In the last few years of Kevin's life, he tried to participate in community events as much as he could, however he required a lot of support to do so. It was his lovely nature that drew people to him, and many people wanted to support him. Kevin really did make an impression on people, and one year when Kevin received royalty money, he had a few people drive him to the Council office and help him get up the stairs. He had some money that he wanted to donate to an overseas charity. When he left, the fellow in the office remarked what a special man he must be — despite his own personal circumstances, he found it in his heart to donate to a charity.

Kevin became sick and was in Royal Darwin Hospital; he had developed a bowel obstruction and went into surgery. Sadly, he did not come out of the operation. After his death, the autopsy was conducted, and it was confirmed that his illness was Machado-Joseph Disease — this finding was important, as it finally gave the illness that impacted many Groote Eylandt people a name.

Kevin's death also brought to light the need for support: nutritional support, family support and extra personal care for those living with the debilitating impacts of MJD on Groote Eylandt, and beyond.

Ernie Nanjirrilala Lalara

12 September 1947 — 2002 (55 years)

By Bryan Massey

When Kathy and I, and our eldest child, Libby, went to Groote Eylandt for the first time to live there in the early 1970s, Libby was only a very young girl of about 14-months old.

At this time, all of the men who have since died of MJD had not even started to show signs of the disease. Harry, Kevin, Ernie and Jock — all Lalara men from the same family — were running around freely, hunting, fishing, and enjoying their lives with no visible symptoms of the disease.

People referred to the disease as 'Groote Eylandt Syndrome', and it was thought to be caused by manganese toxicity. Some of these men were working at the GEMCO manganese mine, and at Angurugu Mission and Umbakumba.

In the early years after our arrival, our family did not see anyone walking around with MJD-like symptoms, but looking back now, we realise that there must have been people in the community keeping a low profile because of shame surrounding the encroaching weakness to their bodies.



● The one-armed bandit and mate. Ernie Lalara loved fishing, and Bryan Massey loved taking him out. On this trip he hooked a turtle but couldn't get it into the boat. (c. 2000)

When the disease showed itself, Kevin Lalara was the first of the men to show some visible signs, and it wasn't long before Ernie started to show symptoms, too. Kevin worked on the mining conveyor belt and was constantly exposed to manganese dust.

Ernie Lalara was a lovable bloke. In his younger years, he travelled to Gunbalanya (Oenpelli) and stayed there for a time. Later he returned to Angurugu to marry his promised wife, Caroline Wurramarra, and together they had three children.

In his earlier years, Ernie enjoyed a few drinks, and he sometimes had a few scrapes due to his fighting. In one instance, he had to go to Nhulunbuy (Gove) Hospital for treatment to his injured arm. During his time there, due to his need to drink, each day he was seen walking from the Gove Hospital down the hill to the Walkabout Hotel, driving his drip stand



Ernie Lalara was always happy. (c. 2000)

with his 'good' hand. Ernie considered it a necessary trip to satisfy his thirst. Eventually Ernie had to have his injured arm amputated. He was still a good fighter, despite having one good arm and a stump as the other!

In his 40s, the MJD started to take hold of his body, and he was showing visible signs of weakness. Ernie decided to give up drinking, and he became a very responsible community member. He started working at the Council office, and was also the one-armed courier driver.

Ernie was warm and friendly, and always had a huge smile on his face. There was a joke going around that, when Ernie was driving his specially modified bus on the main road, you should not wave to him to say 'hello', because he would always take his good hand off the steering wheel to wave back!

When it became obvious that the MJD had taken over his body, and he could no longer do his work, he had to retire.

Memories of trying to encourage him to get a wheelchair bring back a smile to my face, and a deep sorrow in my heart — the cruelty of this disease is heartbreaking. To me, the disease is like watching someone you love slowly pass away before your eyes.

With the establishment of the Angurugu Aged Care Facility, Murabuda Wurrumarrba and his team took

over to help those living with MJD. During that time, the Facility would organise fishing excursions to take folk out for the day. Ernie was a keen participant on many of these excursions, and on one such trip, he hooked a rather large turtle — with one arm and all! The catch was almost brought into the boat, but the hook dislodged and the turtle swam away. As the very relieved turtle swam away, the men in the boat discussed it and decided it was not a good turtle to eat anyway, because it was a 'stinky one'!

This MJD is a terrible disease. Ernie was my dear friend, and little did I know that I would be caring for his son and granddaughter as well, before I left Groote.

Like all the other MJD men who I have had the privilege to call brothers — on Groote Eylandt, I became a Lalara man — I love Ernie and miss him a lot.

The old Angurugu Workshop was called 'Massey's Bomb Boutique'. Note Ernie Lalara, with two arms, prior to the amputation (front row, second on left). (1972)



Ernie Lalara with his brothers at Bible Study, on the church grounds at Angurugu. (c. 1998)



Gwenda Lalara

3 May 1951 — 24 June 2011 (60 years)

By Steve 'Bakala' Wurramara

She was a nice lady, my mum. She was a very hardworking mum. When she got this MJD, when she had this disease, I couldn't ask her, because I didn't know about this disease. Now, I have got this disease.

I remember everything in her lifetime, because I have seen it all with my own two eyes. Same with my uncles. She liked jokes about everything. She loved to laugh, like her brothers Ernie, Jock and Warren. They made us happy too, with their smile and laugh.

My mum, she was a really hard worker. Even when she was wobbly, she managed all of it on her own: looking after the house, cleaning, washing ... everything.

For her, speech was difficult to pronounce. She was hard to understand, and I was the only person that could understand her speech.

When I was only a baby, my mum and dad, they had to look for sugar bag. They had to cut the tree down to get the sugar bag, and the tree fell towards me! My mum started screaming. She thought the tree was going to fall down on me, but only a branch of the tree fell near me ... its leaves were touching my face!



Gwenda Lalara, in her favourite spot under the trees with her family. Sister to Gayangwa and Gwen Lalara, mother to Jane, Jackson, Ursula, Steve ('Bakala'), Liyandra, Jamie and Raema Wurramara.

'When all her nieces and daughters were having fun, she would always give a big smile.' — Liyandra Wurramara, Gwenda's daughter (c. 2008)

I used to stay with my mum and dad, Juruba Wurramara ('Milton'), on Bickerton. We used to go fishing and hunting while we were camping at Bickerton. We were climbing down the rocks with mum and dad, so dad could show us the area. We were climbing and hiking down the rocks. My mum, she walked long distance, knowing the disease she had. She would walk fast too, just so she could get there first! She had a broken stick from a column tree that she would use to help her walk.

I have too many memories of my mother and father, and their families — memories like a notebook.

Memories are like a camera: you can only get them if you're there. I've got too much memory of history.



Secret agent '007 Gwenda', always ready for adventure. (2010)



Gwenda Lalara and carers, on her 'Holiday of a Lifetime' (organised by the MJD Foundation) to Brisbane and the Gold Coast.

'What a great time we all had — we went everywhere!' — Kathy Massey (2010)

At Australia Zoo with a couple of slippery friends! (2010)



'Gwenda was a strong lady in her mind, and then after, her body got wobbly.' — Gayangwa Lalara, Gwenda's sister (c. 2009)



Gwenda Lalara and her daughter Jane Wurraramara, and one of the best carers ever, Lisa Wurrawilya (pictured right) — a great bunch of people.

'I used to stay over at Bickerton with my sister Gwenda. When she was a little bit stronger, we went out sugar-bagging, going out fishing, yamming, and we used to have lots of fun! She was a nice lady, kind lady. She took care of her children.' — Gwen Lalara, Gwenda's sister (2010)

By Lisa Wurrawilya (with input from Jamie Wurraramara)

When I married Jamie, I find out what Jamie's family like. It's pretty hard for them. Very hard for this family, and very sad. But Jamie's mum was a strong lady for a long time. She'd go by herself down to the store when she was staying at Angurugu. She was buying people fruit. I remember when I was little girl, I saw Jamie's mum doing a big shopping.

Jamie was talking about long time, him and his mum and dad and all the family went out camping overnight, and he remember about his mum she was in the morning — she woke early, she lit the fires, she was making a damper for all the kids. She had seven children. She was a good mum looking after everyone.

On Bickerton [Island], we take her when we go out fishing all the time, when she was strong, and we

would sit around the beach, the barge landing — more easy to sit at that beach. She liked to fish. She was a good fisher like Gayangwa and Gwen! Jamie was helping her putting all the sinkers and hooks, and he was throwing the fishing line out. She liked sugar bag, and she can see the sugar bag in the tree. She was pointing, pointing to that tree anyway, and Jamie and I was chopping.

She's a great cooker too! When Jamie was asleep, she always get up and she go down to the store. She about to cook a proper porridge for Jamie, breakfast, but I saw her when she was holding that saucepan, and she was putting the oven on. I didn't know, but I find out she was standing here! She was in wheelchair then. She was sliding out of the wheelchair and putting the oven on, and she was making breakfast for him, Jamie. That I was a remember.

Gwenda Lalara with son Jamie Wurraramara and Lisa Wurrawilya, Jamie's wife, relaxing at home.

'She was a strong lady, then she was a little bit wobbly when she was walking. Still, when she was in a wheelchair, and she was hard to lift, she was happy, giggling.' — Desiree Lalara, Gwenda's niece (2010)



Gwenda Lalara, all dressed up for the Christmas Party at the Angurugu Aged Care Facility. (c. 2009)

Warren Nanilyimbayinga 'Mimandi' Lalara

21 October 1954 — 23 September 2010
(55 years)

By Jenny Baird

Warren was born on the 21st October 1953, and was the second last son of Mandaka Lalara and Dangawinda ('Dagunda') Amagula. He was named after Mr Warren, a Missionary from the Church Missionary Society (CMS), who lived on Groote Eylandt at the time. He grew up in Angurugu, surrounded by his family and extended family. His Anindilyakwa name was Nanilyimbayinga, and his nickname was 'Mimandi', given to him by his sister, Gwen.

Warren loved his family: his parents and all his brothers and sisters. He was of a similar age to his nieces and nephews, who he would share his childhood adventures with. He also loved his culture and ceremonies. He went to the old Mission School at Angurugu and would remember how each Saturday he was given vanilla ice cream from the shop as a treat.

His parents in particular had a deep impact on his life, and they instilled values that became important to Warren. His father was very strict with the children, and they all had to be at home



One of the notable characteristics of the Lalara families is their beautiful smile. Smiles that hide sorrow and pain, but that also instil hope in the lives of those with whom they come into contact. Warren Lalara, pictured here at the MJD Foundation launch. (August 2008)

when it became dark, or the children would be in serious trouble! The stories that Warren told also showed that Mandaka was not afraid to speak his mind if he saw that something was wrong. He was an important figure in Warren's life and someone that was loved. He taught values such as working and providing for your family and always protecting your family. Life was spent hunting and gathering with family and learning from his Elders. His mother was very knowledgeable with bushcraft and bush medicines, and would pass this on to all her children. As Warren got older, he participated in ceremony life and loved all that he was involved in. There was always great reverence to Gula Lalara and Jabani Lalara, and the important role they played as brothers and in ceremonial roles.



Warren Lalara knew exactly what the MJD Foundation was doing, and that the needs of his family and subsequent generations would be on the agenda at a national and international level. More importantly, he knew that the hope for a cure would someday become a reality. (2009)

Warren Lalara was passionate about finding a cure and took every opportunity to advocate with politicians and his own Land Council, making sure everyone was aware of the needs of his MJD family. Pictured here with Dawn Lawrie, the NT's inaugural Anti-Discrimination Commissioner, at the MJD Foundation aircraft wheelchair lift launch at Vincent Aviation. (July 2010)



'As Warren grew older, he became aware of an illness affecting his family. Initially it wasn't talked about, as it only affected his father and older brothers and sisters. Slowly, it began to affect all of his siblings, except for two sisters and one brother.' — Jenny Baird (2008)



GEMCO was often referred to as 'the Company' and was always held with high respect. GEMCO brought with it opportunities for training and employment for Aboriginal people in many areas of the mine operation. Warren worked for GEMCO as a plant operator, and he learnt to operate many different types of machinery. He enjoyed working with the non-Aboriginal workers and developed many lasting friendships. One such friendship was with Peter Scott, who was the Supervisor of Warren's team; for some reason these two just clicked. Warren would say that one of the reasons he enjoyed working with GEMCO was that he and the other Aboriginal employees were treated the same as everyone else — everyone had a job to do and they did it. Peter and Warren worked together to build the Dalumba Bay road, which enabled people to travel to the other side of the island. Building a road from scratch

was a long and difficult process. He was proud of this achievement and would often smile when he thought of Peter.

Warren and I were married in 1985, and we had two children, Daniel and Anna. We lived in both Alyangula and Angurugu. Our children enjoyed a childhood spent going to the beaches and playing with family. They would often play 'remember when ...' Their childhood friends were the Manggurra boys: Terrence, Hilroy, Steve and Adam. As they were of similar ages, they did everything together. Even today, some 30 years later, they are close and in contact with one another.

It became obvious that Warren had developed MJD while he was still working for GEMCO. At night it became more obvious, as the first symptom that is



1 This beautiful knee rug was a favourite of Warren's. An engaging smile and strong words were his mantra. Pictured here with Peter Fisher (ex Anglicare NT CEO, and long-time supporter of the MJD Foundation). (2010)



2 Warren Lalara and his daughter, Anna Lalara. Their best smiles were reserved for each other. (2009)



3 'My brother Warren always had a big smile.' — Gayangwa Lalara

Hope shines in Warren's eyes and in his smile. This is why the MJD Foundation is both passionate and persistent about delivering services in remote areas. (2010)



4 'That's my granddaddy. He was a very brave man.' — Jenayah, daughter of Anna Lalara, and granddaughter of Warren Lalara and Jenny Baird. (c. 2018)



5 Jenny Baird, Warren's wife, can only be described as an MJD warrior, with many years of caring for family living with the disease. She is a board member of the MJD Foundation. A passionate woman, reminding everyone that the main objective should be a cure. (c. 2018)

often noticed is the loss of balance at night. Warren was finding it difficult to walk. He went from working shift work to doing days only. When it became too difficult, Warren eventually took a redundancy package from the company.

Eventually we moved to Darwin to be closer to specialist care that was not available on Groote Eylandt, such as physiotherapy, hydrotherapy, and other specialists. This process was difficult but it gave Warren the best chance at fighting the disease. He had a lot of self-discipline and would do all his exercises regularly so that he could be as fit as possible. He would often say that he wanted to be in his best health in case a treatment for MJD came along, and he would be ready. As time went on, wheelchairs and other disability aids became a part

of his life, but he still maintained his regular exercise regime.

Warren did have some precious trips back to Groote Eylandt to see his family, and by this time, Murabuda, along with Libby, Kathy and Bryan Massey, had built the Angurugu Aged Care Facility. The Facility was built so that 'sick ones' could come and get some support during the day, and so that those that were too sick could stay overnight. This is where Warren stayed during his visits home, and he made some very special memories. He and his family would go out 'On Country', share stories, favourite foods and laugh a lot. All of these activities became special, as it was part of the inner healing of the soul that strengthened Warren to keep going.

When Warren saw a specialist, he would always ask about research into MJD and possible treatments; he was eager to participate in any trials. Sadly, during his lifetime, there was little money invested into MJD research and treatment, and this did not happen.

Warren's condition deteriorated to the point that I could not care for him at home anymore; he needed 24-hour care and went to a nursing home. This was hard for me to accept, but the reality of the illness was that I could not provide the care that was needed.

Although the last few years were spent in a nursing home, the greatest joy that Warren had was to see his children and grandchildren — he was immensely proud! Warren was to return home on 22nd

September 2010 for a holiday. He was going with two carers, his son Daniel and Bryan Massey. They were going to go fishing, catch up with family, etc. Sadly, Warren became ill and went to hospital the day he was due to fly home. He passed away the next morning.

In our hearts we know that he is home and enjoying all the things he loved — fishing and being with family.

Jock Nanayanbayinga Lalara

7 April 1957 — 16 May 2013 (56 years)

By Jenny Baird (with input from Kathryn Massey)

Jock was born in 1957, and was the youngest son and child of Mandaka Lalara and Dangawinda Amagula. He was born and raised at Angurugu, Groote Eylandt. Being the youngest in the family, he was given a few extra freedoms than his older brothers and sisters, but at the same time, he had his elder brothers reminding him of what he should and shouldn't be doing.

Jock had a carefree life and had many different jobs: working for GEMCO and the local Council in various roles. Jock's laidback attitude to life made him a well-loved man among his family, especially with his brothers' children.

When the disease started to show itself in Jock, he already knew what would happen to him, as he saw the illness develop in his brothers and sisters over the years. Jock used alcohol as a way to escape from the reality of what was happening to him. He said to me that the reason he drank was because he preferred people to think that he was drunk, rather than as having MJD.

Eventually Jock realised that he couldn't hide it

Despite the many challenges he faced later in his life, Jock Lalara was always ready to share his music and his love for his family with others. He rocked a 'dirty blues' selection on his iPad, which he was fastidious about ensuring was charged. He often entertained those around him with his (sometimes loud) appreciation. (2010)

any longer and accepted the fact that he had MJD, and that it was affecting his life. In the early stages of his illness, Jock had married Lois Wurramarra. This relationship did cause issues within the family but was accepted. Lois's children loved Jock, and they shared many hours laughing and telling stories together. Although, the children were often concerned that Jock was drinking too much, as they knew it was affecting his health.

Eventually Jock had ramps added to his house, when he became dependent on a wheelchair. He was keen to upgrade to an electric wheelchair, as he knew this would give him more independence, and that he would be able to get around the community. Despite his family being a bit worried that he might have an accident on the road, Jock eventually did get an electric wheelchair. Nadia and Libby recount a story where they were called into the Nursing Home manager's office to be told Jock was no longer



When living in Darwin, Jock Lalara was much loved by those who cared for him. He was able to swindle a packet of cigarettes from even the most dedicated anti-smokers, despite not using a word — a source of great fun! Who could ever forget his enthusiasm to catch, cook and eat the barramundi in such plentiful supply at the Berry Springs Reserve, and then with bemused irritation, realise that this was not 'the done thing!' (2009)



Jock Lalara and Bryan Massey, waiting for departure on Jock's 'Holiday of a Lifetime'. Jock was always ready hours before departure time — his excitement spread to those around him. (2009)



Family was Jock's world, and he always had a great time on his 'Kin Connect' trips home from Darwin. He is photographed here with Joyce Lalara in Darwin, with his brand-new teeth, ready for a trip home to Groote Eylandt. (2012)



able to use his electric wheelchair in the facility, because he was creating some chaos with it by crashing into furniture and speeding down hallways, putting a hole in the wall (Nadia and Libby could not help but get the giggles when telling this story) — Jock certainly loved it, but nursing staff did not. Over the years, Jock had respite in Darwin and was able to stay at the same nursing home as his brother, Warren. Respite at a nursing home became a regular occurrence, as it gave Jock the chance to have a break from his home situation and gain some strength again.

I particularly remember an occasion on Groote Eylandt when Warren was returning to Darwin after attending a funeral. Jock wanted to go to the airport to say goodbye. As Warren was going towards the gate, to get on the plane, Jock came over and shook his brother's hand. I felt very touched by this gesture, as it was a demonstration of their bond,

as well as a way of expressing that it could be their last time seeing one another — and unfortunately, it was. Warren passed away shortly after this encounter.

The older Jock grew, the more reflective of his life he became, and he started to appreciate what he had had in life. He was very appreciative of the support and care the MJD Foundation gave to him, as he realised that his earlier concerns about showing signs of MJD and trying to cover it up by drinking were futile. Jock participated in the physiotherapy programs that were available to him and could see the benefit they were bringing to his body. He particularly loved his hydrotherapy, which was possible after the MJD Foundation secured funding to get a lift for the Alyangula Pool. The support he was given by the MJD Foundation staff also made him feel a part of something that was making a difference to people's lives. He was able to share



Family, about to say goodbye to their grandfather at the Groote Eylandt airport. (c. 2008)



Howdy pardner! Cowboy Jock at Australia Zoo on his 'Holiday of a Lifetime', organised by the MJD Foundation. (2009)

'Staying Stronger for Longer'. Jock Lalara, doing hydrotherapy exercises at the Alyangula pool on Groote Eylandt. He loved his hydrotherapy. (2011)



Jock Lalara with MJD Foundation staff member Simone McGrath, at Groote Eylandt Airport. (2012)



with his brothers and sisters' children, who now too had MJD, what was happening to him. They all loved Jock and enjoyed being with him, as he would tell them funny stories and make them laugh. He was much loved.

He loved his Eylandt home, and understandably never really came to terms with having to move to Darwin and into a nursing home, in early 2011. The MJD Foundation 'Kin Connect' trips back home were the highlight of his life in his last years.

Jock passed away while living in the nursing home in Darwin. What was learned from Jock's life was the importance of client and family support to prolong quality of life; the importance of feeling

connected with family; and that good nutrition and physiotherapy programs do help those with MJD to maintain muscle strength.

It is difficult to explain the importance of carer support. Carer support always involves family members, and being able to be with family together on this journey helped to ease the pain of physical loss. MJD Foundation staff were always respectful of the cultural connectedness and the importance of relationships with family.

Rose Labanbayi Mirniyowan

18 September 1961 — 2 October 2014 (53 years)

By Libby Massey

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

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

Rose you will never be forgotten.



Rose Mirniyowan and her koala friend, at Australia Zoo (she didn't want to hand her back!). (2011)

By Nadia Lindop

Rose was one of a kind, and taught me a strong lesson in planning client-centred supports. I remember our MJD Foundation 'Holiday of a Lifetime' program was taking off, and we had several clients wanting to go to the Gold Coast and swim with the dolphins. I was talking to Rose about her holiday and enthusiastically telling her she could swim with the dolphins, too. She motioned for me to come closer, and whispered in my ear: 'none of that swimming with dolphins shit'. We had a big laugh together, and I have never forgotten this important lesson.



➡ Rose Mirniyowan (left) and her sister, Roseanne Mirniyowan — Gayangwa Lalara's nieces, and warrior women. Always close, until death parted them. There are LOTS of stories to share about these two, but only so much space! (2013)

➡ Thanks QANTAS.

Rose Mirniyowan, arriving in Brisbane for her 'Holiday of a Lifetime' at Bribie Island (organised by the MJD Foundation). (2011)



➡ Rose Mirniyowan at Australia Zoo with Suzanne Wurrarama, getting close to the Yingana (snake). (2011)



➡ Rose Mirniyowan on the innovative beach wheelchair (funded by the MJD Foundation), getting so close to the sea she was able to dip her feet in the water. (2014)



➡ A Bickerton Island mob visit to Angurugu. It was always a happy time when all the family got together. (2014)

➡ Warrior women and sisters, Roseanne and Rose Mirniyowan. (2012)



➡ 'My niece, Rose, she was always being silly. She used to stick her tongue out all the time, especially if she didn't want to have her photo taken.' — Gayangwa Lalara

Photographed with Simone McGrath doing hydrotherapy ('water dancing'). (2012)



➡ Rose Mirniyowan, pictured right. A special family gathering when cousin, Daniel Lalara, came to visit. (2011)

Jane Gayinduba Wurramara

16 January 1969 — 10 January 2014
(45 years)

By Libby Massey and Nadia Lindop

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

Jane's devotion to her husband, Naaman, and his to her, despite the marathon they endured with MJD was legendary. Their joint love of being 'On Country', and their refusal to allow Jane's illness to limit them led to many, many (sometimes funny) stories of escapades and dramas — who could forget the 'wheelchair dinghy' ride to Bickerton Island from Groote Eylandt, or the time Naaman piggy-backed Jane five kilometres home after a flat tyre on a bush trip. The first piece of equipment ever purchased by the MJD Foundation was an ocean-standard life jacket for Jane, to provide some safety for these journeys.

Jane was the inspiration for the MJD Foundation iPad program. MJD causes people to lose their ability to speak, yet they retain their intellect. The MJD Foundation has provided iPads to clients since 2012, to support communication. The power of the iPad



1 Beautiful Jane.

Jane Wurramara loved the sea, fishing and just sitting. She was a strong Christian woman, and loved to sit and read the Bible and talk to her aunty Gayangwa. (2010)

program to bring communication back to those who had lost their speech through MJD was made unforgettable when Jane used her iPad to write a welcome speech to the Governor General, when she visited Groote Eylandt in 2013. Her ability to use the device to help us understand her world ensured that we will continue to try our hardest to unlock the worlds of others living with MJD whose speech fails them.

We miss her enthusiasm and precision (and some of us miss our spelling being corrected by her!), but most of all, it is Jane's grace, dignity and courage that we miss.

She lived her life with so much hope and love.



2 Peace, and hopefully some fish for dinner. Pictured here fishing at Bickerton Island with husband Naaman. (2009)



3 Jane Wurramara was a beautiful soul. She had a bit of a hard life but was at peace with herself. Members of Jane's family were also living with MJD. She still had hope for a cure. Jane loved her nieces and nephews, but had no children of her own. (c. 2006)



4 Cousins: Joyce Lalara and Jane Wurramara. (2011)



5 At home and happy with a visit from Lorna Brunton from Anglicare. Visits from services provider were not regular, usually every six to eight weeks, but were such an important part of Jane's life. (2011)



6 Jane loved her iPad. It brought some normality to her life, enabling her to communicate, take photos and send messages. The joy was beautiful to see. (2013)



7 Jane Wurramara (right) and Gayangwa Lalara, with Jane's mother Gwenda Lalara — that's the '007 lady' on the left! (2009)

8 Coming to the beach anyone? The beach wheelchair made visiting the beach really fun, taking Jane closer to the sea she loved so much. (c. 2008)



Frederick 'Digger' Lalara

25 May 1971 — 24 June 2009 (38 years)

By Bryan Massey

Frederick was also known as 'Digger' — a nickname given to him by his family, because as a young boy, he was always digging holes around the place.

Frederick was exhibiting the early signs of MJD when his father, Ernie Lalara, was well into the final stages of the disease. At this point in time, Frederick was married and was the proud father of two beautiful girls. Of course, none of us knew if MJD was dormant in one or both of the girls. As his MJD symptoms progressed, his wife, as his main carer, found it extremely hard to cope, and carer burnout became an issue. She went to live in Palmerston, and the girls would share time between there and Angurugu.

Frederick was gifted a three-wheeled tricycle to ride on as a means of transport. It was not uncommon to encounter Digger doing errands around Angurugu. I do not think he ventured further afield.

As with his dad Ernie, I became good friends with Digger, perhaps like a father and son.

He joined us at the Angurugu Aged Care Facility for breakfast each morning, had his personal care needs catered for, and then he would be off on his rounds.

Anyone who felt the warmth of that amazing smile will know that Frederick 'Digger' Lalara was a motivating force for all in the fight against MJD. (2008)

There is a small narrow concrete culvert over a drain at the entrance to the Aged Care Facility grounds. Many a time we would sight Digger entering the driveway, and respecting his strong need for independence, we would hold our breath until he was safely over the culvert. The tricycle had a mind of its own, and it often came close to falling over the edge.

As with his dad, he would always sit in the co-pilot's seat of the vehicle when we were going to Alyangula, rather than in the back in his wheelchair. This only happened leading up to the end of his life.

He loved his music on CD, and it was a highlight of pension week to go to 'Retravisation' at Alyangula so he could peruse the latest releases. In the days before disability needs became a focus, and the entrance to the shop was not disability friendly, I would somehow manage to get the wheelchair and



Our hero, fearless on his bike, giving us all a lot of joy just watching him enjoy himself. Transport gave Frederick independence: he was able to visit his family whenever he wanted to, enjoying the adventure along the way. (2007)



Friends forever — best mates and a bit naughty when they got together. Bryan Massey was Frederick 'Digger' Lalara's carer for many years. (2007)



Frederick 'Digger' Lalara went on an amazing road trip with Bryan Massey, the MJD Foundation's very first 'Holiday of a Lifetime' trip — driving from Darwin to Brisbane, and swimming with dolphins along the way. He enjoyed every minute. (2008)

passenger up the eight or so steps into the shop and out again, to the general amusement of all. We used to enjoy this exercise.

Frederick and I also went for a road trip across to Broome to attend a disability conference, run by the Western Australian (WA) Health Department. We spent many hours chatting together on the way there and back home again. Digger was a delightful young man.

In 2008, we also did another trip from Darwin to Brisbane for the MJD Foundation's very first 'Holiday

of a Lifetime', and we came back by Qantas jet.

When Frederick became very unwell, his desire was to finish up at home, in Angurugu. I had the honour of being with him, to care for him on his final flight home to Groote, and I camped at his bedside in his house until his final breath.

I remember thinking then of how much more could be done for those living with MJD, and made a commitment to myself to do all that I could along with others to make this happen.



➊ On the day Bryan Massey left Groote in 2008, after 38 years: a sad day, but the famous 'Digger' smile is still there. (2008)

➋ Frederick 'Digger' Lalara and Natalya Lalara, one of his two little girls. (2009)



➌ When his family wanted him to fly home to finish up, he was able to be flown back to Angurugu. (2009)



➍ Frederick 'Digger' Lalara's headstone (Angurugu Cemetery), a tribute to a young man whose life was a journey of hope. The text, put together by his mother Caroline, tells a story so that people would know about this disease. (2009)



➎ MJD Foundation's first 'Holiday of a Lifetime'. Bryan Massey and Frederick 'Digger' Lalara's Road Adventure. (2008)



Natalya Genise Lalara

1 June 1993 — 2 October 2014 (21 years)

By Kathy Mamarika and Norelle Mamarika

When this little girl was born, she was just like a normal child; she played with the other little kids, she was having fun, and she was always happy. Family and her mother (Dulcie) relied on Norelle and Kathy (her aunties) to care for her. We have so many stories, cause she grow up with us. So many stories from when she was little girl and until she passed away.

We didn't know she had this disease but we started to recognise — her eyes went wider, we started seeing her walking wobbly, and she was always dropping things all the time. When she was so young, she started falling down, she was so wobbly, dragging her feet after that, walking wobbly. When she was playing with other kids, she was falling over often. We started to tell her not to play, but she wouldn't listen and still played. She was shamed to stop.

She was fishing every day at the wharf, and she had sores on the legs cause she was falling down. We stopped her going fishing in case she hit her head on a rock.

She went to school every day from when she was only four years old with her younger sister (Alzana Lalara). When she was eight years old, she came to



➏ Natalya Lalara and her grandmother. Natalya was a brave young woman. She loved her iPad, a lifeline of communication. (2011)

live with us, her aunties.

They grew up as one sister. Alzana especially helped. She started to change when she was eight years old.

She had to finish school.

Day by day the MJD Foundation mob did things in the house: her bedroom was made brighter, she got an air-conditioner and equipment.

She went on a holiday with MJD mob to Cairns and the Gold Coast.

After that, she got weaker and we cared for her day and night. She didn't sleep very well.

She passed away on 2nd October 2014.



1 Natalya Lalara, pictured here with Gayangwa Lalara, meeting Quentin Bryce, the Governor General of Australia, when she visited Groote Eylandt in 2013.



4 Family being together and chatting was an important daily activity. Natalya's family understood MJD from their caring roles with other family members over many years. (2011)



3 Natalya Lalara, pictured here with her carers and family on her 'Holiday of a Lifetime' trip to Cairns. At Kuranda she loved the koalas, but the whole holiday was exciting. (2013)

By Libby Massey and Ros Kempton

During her lifetime, this very beautiful young lady was the absolute centre of an amazing strong and caring family. She shared a wonderful bond with her younger sisters: Alzana, Mariah, Danielle, Vinaigrette and Italiana. Along with Greta, Norelle and Dulcie, there were many happy day trips and adventures shared. Natalya especially loved outings with her family and was a big fan of spending time at the Groote Eylandt Lodge or at the Alyangula boat ramp, eating picnics, spending time with family and enjoying the view.

Natalya and her family had a very special way of communicating, especially when it became more difficult for Natalya to verbally communicate. As if by magic, they were able to understand each other and with almost no words spoken. The care that she received from these incredible women, her aunts, was heart-warming to see.

Natalya had the most gorgeous smile and was always interested in what was going on for everyone around her. Beautiful Natalya was not with us for very long, but she is forever missed.



2 HAPPY BIRTHDAY! Natalya loved cake, and especially birthday cakes. (2011)



5 Family together. (2012)



6 Family cooking a cake for Natalya at the MJD Foundation Office in Angurugu. (2011)



7 Natalya Lalara's gravestone.

'We will remember your beautiful smile, and your beautiful eyes.' (2014)



● Murabuda Wurramarrba and Bryan and Kathy Massey worked together for many years establishing the Angurugu Aged Care Facility and other programs such as Meals-on-Wheels and respite. (2000)

Murabuda Wurramarrba

31 December 1934 — 31 December 2015 (81 years)

By Kathryn Massey

Going back to when we first arrived on Groote Eylandt in 1970, Murabuda Wurramarrba was starting his family. He was the market gardener for Angurugu. He was always a family man. He would meet with all of us before work, mostly with one of his children in tow (usually sitting on his shoulders).

As the years passed, he left to work for the mining company, GEMCO, as one of the security officers. He was always honest and fair in his dealings with everyone.

Murabuda was a very important Groote Eylandt man, a chief ceremony man.

Substance misuse, mostly petrol sniffing, was prevalent about this time. He was very concerned for his community. He was very vocal about this, asking everyone he knew he thought could solve this problem for help.

It wasn't until the Anglican Church decided to help that we were asked to join him, his brother and some of his family at the Council for Aboriginal

● Murabuda Wurramarrba, receiving a Territory Hero Award from then NT Chief Minister, Steve Hatton. (c.1967)



Alcohol Program Services (CAAPS), using an Alcoholics Anonymous (AA) program modified to suit remote Aboriginal communities. The program was special and it worked.

He then decided he wanted to help people he called 'the poor, sick, tired, damaged ones'. With some help, he was able to secure Commonwealth funding to erect a twelve-bed facility that would look after these people. It was named Mungkadinamanja (Angurugu Aged Care Facility).

When the 'poor and sick' people discovered they had MJD, the Facility was just the place to accommodate and support them. The Lalara family were the ones predominantly affected.

My husband Bryan Massey recalls: 'Of all the folk I have had the privilege to meet and work alongside, and there were many, Murabuda was the most selfless, most compassionate, person. I believe him to be the greatest man to have ever lived on Groote Eylandt. I trust his name will always be remembered and celebrated.'



Carers — a journey through love, strength and struggle

‘Love never ends’

By Jenny Baird

The story told in these pages ranges from the humble beginnings of a few people struggling to deal with a debilitating illness on Groote Eylandt, through to the founding of an internationally recognised organisation leading the way in research and provision of care for people living with MJD.

It all began when Mandaka Lalara was diagnosed with a mystery illness then known only as ‘Groote Eylandt Syndrome’. As more family members became afflicted, knowledge was gained regarding proper provision of care. (For instance, through the experiences with Kevin and Ernie, we learnt the importance of good nutrition to counter bowel obstruction.) It also became increasingly clear that social interaction is really important, giving people living with MJD an opportunity to feel they are still valued members of the community. In the early days of the disease, families kept MJD to themselves, and had to deal with care issues on their own, since the wider community was having

trouble grappling with this strange and unknown illness. Gradually, over many years, the community began to understand what MJD was; and then, via the MJD Foundation, there came funding and research.

When my husband Warren was diagnosed with MJD there was no Foundation to support us with anything; we were just going on instinct. As a carer, I had no support at all. I remember a visiting health professional advising me to help Warren in his exercises, and to do his chest percussion for him, on top of having to do everything else in my life, such as continue working. The health professional did not visit us again for another six months. I just felt so overwhelmed! I couldn’t believe her lack of understanding of what a carer goes through. No one asked me how I was coping, or what they could do to help. Carers face an immense burden: loneliness, coping with the impacts on the family’s children, dealing with bureaucrats who believe they know your situation better than you do! I

could go on — but suffice to say, carers need a lot of support, even in these times of the National Disability Insurance Scheme (NDIS).

In remote locations, carer support was non-existent in the early days, and in many places it still is today. Eventually, the stress and pressure led our family to relocate to Darwin, which provided more carer support — and so began my involvement with Carers NT. I served as President, and as a Board Member for 17 years — continually advocating for improved services for carers in the Northern Territory. Any opportunity that came my way, I would speak up for this relatively unknown disease.

Eventually in 2008, the then Federal Minister for Families, Community Services and Indigenous Affairs, Jenny Macklin, allocated seed funding to the MJD Foundation. From this small grant, matched generously by Anindilyakwa Land Council funding, the organisation grew. No longer did MJD clients and families need to feel isolated and alone in their daily battle with the illness, and I am immensely grateful for this.

How did I manage over the years? There were many times when I didn't, and felt robbed of my life. My Christian faith has helped. It has also been a great

test to understand the definition of love. We are told that love is patient, kind, forgiving — but it is true that love also requires strength, both physical and spiritual. My faith in God helped me get through the hard times.

It has been a cathartic experience to write of my family's experiences in these MJD stories, and it has been done with tears of both joy and sadness. Joy that I had the privilege to know these people, and sadness that they never got to see the end result of their struggle. To see full recognition and support given for MJD, and know that their struggle had not been in vain. We have learnt from their lives, and today the support and care given is first class, in all areas of care.

During all this, I also came to better understand Warrens' parents and their values, and to appreciate the importance of their culture. Warren's mother was exemplary to all her children, offering the best she could give them. Today, when I see their daughters, Gayangwa and Gwen caring for their family, I think how proud their parents would be of the encouragement and support their daughters give to their nieces and nephews; and how delighted they would be of their work with the MJD Foundation. In many ways, the values of the parents shine through

in their daughters. It is important to remember our values, and where we come from, as these lead us and guide us to our future. If we forget this, we are lost. The strength and memories of our passed loved ones is a treasure to have and to hang onto.

There is a lovely verse in the Bible's Book of Corinthians on the subject of love. It says: *Love is patient; love is kind; love is not envious or boastful or arrogant or rude. It does not insist on its own way; it is not irritable or resentful; it does not rejoice in wrongdoing, but rejoices in the truth. It bears all things, believes all things, hopes all things, endures all things. Love never ends.* (1 Corinthians 13:4-8.)

I believe these stories and memories of past family members are laid in the work of the MJD Foundation: the way we treat all our MJD clients and their families with love; in the content of our policies; the 'both ways' ethic we use across our organisation; and, the respect for culture which we show in all our work practices. The MJD Foundation honours and respects all those with MJD, enabling them to have the best possible life that they can have.

I am now watching my son Daniel and daughter Anna battle with the disease. My son has severe

MJD and cannot walk or talk, but the strength of his character and the love that he has for his family are amazing — I have never seen such honour in the character of anyone I have met. He is a constant source of encouragement for me, and a reminder that we can all make a difference to the lives of others. Anna is still in the process of learning — and I know that through her aunts, Gayangwa and Gwen, the strength of her grandmother (Dagunda) lives on.



'My life living with my family who have this disease called Machado-Joseph Disease'

By Caroline Wurrarama

In my younger years in the 1970s and 1980s, living with my husband [Ernie Lalara] was a bit different from the 1990s up until 2002. The life was good: he was a strong man, a working man, a good caring father to his children, a good hunter and a good dancer. We had three children, and Frederick was born normal just like any babies, and like his two sisters.

In 1989 my husband had these signs of MJD. When he was walking, he was out of balance and sometimes starting to trip and fall. Then in the 1990s, he had it ... he was no longer strong, and so he stopped working. And that's when I began to work with him, helping him to walk to the bathroom. Sleeping at night was starting to get worse ... whenever he slept he used to have cramps in his muscles, and stiffening, and started to have the tummy cramps whenever he passed urine.

In 1993, that was the worst year for me with my husband. Every day and every night, that was the worst time of my life. Working with my husband was very tiring and very distressing. Every night he used to have lots of spasms and muscle and tummy cramps. And also his leg stiffening and

his whole body was affected. The bed was not comfortable for him when he was put into it. He kept moving around, I had to lift him again back to his wheelchair — that is the only comfortable way that he could sit and sleep. He also had a speech problem, and holding things like a spoon and a cup, and other things because his hands were starting to get weak. We had to feed him. Very often he used to get sick and was flown to Gove or to Darwin Hospitals.

All those years of living and caring with my husband was too much for me. Then, the carers and the health people had been a very great help with me. The Aged Care Centre was a great help to me and to others, too.

When my husband died on 23rd May 2002, this was the end of my hard work with him. It was over. I was thinking I could start a new fresh life with myself. But it was not like that. My son Frederick had this disease too. It all started out again — but thanks to the people of the Aged Care mob who were a great help to me and to the others. I did everything for him at home, like doing the cleaning and laundry and shopping and cooking, but my worst part was seeing my son also get sick and weak, and then finish up [pass away], too.



1 'Both sisters, Rose and Roseanne, stayed with me. I didn't want other families to help the wrong way. Nieces and nephews, brothers and sisters — I helped them all.' — Gayangwa Lalara (2014)

2 'I remember thinking then of how much more could be done for those living with MJD, and made a commitment to myself to do all I could along with others to make this happen.' — Bryan Massey (pictured here with Frederick 'Digger' Lalara) (2008)



3 'Jamie and Lisa looked after that lady [Gwenda Lalara] so beautifully. She had better care with them than she would have had at a hospital or hotel, anywhere. She was always so well looked after.' — Libby Massey (pictured is Jamie Wurraramara and Lisa Wurrawilya). (2011)

4 'Carers are a special group of people. Daily they have many tasks to do with very little support. They burn out; they too need support. These people are the unrecognised Australians.' — Kathy Massey (pictured here with Gayangwa Lalara) (2016)



5 'When I went to see my uncles, Jock, Ernie and Harry, I know I felt this MJD, but I still wanted to see them, to go visit and see them, and I did all for them. I made them tea, showered them ... everything. Sometimes other people wouldn't help them, so I had to. Sometimes there was laughter, talking funny stories, some of them way back to when they were kids. They did something for us when we were kids, and that is why we have to visit and help them too.' — Steve 'Bakala' Wurraramara. (2014)



6 'Warren's condition deteriorated to the point that I could not care for him at home anymore; he needed 24-hour care, and he went to a nursing home. This was hard for me to accept, but the reality of the illness was that I could not provide the care that was needed.' — Jenny Baird (pictured here with husband Warren Lalara). (2010)

7 'Caring for a person with severe MJD is incredibly hard, emotionally and physically. I find comfort in the small moments, smiles, laughter, and in any small gains made — no matter the length of time they last.' — Ashley Murray (pictured here with Roseanne Mirniyowan at Alawa House, Darwin). (2021)

8 'Dambayana, Harry's wife and Melinda's mum, went to Darwin when Harry's MJD started getting worse. It was too hard. So Harry lived with me and Melinda, and Melinda's sisters, after that. We all took care of him, until he passed away.' — Brett Mamarika (pictured here with his wife, Melinda Lalara). (2011)

9 'It was really hard to care for her [Natalya]. We cared for her and cleaned the house every day. We took turns to keep waking all night to take care of her. When the others were older, they got wobbly, but our little girl started so young. That's why she passed away so early. It was so sad.' — Norelle and Kathy Mamarika (Natalya Lalara's aunties and carers). (c. 2017)



Along the Way — 'No Shame, No Blame, Just Hope'



➤ Bryan and Kathy Massey OAM worked in Angurugu for 38 years and retired in 2008.



➤ Warren Lalara at the Angurugu Aged Care Facility with Bryan Massey. So happy to be home on Groote Eylandt, from Darwin — the smile says it all. (2003)



➤ St. Andrews Anglican Church at Angurugu, formerly an Anglican mission, then a township. This church has always been a peaceful meeting place.



➤ Frederick 'Digger' Lalara loved going out in the Angurugu Aged Care bus. He always wanted to sit up front, and always asked to be seated there. The bus lift was broken, and so the MJD Foundation funded this ramp to help. (2008)



➤ 'Give me your shoulder to cry on, hold me when my strength is weak. Be my friend. We are on this journey together.' Kathy Massey and Gayangwa Lalara, long-time friends and co-workers. (c. 2008)



➤ Jock Lalara and Bryan Massey. In 2009, Jock went on one of the first MJD Foundation's 'Holiday of a Lifetime' trips — a holiday location of choice, funded and supported by the MJD Foundation. Jock chose the Gold Coast. This tradition continues today. (2009)



➤ Discussing therapy options out on the veranda. Family meetings, communications, assessments and therapy don't always have to happen in a closed room or clinical setting. (2008)



MJD Foundation co-founder and occupational therapist, Libby Massey, with Gwenda Lalara. Occupational therapists have always played a huge part in the lives of those living with MJD. (2008)

➤ Trying out the new beach wheelchair ... now to find the beach, feel the sand and listen to the sea. (2008)

➤ Speech Pathologist, Professor Deb Theodoros, visits Frederick 'Digger' Lalara. These visits were always a highlight, as they opened up new communication options. (2008)



➤ Jock Lalara's ramp, an exercise in patience and greatly valued by Jock. GEMCO played a big part in making this happen by supporting the MJD Foundation. (2008)

➤ Mungkadinamanja, the Angurugu Aged Care Facility, on Groote Eylandt. A dream belonging to both Murabuda Wurramarrba and Gayangwa Lalara. (2021)



➤ Nadia Lindop, doing a tour of the Angurugu Aged Care Facility. (2009)





➊ MJD Foundation's first 'Office', on Groote Eylandt, located within the grounds of the Angurugu Aged Care Facility. Pictured are the co-founders, and tireless advocates, Nadia Lindop and Libby Massey. (2009)



➋ Young Men's Camp, outside Darwin in 2009, one of the MJD Foundation's most ambitious early projects, held at Annaburroo Station. (2009)



➌ Co-founders, Nadia Lindop and Libby Massey do a test drive with Professor Garth Nicholson, lowering him into the water at the Alyangula Pool Hoist opening day. The pool hoist supports MJD clients to safely enter the water for hydrotherapy. (2009)

➍ The Groote Eylandt community bike ride from Umbakumba wharf to Angurugu airport, organised by the Alyangula Cycling Club. Just the excuse the MJD Foundation needed to try out some tricycles, so those with mild MJD could participate. (2010)



➎ A large shipping container, filled with wheelchairs and equipment for MJD clients, stands as a symbol of hope. (2009)



➏ The MJD Foundation logo, branding (and spraying!) done by Nadia Lindop. (2009)

➐ Hydrotherapy was renamed 'water dancing' by the ladies. Popular in the heat of the wet season, but in the dry: 'it's too cold!'. (2010)



➑ Winners (or maybe the 'highly commended'!) of the 2010 bike ride. (2010)

➒ MJD Foundation staff undertook a 'bedroom blitz' in Natalya Lalara's room. The newly renovated room was pink themed (Natalya loved pink!), and included a 'The Veronicas' bedspread, one of her favourite bands. (2010)



➓ Daniel Lalara (Jenny Baird and Warren Lalara's son) and Hilroy Manggurra at the Young Men's Camp. (2009)



➔ The MJD Foundation had ramps installed at Natalya Lalara's house, thanks to GEMCO — a great cause for celebration, and very much appreciated by Natalya and her family. (2009)



➕ A very special occasion, and a very valued piece of equipment, making the transport of clients onto aircraft an exercise in dignity. Kathy Massey, Neil Westbury (MJDF Chairperson), Tony Wurrarrarra, Libby Massey, Gayangwa Lalara, Jenny Baird, Claud Freeman, Senator Trish Crossin, Fiona McKenzie (nee Goulding) and Nadia Lindop. (2010)



➖ Tony Wurrarrarra at the launch of the aircraft wheelchair lift (DPL) in Darwin (Vincent Aviation hangar). (2010)

➗ Needless to say, Natalya loved her new room! (2010)



➘ An early ambitious project of the MJD Foundation was aircraft wheelchair lifts (DPLs), installed in Darwin and Groote Eylandt (with further lifts to come later at Galiwin'ku and Nhulunbuy). (2010)





1 A visit to the zebra fish laboratory in Sydney (then located at the Brain & Mind Institute, and since relocated to Macquarie University). A unique research project with zebra fish, under the watchful eye of Dr Angela Laird. Seed funding for this project was funded by the Anindilyakwa Land Council (through the MJD Foundation). (2011)



2 Jamie Wurramara chose Cairns as his 'Holiday of a Lifetime'. Jamie, with partner Lisa Wurrawilya, and the Masseys, on the Green Island jetty, offshore Cairns. (2011)



3 The MJD Foundation's Women's Camp at the 'Dugong Beach Resort' (now the 'Groote Eylandt Lodge'). See the YouTube clip here: https://youtu.be/FRV_I39nrnc (2012)

4 Women's Camp. (2012)



5 Gayangwa Lalara, observing the zebra fish through the microscope at the zebra fish lab. (2011)



6 Rails installed at Joyce Lalara's Baniyala house. (2010)

7 Hilroy Manggurra, Daniel Lalara and Steve ('Bakala') Wurramara, filming for the 'Our Story' project, where they captured footage and developed stories about their lives. (2011)



8 'Backyard blitz' Angurugu — a team of happy gardeners. Fun YouTube clip here: <https://youtu.be/vopQFhb6kzg> (2012)



9 Dr Angela Laird, showing Gayangwa Lalara how the zebra fish are cared for in the lab. (2011)

10 A dedicated team of carers at a MJD Foundation careworker education session. (2011)



11 Steve 'Bakala' Wurramara, receiving an award in Canberra, pictured with then Prime Minister, Julia Gillard. (2013)



12 'Staying Stronger for Longer' — physiotherapy out 'On Country' continues to be important for clients. (2014)

13 Sisters, Melinda Lalara and Joyce Lalara, at Umbakumba. (2011)



14 Melinda Lalara with Simone McGrath. (2012)

15 The Governor General, Quentin Bryce, visited Groote Eylandt in 2013 and spent time with families living with MJD. The power of the iPad program to bring communication back to those who had lost their speech through MJD was made unforgettable when Jane Wurramara used her iPad to write a welcome speech to the Governor General.





➊ From shipping container to office. In 2014, the MJD Foundation established a proper office within the Groote Eylandt Aboriginal Trust (GEAT) building, Angurugu. (2014)

➋ The MJD Foundation Groote Eylandt team photo in 2014.



➌ The Groote Eylandt 'Staying Stronger for Longer' program. Nick Kenny has been a strong advocate for regular (and fun) physiotherapy since 2011. (2018)



➍ Steve 'Bakala' Wurramara, on tour for the 'Bakala' film, an award-winning short film based on the true story of one man's fight against time to beat MJD. <http://bakalathefilm.com/> (2017)

➎ Gayangwa Lalara's sister and right-hand lady, Gwen Lalara, who has worked tirelessly alongside her sister. (2014)



➏ Steve 'Bakala' Wurramara and Joyce Lalara, keeping strong. (2014)



➐ Speech therapy at the Angurugu Aged Care Facility. (2014)



➑ Gayangwa Lalara and Gwen Lalara are the remaining two siblings in their family — nine of their siblings had MJD. (2014)

➒ Hosted by the MJD Foundation, the 2015 International MJD Conference was held in Cairns, Queensland. It was an amazing event, and was attended by researchers in MJD from around the world.



➓ Physiotherapy and speech therapy out 'On Country'. (2015)



➔ A 'David and Goliath' moment. The MJD Foundation (backed by brave clients) took up the fight against Senator Scullion when he overturned a \$10 million Aboriginals Benefit Account (ABA) grant. The MJD Foundation was later successful, and this funding continues to provide critical support to families today. Pictured here are Joyce Lalara, Gayangwa Lalara, Julie Wunungmurra and Steve 'Bakala' Wurramara. (2014)

➕ Pictured here is the Australian MJDF contingent with researchers from Portugal and Israel, at the 2015 International MJD Conference.



➖ The 2019 International MJD Conference was conducted on the 11 and 12 November as a satellite of the larger International Ataxia Research Conference (IARC), in Washington D.C. The aim of the conference was to advance international research in MJD, and to foster international collaborations. It was attended by sixty-nine delegates from ten countries and included researchers, industry representatives (pharmaceutical and biotech companies) and people living with MJD and their caregivers.



➗ Highlights of the conference included the first Aboriginal international speakers from the MJD Foundation, including Aboriginal researchers living with MJD (go Joyceca!), as well as an interactive interdisciplinary workshop and a patient and family-caregiver panel session. These activities offered a rare opportunity for clinicians, patients, families, and scientists working in basic research to interact, learn from one another and share suggestions about advancing MJD research, clinical care and wellbeing.





1 Family farewell Roseanne Mirniyowan on her way back to Darwin after her 'Kin Connect' trip back to her home, Groote Eylandt. The MJD Foundation's 'Kin Connect' program supports MJD clients that are living in supported accommodation in urban centres to travel home for a visit. (2019)



2 Steve 'Bakala' Wurramara and Daniel Lalara, cousins together. (2017)



3 Melinda Lalara and Roseanne Mirniyowan at MJD House in Darwin, resting after an outing. (2020)



4 Groote Eylandt's 'On Country' physiotherapy program has been running since 2011. Melinda and Joyce Lalara, exercising on the beach with physiotherapist Simon Mead. Therapy has come a long way since the early days, and Harry's daughters are now able to 'Stay Stronger for Longer' with much more support. (2020)

5 Bryan Massey, Melinda Lalara and Brett Mamarika, in Darwin. Melinda and Brett were staying at 'MJD House', MJD Foundation's wellbeing hub in Darwin, which provides clients and carers with respite from the demands of living with MJD. (2020)



6 Laying flowers, Angurugu cemetery. (2019)



7 Gayangwa Lalara pays tribute to Rose Mirniyowan, Angurugu cemetery. MJD Foundation clients, families and staff visited the newly installed headstones of family members lost to MJD. (2019)



8 Liyandra Wurramara and Joyce Lalara. (2021)



9 One day every week, the Groote Eylandt MJD clients, families and staff head out 'On Country', for physiotherapy, family time, hunting, fishing, and lots of fun. (2020)





Frederick Nenilinguyinda Lalara

Born: 21 - 5 - 1971 Darwin

Died: 24 - 6 - 2009 Angurugu, Groote Eylandt

Frederick was born as a normal child.

He played well with his cousins like any other child. As he grew older he was a happy boy and had a great big smile. When he was a young man and he had M.J.D., he still had this smile.

Everybody loved this man. We never forgot his birthdays and bought gifts for him as well as birthday cakes. His two daughters came to visit him and sat with him on the verandah. We all miss him very much.

Caroline Wurramara (His Mother)

Alzana, Natalya, Yvette, Desiree & Children.

Ecclesiastes 12:7

*Our bodies will return to the dust of the earth,
and the breath of life will go back to God,
who gave it to us.*

For more information on Machado-Joseph Disease (MJD), or on the MJD Foundation, visit:

<https://mjd.org.au/>

Donate to the MJD Foundation here:



Or visit:

<https://www.givenow.com.au/mjdfoundation>

The MJD Foundation would like to thank the following organisations for their ongoing support, especially for our Groote Eylandt clients and families: Anindilyakwa Land Council (ALC), South32-Groote Eylandt Mining Company (GEMCO), Groote Eylandt Aboriginal Trust (GEAT), Groote Eylandt & Bickerton Island Enterprises (GEBIE), SeaSwift and the Telstra Foundation. The Foundation would also like to thank the NT Library for contributing to the production of this book.

'These stories offer an insight into the lives of Aboriginal people affected by Machado-Joseph Disease (MJD), their families, friends, carers and supporters, both before and after the MJD Foundation was established on Groote Eylandt in 2008.'

Kathryn Massey OAM
Project Manager

