



FOUNDATION



ANNUAL REPORT
2020–21



staying



stronger for longer

A visit to Croc Cove, Darwin –
Mary, during her stay at
MJD House.

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A photograph showing a person, Cara Rami, standing in a shallow, greenish-yellow billabong. She is bent over, reaching towards the water. The billabong is surrounded by lush green vegetation and rocky hills under a clear blue sky. The water has small ripples and some floating plants.

Cara Rami collecting water lily bulbs at Wulmaja Billabong, near Ngukurr.

About Us

The MJD Foundation works in partnership with Aboriginal Australians*, their families and communities living with Machado-Joseph Disease and other closely associated Ataxias. We provide comprehensive supports and engage in research, increasing understanding of the disease and providing hope for the future.

Established in 2008 across the Groote Archipelago communities of Angurugu, Umbakumba and Milyakburra, the MJD Foundation now works across Darwin, Alice Springs, Nhulunbuy (and the Gove Peninsula), Galiwin'ku (Elcho Island), Ngukurr, Numbulwar, Papunya, Ntaria (Hermannsburg), Ltyentye Apurte (Santa Teresa), Gunbalanya (Oenpelli) and Far North Queensland (Cairns, Yarrabah and surrounds).

The MJD Foundation prides itself on having strong community and family connections – always working from a grassroots perspective – ensuring we are listening to the needs and desires of families affected by MJD and SCA7.

The MJD Foundation is a registered NDIS provider, and a registered ACNC Charity with Deductible Gift Recipient status.

ABN 65 159 208 867

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

Julie and family,
eating oyster
('maypal')
and damper,
Galiwin'ku.





Key Highlights 2020-2021

Ngukurr Family BBQ

Welcomed The Hon Jenny Macklin as our new Chairperson.

6

Published and launched 'Ngeniyerriya – The story of Machado-Joseph Disease on Groote Eylandt'.

Welcomed almost all clients to MJD HOUSE, our wellbeing respite hub in Darwin.

Achieved eight research publications across topics: communication, therapy, staying strong, genetic services, cultural safety, Indigenous disability assessment, drug treatments.

Overturned an NDIS pricing decision for Gunbalanya NT, keeping it at 'very remote' pricing.

Demonstrated sector leadership by mandating staff COVID-19 vaccinations, with 90% of staff vaccinated so far.

Launched MJDF's SCA7 Program, supporting families in Far North QLD living with Spinocerebellar Atrophy Type 7.

Purchased MJDF Multipurpose Facility (Umbakumba) 'MJD School'.

Conducted 13 health professional in-services, and 11 support worker workshops.

Thrilled that Bakala was acknowledged as inspiration in Trent Dalton's book, 'All our Shimmering Skies'.

Welcomed our first MCS to be based in Alice Springs.

Supported a young client to go home to Galiwin'ku on a Kin Connect trip — a particularly special trip, now treasured by all that knew her, as she tragically passed away five weeks later.

Message from the Chair

The MJD Foundation is an amazing example of reconciliation and community initiative in action. It addresses the adverse consequences of a catastrophic debilitating genetic disease that targets numerous communities in northern Australia by focussing on creating opportunities for clients and their families to live fulfilled and culturally enriched lives for as long as is humanly possible.



Since its establishment in 2008, the Foundation has progressively improved its capacity to meet this aspiration by remaining true to our values and staying close to the communities we seek to serve. Whatever challenges we face in the future, we have much to be thankful for. Most particularly, the communities we work in, and our own people have grown stronger together because we seek to put people and their needs first.

In last year's annual report, I identified the potential catastrophic consequences if the COVID-19 virus spread into remote communities.

The continued threat posed by the COVID-19 pandemic and its latest Delta variant remains a major serious risk to the remote communities where most of our families living with MJD reside. As I write, just how serious is being amply demonstrated by the major impacts of the pandemic on Aboriginal communities in Western NSW.

These have highlighted various shortcomings including low rates of vaccination, poor underlying health, and severely overcrowded housing. The fact that the various authorities were previously warned and should have been aware of these issues, again holds up a mirror to the nation regarding the implications of the ongoing failures to

seriously address Aboriginal disadvantage. It also points to the urgency of adopting culturally informed short-term measures to secure high levels of vaccination.

As identified in the CEO's report, MJDF itself continues to adopt measures that seek to protect both our staff, clients, and the communities where we work, and to support the work of others in this regard, including Aboriginal Medical Services.

Another major ongoing issue is the NDIS, the challenges regarding the Commonwealth.

Government's attempt to reform the scheme, and its failure to come to terms with the fact that free market pricing is unworkable across the scheme. This is particularly self-evident in remote communities. MJDF devotes considerable time and resources to constructively engage with governments, the NDIA and fellow NGOs to identify innovative solutions to improving clients' supports under the scheme. In this context, the continued support of all the wonderful MJDF sponsors and supporters will remain and likely become even more critically important in enabling us to deliver meaningful and relevant services on the ground. We cannot thank you enough both for your past and continued support.

Despite these challenges, it is pleasing to report MJDF has been able to further enhance its work via several initiatives identified throughout this report, but also by placing a deliberate emphasis on consolidation.



Dwayne, Wyam, Michelle and Ernest attend the Synapse NAIDOC celebration in Cairns.

I have also had the privilege of working with a fabulous CEO and highly dedicated staff who continue to tirelessly support our clients and their families. Finally, I acknowledge and thank our wonderful clients and their families for their continued support and guidance.



NEIL WESTBURY PSM

What is Machado-Joseph Disease?

Machado-Joseph Disease (MJD) is a hereditary (genetic) neurodegenerative condition. It is in a 'family' of neurodegenerative diseases called Spinocerebellar Ataxias (SCAs). MJD is also sometimes called SCA3.

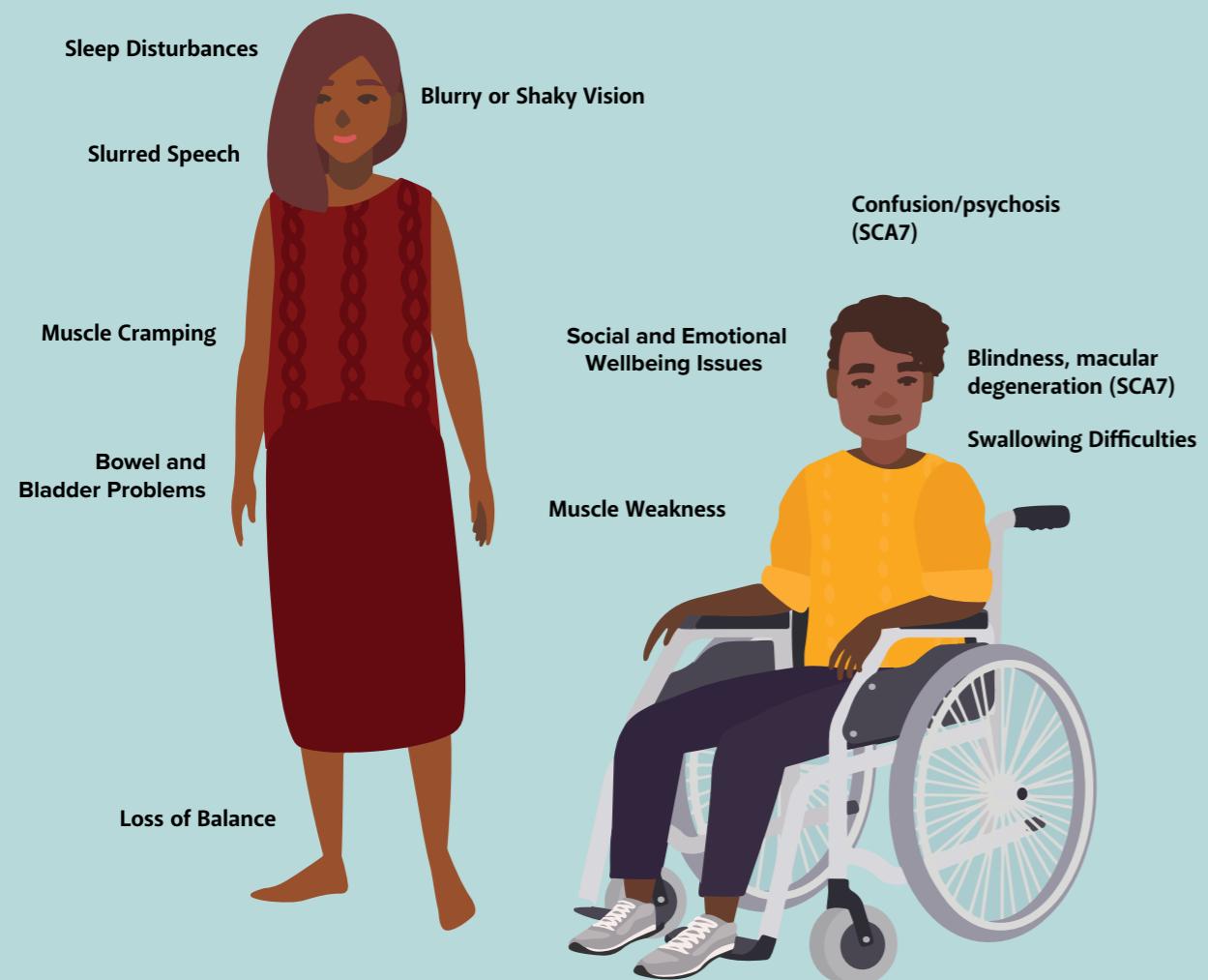
MJD occurs because of a fault in a chromosome that results in the production of an abnormal protein. This protein causes nerve cells to die prematurely in a part of the brain called the cerebellum. The damage to the cerebellum initially causes muscular weakness and progresses over time to a total lack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

MJD is an inherited, autosomal dominant disorder, meaning that each child of a person who carries the defective gene has a 50% chance of developing the disease.

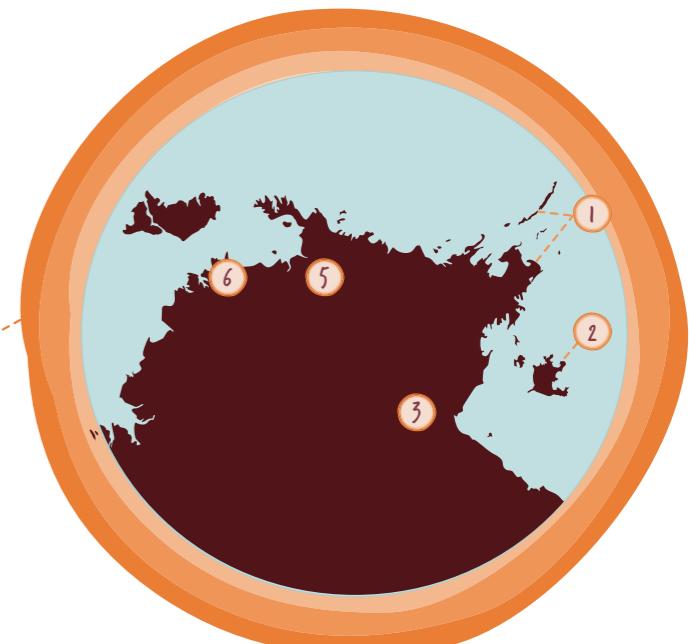
The mutation is typically expanded (worsened) when it is passed to the next generation (known as an 'anticipation effect'). Symptoms of the disease sometimes appear around 8 to 10 years earlier for each generation, and are more severe.

There is no known cure for MJD. Progression to dependence occurs over 5 to 10 years after the onset of symptoms, and most people are dependent on wheelchair use for their mobility and are entirely dependent on others for all activities of daily living within 10 to 15 years of the first symptoms emerging.

How MJD and SCA7 Affect your Body



Languages spoken by our clients, staff and families



1 East Arnhem	3 Roper River Region	5 West Arnhem
Gumatj Djambarrpuru Gupapuyngu Galpu/Golumala Datiwy Warramirri Wangurri	Kriol Marra Wubuy Anindilyakwa	Kriol Kunwinkju Andindilyakwa
2 Groote Eylandt	4 Central	6 Bagot Community
Anindilyakakwa Kriol Nunggubuyu / Wubuy	Arrente Eastern Arrente dialect Luritja Luritja / Arrente	Pigeon English
7 Cairns Region		Djabugay

MJD in Arnhem Land and Beyond

The effects of MJD have been known to the Aboriginal people of this region for at least four generations, although the first confirmed case was not diagnosed until 1995. Research that was released in 2012 used DNA Haplotyping and linked the genetic strain of MJD found in Australia to that found in Asia. Although it is impossible to predict the number of Aboriginal Australians who will develop MJD, there are currently over 790 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).

What is Spinocerebellar Ataxia Type 7 (SCA7)?

SCA7 is sometimes described by the MJD Foundation as 'like a cousin' to MJD, as it is in the same 'family' of diseases: the Spinocerebellar Ataxias (SCAs). Like MJD, it is also caused by a chromosomal abnormality, creating the buildup of a toxic protein which causes many of the same symptoms as MJD. However, SCA7 has the added burden of causing progressive blindness, especially for

people who show signs of the disease when they are young. The 'anticipation effect', described in MJD, is also more pronounced in SCA7, meaning there is an increased likelihood of subsequent generations having significantly earlier onset of symptoms and, like MJD, there is no known cure or medical treatment for SCA7.

The MJD Foundation was first introduced to SCA7 families in North QLD in 2017, however a more in depth engagement did not commence until 2020. Since 2017, the MJD Foundation has been working closely with families to compile the family tree (pedigree), which now spans seven generations and has over 250 family members that are potentially at risk of inheriting SCA7, with 17 confirmed cases.

In many ways, the situation with SCA7 in North QLD is similar to what we initially encountered on Groote Eylandt, and across the Top End, with MJD: a poorly understood disease that many health professionals, as well as family members, knew little about.

Our hope is that we can provide the SCA7 families, and those connected to them, with the same level of care and support as our MJD clients.

Strategic Overview (2018-2021)

Education

- 1 Improve the MJDF website (and other social media) engagement, design and content to make resources more accessible and readily understood.
- 2 Better target education through delivering in local language and gender specific mediums.
- 3 Collaboration with universities and other relevant partners.
- 4 Deliver genetic education and counselling in partnership with Victorian Genetic Services.

Community Services

- 1 Map and increase our capacity to deliver equitable supports across all communities where Aboriginal Australians live with MJD.
- 2 Ensure National Disability Insurance Scheme (NDIS) planning and implementation remains a priority to ensure best possible plans for clients.
- 3 Prioritise community capacity building projects for improved accessibility and transport options.
- 4 Conduct feasibility study with a Groote Eylandt consortium for Assistive Technology.

Research

- 1 Develop internal frameworks to support current and future research projects.
- 2 Increase international research linkages and partnerships.
- 3 Assess the Research Advisory Committee in terms of Terms of Reference and membership (including optimal composition and operation of the RAC).

Advocacy

- 1 Stakeholder analysis and engagement plan.
- 2 NDIS policy advocacy.
- 3 Publish MJDF's disability supports model.

Governance

- 1 Fundraising strategy to broaden MJDF income streams and projected NDIS income.
- 2 Workforce strategy across staff, board and volunteers including succession, recruitment and location (including skill diversity across locations), education/training and focused on increased Aboriginal staff collaboration (two-way working) across all activities.
- 3 Ongoing commitment to clients, carers and families being involved in the governance and operations of the MJDF Foundation at every level.
- 4 Increase community partnerships to deliver supports.
- 5 Increase infrastructure across MJDF sites including Ngukurr, Elcho and remote staff sites.
- 6 Include a Research Fund in the Fundraising Strategy.



Brett Mamarika and Melinda Lalara from Groote Eylandt, celebrating the launch of the MJD history book, 'Ngeniyerrinya'.

Highlights from the CEO

A Change of Guard

After over a decade of outstanding leadership, our Chairperson Neil Westbury stood down as Chair of the MJDF. We're not letting him go too far though, as per the unanimous request of all MJDF Board members, Neil has agreed to remain on the Board. We are very excited to welcome The Hon Jenny Macklin as our new Chairperson (from June 2021). It was during her time as Minister for Indigenous Affairs (2007-2013) that Jenny visited Groote Eylandt several times and began to understand the high prevalence of MJD and admire the work of the MJDF.

COVID-19

We've been fortunate that throughout 2020-2021, the MJDF and our clients/families have escaped most of the challenges of COVID-19, and in the NT and Far North QLD, we've not been largely impacted. Our COVID-19 safety plans are firmly in place; our PPE and operating protocols have changed forever; several staff members have enjoyed the facilities at Howard Springs Centre for National Resilience (COVID quarantine); we ran a 'who has had the most COVID tests competition'; and like everyone else, we have QR codes at all of our locations. We were getting a little blasé, and then boom! Darwin and Alice Springs locked down at the end of June, and then again in July. We are fortunate again (for now), but we're watching Sydney and Melbourne struggling with the Delta strain as we see the impacts on the unvaccinated members of society. In February 2021, the MJD Foundation Board mandated the COVID-19 vaccination for all staff, and we are actively dedicating resources to supporting our clients and families to get vaccinated. I am proud that we are well on our way to ensuring we can work safely with our clients/families, with 90% of staff vaccinated.

NDIS and Remote Australia

We continue to highlight the barriers and challenges to remote service delivery and communicate the policy and implementation issues relating to the NDIS in remote communities. We participate on several Boards, reference groups and communities of practices that present opportunities for raising these challenges, and we actively encourage the sharing of innovative remote service delivery solutions through our use of #RemoteAustraliaMatters across our social media platforms.

We are extremely grateful to our wonderful supporters like the Anindilyakwa Land Council, South32/GEMCO, GEAT, GEBIE, Sea Swift, ALPA and Youngcare, who enable us to be sustainable under the NDIS despite these challenges.

When our supporters step up to fund projects that are critically important to our clients, we have started a new hashtag #NDISdoesntpayforthis to further highlight key goals of our clients that are not met by their NDIS plans.

Highlights:

- **'Ngeniyerrinya'** — The History of Machado-Joseph Disease on Groote Eylandt'. This is a story of strength, and honours the lives of Groote Eylanders who have passed away from MJD. A launch of the book at Parliament House in June 2021 (generously hosted by Minister Selena Uibo) was a wonderful event. This publication was predominantly funded by the Anindilyakwa Land Council, along with a small grant from NT Library.
- **MJD HOUSE**, our wellbeing respite hub in Darwin, had great outcomes this year with the program at full capacity for part of the year. Most of our remote clients had the opportunity to rest, relax, access MJD specialist supports, and have fun. The goal is to keep our clients stronger for longer so they can remain living in, and cared for, in their remote communities. We were thankful to host several visitors through the year including: Minister Kate Worden (Minister for Disabilities), The Hon Vicki O'Halloran (The Administrator of the NT), South32 CEO Graham Kerr, and Minister Selina Uibo. We thank them for their interest and support of the program.
- **Research publications** — MJDF either published or was involved in the publication of 8 research publications this year. Topics included: communication for Yolŋu living with MJD; Staying Strong Toolbox; culturally safe clinical genetic services; culturally competent communication in Indigenous disability assessment; and potential drug treatments for MJD.
- MJDF successfully advocated to **overturn an NDIS pricing decision for Gunbalanya** NT, that would have seen the community's NDIS pricing reduced from 'very remote' to 'remote'.
- After being invited by families affected by SCA7 (Spinocerebellar Ataxia type 7) to visit Yarrabah in Far North QLD in 2018, this year we formally commenced our **SCA7 program**, with the aim of building trusted relationships with affected families, developing education resources, and working with families to understand how the MJDF can best support them.
- **MJDF Multipurpose Facility (Umbakumba) 'MJD School'** — we purchased this facility on Groote Eylandt and plan to transform it to provide intensive therapy for our clients, allied health student education, careworker education, family education and research opportunities.
- **Education** — despite wariness to travel and hold large face to face events, the MJDF managed to conduct 13 in-services for health professionals and 11 support worker workshops this year. We were also privileged to again conduct Flinders/CDU medical student training — a highlight of the year for our dedicated clients who attend as teachers, and delight in the opportunity to reiterate the importance of their culture and to teach the 'baby doctors'.
- We were thrilled that our very own Bakala was acknowledged as inspiration for the character of Sam in Trent Dalton's new book, **'All our Shimmering Skies'**.



Nadia Lindop,
Nick Kenny,
Kirsteen Daniels
and daughter
at Roper Bar.

- We welcomed our first Manager, Community Services who is permanently located in Alice Springs enabling us to increase the supports we provide to our clients/families living in Alice Springs, Papunya, Ntaria (Hermannsburg) and Ltyentye Apurte (Santa Teresa).

Thank you so much to our sponsors and partners who enable us to support our clients, provide education to health professionals and support workers, collaborate with researchers and lead our own research based on the priorities of our families.

And finally, we were devastated to lose three much loved clients in the past year. Thank you to their families for the graciousness shown to us in sharing significant cultural traditions. Thank you also to our dedicated staff members who are working through the vicarious trauma of these losses to remain passionate and committed to the work we do for our clients and families.

NADIA LINDOP OAM
CEO

Research

In the wake of the 2019 international MJD conference, we have moved into a phase of consolidating, bedding in longstanding projects, and presenting findings through peer-reviewed literature. However, the energy and sense of community produced by the conference have persisted, and collaborations with world-class researchers continue.

In the spirit of the global 'new normal', the MJD Foundation research team has also changed this year, with our dynamic and longstanding Research Officer, Desiréé La Grappe, moving on. Janine Ryan, who is already our MJDF genealogist, is our new Research Officer. Janine has spent a lot of time in remote communities, has put her 'ear' for our clients to good use, and has already spent countless hours transcribing and analysing interviews. This year, Libby Massey also relocated home to Groote Eylandt, to begin work with families living with MJD on Groote Eylandt. Her PhD project through JCU aims to improve understanding of family planning and reproductive technology acceptability for these families.

The academic component of our research into keeping families walking and moving around, conducted by community researchers Joyce Lalara, Gayangwa Lalara, Gwen Lalara and Jen Carr, concluded this year. Jen was awarded her PhD in June. Over the four years of the project, the team have produced four academic articles (three published to date) and established an enduring process to support people living with MJD. Their 'Staying Strong Toolbox' program is now available as best practice evidence to keep remote families stronger, healthier and happier.

Returning from maternity leave, Charles Darwin PhD candidate and Speech Pathologist, Rebecca Amery, along with a team of Yolŋu researchers, have continued to work through the complexities of developing first language augmentative and alternative communication tools to assist those people living with MJD who have lost speech. The team have published information about a suggested core vocabulary, and have also documented the design process in two journal articles currently undergoing peer review.

Zebrafish and mice are both now assisting Dr Angela Laird and her team at Macquarie University with the search for treatments to help people living with MJD. Angela's

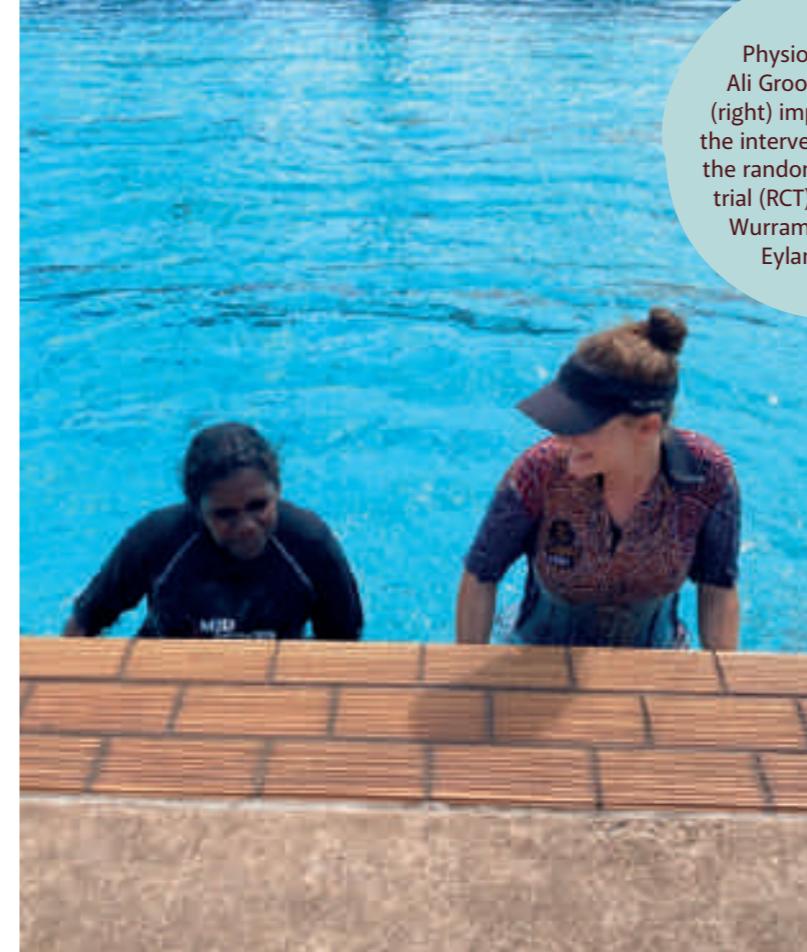
team focuses on four areas: (i) Medicines that are already approved and used to treat other similar conditions, (ii) new ideas for medicines, (iii) traditional or 'bush' medicine or natural products that the body already produces (such as from digestion), (iv) substances extracted from natural products. Publications from this year have focused on compounds with therapeutic benefits, and a review article within a special edition on Spinocerebellar ataxias.

Information about the complex sleep issues experienced by people living with MJD in remote communities will shortly be available for review, with the first of two papers now ready for submission. Quantitative information about the type and implications of sleep disorders has been presented in a standalone paper, with another to follow outlining the important contextual and environmental issues faced by our cohort.

In mid-2020, MJDF embarked on a new collaboration, the Achieving Equity in Genomic Health for Indigenous Australians (AEGH) project. The Medical Research Futures Fund's (MRFF) Genomics Health Futures Mission (GHFM) funded the project, which follows on from the Better Indigenous Genetic (BIG) Health Services project. It focuses on increasing the benefits of genomics for Aboriginal and Torres Strait Islander people by improving support for equity at both the health-service and health-system level.

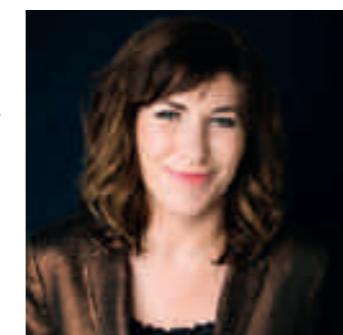
To better understand and respond to the impacts of COVID on our organisation, the research team also embarked on a small project funded by the Melbourne Disability Institute during 2020 and 2021.

The BIG, AEGH and COVID projects were led by the late Professor Margaret Kelaher from the University of Melbourne. Margaret sadly passed away in March 2021. We will remember her as a true friend of the MJDF, and an outstanding researcher and collaborator, determined to ensure equity in healthcare for First Nations peoples. We will miss her.



Physiotherapist Ali Grootendorst (right) implementing the intervention phase of the randomised control trial (RCT) with Liyandra Wurramara on Groote Eylandt.

Professor Margaret Kelaher, an outstanding researcher and a true friend of the MJDF.



Another MRFF project the MJD Foundation is participating in also commenced in early 2021. The randomised controlled trial (RCT) investigating rehabilitation for hereditary ataxias is the first, appropriately powered study, to assess the efficacy of an intensive, individualised rehabilitation program on improving motor function for adolescents and adults with HCA and draws participants from Melbourne, Sydney, Perth, Darwin, Groote Eylandt, Gunbalanya and Galiwin'ku. Recognising that an RCT design is essential for the future trial of treatments, but also that there are significant issues for participation for our clients, we added a preparatory component to the project. This additional study component has been designed to build the participant's capacity, knowledge and understanding of the research to facilitate genuine informed consent and maximise engagement. Libby, Desiréé and Janine conducted the part 1 components. Physiotherapist Ali Grootendorst has worked tirelessly across the locations implementing the intervention phase, currently scheduled for completion at the end of 2021.

Publications

Significant publications from the last year are:

Amery R, Wunungmurra JG, Gondarra J, Gumbula F, Raghavendra P, Barker R, Theodoros D, Amery H, Massey L, Lowell A, Yolŋu with Machado-Joseph disease: Exploring communication strengths and needs. International journal of speech-language pathology. 2020 Sep 2;22(5):499-510.

Carr JJ, Lalara J, Lalara G, Lalara G, Daniels B, Clough AR, Lowell A, Barker RN. Staying Strong Toolbox: Co-design of a physical activity and lifestyle program for Aboriginal families with Machado-Joseph disease in the Top End of Australia. Plos one. 2021 Feb 5;16(2):e0244311.

Dalach P, Savarirayan R, Baynam G, McGaughran J, Kowal E, Massey L, Jenkins M, Paradies Y, Kelaher M. 'This is my boy's health! Talk straight to me!' perspectives on accessible and culturally safe care among Aboriginal and Torres Strait Islander patients of clinical genetics services. International journal for equity in health. 2021 Dec;20(1):1-3.

Elsum I, Massey L, McEwan C, LaGrappe D, Kowal E, Savarirayan R, Baynam G, Jenkins M, Garvey G, Kelaher M. A community-based co-designed genetic health service model for Aboriginal Australians. PloS one. 2020 Oct 29;15(10):e0239765.

Ferdinand A, Massey L, Cullen J, Temple J, Meiselbach K, Paradies Y, Baynam G, Savarirayan R, Kelaher M. Culturally competent communication in Indigenous disability assessment: a qualitative study. International journal for equity in health. 2021 Dec;20(1):1-2.

Robinson KJ, Watchon M, Laird AS. Aberrant cerebellar circuitry in the spinocerebellar ataxias. Frontiers in neuroscience. 2020;14.

Watchon M, Robinson KJ, Luu L, Yuan K, Lee A, Cheng F, Don EK, Nicholson G, Laird AS. Treatment with sodium butyrate has therapeutic benefits for Machado-Joseph disease through the induction of autophagy. bioRxiv. 2021 Jan 1.

Watchon M, Luu L, Robinson KJ, Yuan KC, De Luca A, Suddul HJ, Guillemin G, Cole NJ, Nicholson GA, Chung RS, Lee A. Sodium valproate increases activity of the sirtuin pathway resulting in beneficial effects for spinocerebellar ataxia-3 in vivo. bioRxiv. 2021 Jan 1.



Central-Australian staff
Becky Page-Wood,
Dot Roach, Nancy Raggett,
Selvyia Sharpe, with the
visiting Director, Community
Services, Mark Kilpatrick.



Education

The MJDF has a range of resources and conducts educational events designed to strengthen the capacity of those who care for people with MJD. Since the MJDF commenced providing care to people living with Spinocerebellar Ataxia type 7 (SCA7) for Aboriginal people in North QLD, we have also started to develop resources specific to SCA7.

Despite continuing restrictions from the COVID pandemic and reduced opportunities to meet, we conducted 13 in-services for health professionals and 11 care worker workshops this year. This year we have also begun developing the care worker education resources into a stand-alone teachable module. Liz Willis has returned to the MJDF to lead this project, by which we aim to ensure that if face-to-face teaching sessions are not possible, care workers have access to the specific resources needed.

Informal, incidental and ongoing family carer education remains a necessary means of supporting people living with MJD. Community services staff conduct these sessions free of charge and ad hoc as the needs emerge.

Topics covered range from social and emotional to clinical and include PEG, sleep, transfers, safe swallowing, equipment use and care and genetics. Once again, we were also privileged to conduct annual medical student training for Flinders/CDU medical students – a highlight of the year for our dedicated clients who attend as teachers and delight in the opportunity to reiterate the importance of their culture, and to teach the ‘baby doctors’.

Our resources are readily available on the MJDF website and include links to previously completed materials, such as the:

- **Medical Protocols**
- **Family and Carer Help Sheets**
- **RAHC eLearning MJD module:**
<https://www.rahc.com.au/elearning>
- **Audiovisual presentations** – ‘Proper Approach’; ‘Clinical Approach’; genetics and carer resources; instructional manual handling and aircraft travel resources; genetics booklets.
- **MJDF Research Publications** – mobility, continence, NDIS, and communication.



MJDF's Senior Community Worker and Cultural Advisor, Elah Yunupingu, teaching Yolŋu bush medicine at the Darwin Staff Workshops.



Genetic Counsellor, Lindsay Tuer, with Davis and Cara from Ngukurr.

Genetic Counselling

Sadly, every year brings new confirmations of people in our families beginning their ‘official’ journey with MJD or SCA7 through genetic testing. In many cases, the results of genetic testing confirm years of suspicion.

The process of engaging sensitively with families, sharing information, and conducting testing in a manner that is appropriate to individual and family sensibilities is vital to effective engagement with people living with MJD. To do this requires stepping outside of the classic biomedical, outpatient, specialist model of service delivery.

Over the past 12 years, the MJDF has co-designed an effective model with families living with MJD and the Northern Territory Genetics Service (through VCGS). The client-led model incorporates a shared understanding, involves relationships, continuity and trust, and incorporates a family approach. It has been led by our

cohort and results in high levels of engagement. As one of our clients succinctly noted during the Better Indigenous Genomics (BIG) evaluation, ‘The ones I know, I can talk to them. But new ones, when they come in, I won’t talk to till I know them’. We remain committed to sharing and improving this model and are actively involved in research projects to achieve this.

We are now tasked with determining how to best assist the Far North QLD families as they grapple with emerging SCA7. Although the diseases are similar, the contexts are not, and the ways people choose to engage with support need to be determined by them and sensitive to that context. Moving forward, we have planned an ongoing detailed process of engaging with families and local health providers to tailor these supports.

Director, Research and
Education, Libby Massey,
with Roseanne Mirniyowan.



Community Services

The Community Services Team works alongside families affected by MJD and, more recently, Spinocerebellar Ataxia type 7 (SCA7) in Far North QLD.

Many of our staff are from affected families, or are themselves living with one of these diseases. We describe our relationship as a 'Two Way' approach, meaning that we learn from and are guided by our Senior Cultural Advisors, Aboriginal Community Workers, clients and extended families.

This model of working has its roots in the long-standing connection that the Massey family developed while living on Groote Eylandt, where MJD was first identified in NE Arnhem Land. The genesis of the MJDF was the close relationship between the Massey and Lalara families; and, while MJDF has grown over the years, we still place priority on trusted relationships with family, taking time to connect with clients, working respectfully within two cultures, and understanding the importance of listening and learning.

Working in this way means we develop friendships which go beyond 'the job'; we share our families' joys and sorrows, welcome new babies, watch children grow to adulthood, and grieve when people pass away.

This year has been particularly sad as we have lost three much-loved family members to MJD in a short space of time, one of whom was only 23-years old.

But, there have been many 'sparkling moments' as well: sharing stories and laughter, trips to beautiful places to connect with country, seeing the pride of people overcoming the challenges that MJD and SCA7 present, and most of all, experiencing the quiet grace that is so often present in our clients.

Undoubtedly, one of the most rewarding aspects of our work is the Kin Connect program, where we assist clients living in supported accommodation to return to their remote community. For people with complex personal care needs, this can be an enormous logistical challenge, as they can require 24-hour care. Our Operations, NDIS and Finance teams, external care organisations, GPs, CareFlight, local Land Councils, Clinics and Aged Care all need to be involved. But the evident joy we see from

clients and families when people are back On Country makes all the effort worthwhile. We have recently had much appreciated assistance from CareFlight to transport a young woman back to Galiwin'ku, and the CareFlight staff told us that it was one of their most rewarding experiences. One of the pilots even said he would come in on his day off to help out if needed.

Another valued activity we run is the MJD House program, which offers all of our clients, carers and families respite at one of our two Darwin-based houses. It is a wonderful opportunity for our clients and families from remote communities to spend time in Darwin, and we arrange outings, picnics, specialist therapy appointments, movies, shopping, and time to connect with other family members in town. But often our clients and their families just enjoy spending quiet time together, away from the pressures that can exist back home. Traditionally, respite has been geared towards 'giving the carers a break', meaning carers stay home while the client is cared for by others. But MJD House recognises that family connections are paramount, so we welcome carers along — and pamper them as well.

The Community Services team is made up of Physiotherapists, Occupational Therapists, Speech Pathologists, Nurses, Allied Health Assistants and Social Workers, as well as our valued Aboriginal Community Workers. We provide a broad range of clinical and cross-cultural skills, with unique expertise in MJD and SCA7. This is the basis of our Staying Stronger for Longer therapy program which currently runs in Darwin, Groote Eylandt, Galiwin'ku, Alice Springs and Cairns.

Often therapeutic programs concentrate on specific aims, such as improving muscle strength, but our approach is much more holistic. We encourage family members along, often going out 'On Country' to exercise, share food, go fishing, relax, and to enjoy the day. Our accessible 4WD vehicles mean that clients can get to places otherwise impossible to access, often culturally important areas that provide spiritual sustenance, which we recognise as being just as important as the physical therapy they engage in.



Mel and Bronwyn (Bowie) doing hydrotherapy at Ngukurr.

Whilst we utilise NDIS funding to support many of our activities, like our Staying Stronger for Longer and MJD House programs, this funding alone is not sufficient to support our Two Way approach. Most NDIS providers would be unable to fund these types of programs, so we rely on the ongoing support we receive from sponsors, donors, the ALC and others to continue to work in this way.

The MJDF also offers the Holiday of a Lifetime program to our clients, which has taken family members to the Gold Coast, Melbourne, Sydney and Cairns. Unfortunately, because of border restrictions, and risks around COVID 19, this program is on hold for now.

Recently it has become apparent that our fly-in-fly-out model of support in Central Australia has not been adequate to meet the increasing needs of our clients there, so we now have a full-time staff member based in Alice Springs. We have a shared-office space in the Anglicare NT building, and we are now better able to support our clients in town and at Papunya, Ntaria (Hermannsburg) and Ltyentye Apurte (Santa Teresa).

SCA7 is a similar condition to MJD and was recently identified in North Queensland. The MJD Foundation was asked to assist in working with SCA7 families in and around Cairns, and we now have a dedicated SCA7 Program. With the help of family members, we have completed extensive genealogies. As the disease is often poorly understood, we have provided education to local Medical, Allied Health and Care Providers and schools. We are reaching out to family members to offer support and education, often sitting with them to help them come to terms with a condition that they are only just beginning to understand.

The connection, support and friendship that the MJD Foundation makes with affected families is, in many ways, unique. And while there can, at times, be difficulties and sadness, it is also hugely rewarding, both for our staff and for the lovely people we are privileged to share the MJD/SCA7 journey with.

The MJD Foundation Board, Staff, Clients, Families, Volunteers and selected NT Ministers at 'Ngeniyerrriya – the History of MJD on Groote Eylandt' book launch, NT Parliament House, Darwin (June 2021).



'The model of support developed through the MJDF is exceptional in that it is a true collaboration and one that recognises that the impact of the disease in Aboriginal culture goes well beyond the individual and his or her personal journey.'

It is a recognition that the fabric of Aboriginal culture is maintained through a complex set of roles and responsibilities, and that these roles and responsibilities are fundamental to the wellbeing of the individual, family, and community.

It is the belief of the auditing team that the MJDF should be commended for their understanding of the importance of this fundamental right and the development of such a mutually respectful relationship between the participants, family, community and non-Aboriginal therapy and support teams. The audit team also recognises the important efforts of the MJDF in supporting the research and education necessary to maintain hope for the future.'

'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

Ngeniyerriya

the History of MJD on Groote Eylandt

When a mysterious illness started crippling Gayangwa Lalara's Groote Eylandt community in the 1960s and 70s, no one knew what was happening. Gayangwa watched nine of her siblings suffer from the effects of this strange illness – one by one, they started walking wobbly, and eventually, they lost their speech and all muscle control, resulting in complete dependence on others for all activities of daily living. Gayangwa and her family were heartbroken and desperate for answers.

The local Groote Eylandt People (Warnumamalya) originally referred to the strange disease that was affecting their people 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. Gayangwa's family felt strong feelings of shame and blame.

Kathy and Bryan Massey's family moved to Groote Eylandt in May 1970. As the years progressed, their work became more intensely involved with this group of families and individual people that were hurting. Kathy Massey's 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 this disease. Kathy said of this time: '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 ... 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!'

But, in 1995, Gayangwa's families received the answers they had been searching for; the genetic nature of the disease was finally realised, and it turns out that her family was suffering from Machado-Joseph Disease (MJD).

Gayangwa's nine siblings passed away from complications relating to MJD. Her and her sister, Gwen, are the only two remaining siblings. Today, many of their nieces, nephews and their children have MJD, and there are many more at risk of having the disease. On Groote Eylandt alone, there are now over 200 people at risk of having the disease — that is, people who are direct descendants of someone that was affected by MJD.



Gayangwa Lalara and her sister, Gwen Lalara.

Despite experiencing extraordinary sadness in her lifetime, Gayangwa has never given up hope, and in 2008, the MJD Foundation was born. Co-founders Gayangwa Lalara, Libby Massey and Nadia Lindop launched the Foundation on Groote Eylandt in 2008. The lives of those living with MJD on Groote Eylandt (and beyond) were changed. Gayangwa's 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.

'Ngeniyerriya' — a word in Anindilyakwa (the language of Groote Eylandt) used to express empathy towards someone that is experiencing sadness, difficulty or death — is the title of a short book that captures the story of Machado-Joseph Disease on Groote Eylandt. The collection of stories within this book offer an insight into the lives of Aboriginal people affected by MJD, their families, friends, carers and supporters, both before and after the MJD Foundation was established on Groote Eylandt in 2008. It is also a dedication to those people in Gayangwa's families affected by MJD that have already gone before us, so we can remember them and their stories — as well as their relentless efforts to fight and advocate for this disease for future generations.

Jenny Baird, wife of one of Gayangwa's brothers who had MJD, said about the book: '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.'

For more information on where to purchase the book, or to donate to the MJD Foundation, visit: www.mjd.org.au

Groote Eylandters Steve (Bakala) Wurramara and Daniel Lalara at the book launch.





Our People

Welcome to Country from Larrakia Nation Traditional Custodians – MJDF's Family on Country Day.

MJD Foundation Announces Appointment of New Chairperson

The MJD Foundation is pleased to announce the appointment of its new Board Chairperson, The Hon Jenny Macklin. This appointment follows the former Chairperson Neil Westbury's decision to stand down following 12 years in the position.

Jenny Macklin with Tony Wurramarrba and Gayangwa Lalara at the MJDF launch in 2008.



Responding to the MJDF Board's invitation, Ms Macklin stated 'I am greatly honoured to take up the role and am eagerly looking forward to continuing to support MJDF's critical work in the Northern Territory and Far North Queensland'.

Ms Macklin went on to pay tribute to all those who have come before and laid the basis for such a successful organisation, whilst also highlighting the importance of continuing to be guided by those individuals and families living with Machado-Joseph Disease.

Both MJDF's Deputy Chair Gayangwa Lalara OAM and Board member Tony Wurramarrba AO welcomed Ms Macklin's appointment. 'Jenny brings a wealth of experience combined with a strong personal commitment to the work of the Foundation. These qualities should prove invaluable going forward given the critical challenges being currently faced in relation to the NDIS and ongoing lack of infrastructure and services in remote communities', they both said.

Ms Macklin further stated, 'I am in the particularly fortunate position of joining a Board that includes significant expertise and that is well served by an outstanding CEO, and passionate and committed staff members'.

As per the unanimous request of all MJDF Board members, Mr Neil Westbury has agreed to remain on the Board. He stated 'It has been an enormous privilege and pleasure to have the confidence of the Board and hold the role of Chairperson of the MJDF for almost 12 years. MJDF is a remarkable organisation and I remain committed and willing to stay on the Board as a Director to continue to provide whatever support I can'.



The MJD Foundation Board; the Hon Jenny Macklin (centre front) is the new Board Chairperson.

Board 2020-2021

Jenny Macklin
Neil Westbury PSM
Gayangwa Lalara OAM
Janice Oake
Tony Wurramarrba AO
Jennifer Baird
Jennifer Cullen
Prof Patrick Keyzer
Vacant
Vacant

50% Aboriginal

'When I saw the list of names here on this meeting paper, the staff working together and our clients, it makes me happy to see. All of us are doing a tremendous job, working so good together, to make life better for our clients, and even for ourselves as staff. I am happy just as it is now.'

– GAYANGWA LALARA OAM
SENIOR CULTURAL ADVISOR
AND VICE CHAIRPERSON

Staff 2020-2021

Executive Management Team

- Nadia Lindop OAM – Chief Executive Officer
- Libby Massey OAM – Director, Research & Education
- Melinda Fajerman – Director, Community Services (outgoing)
- Mark Kilpatrick – Director, Community Services (incoming)
- Gayangwa Lalara OAM – Senior Cultural Advisor
- Kim MacDonald – Chief Operating Officer

Management Team

- Mel Asendorf – NDIS Manager
- Alison Grootendorst – Therapy Program Manager
- Zeng Jones – Finance Manager
- Mark Kilpatrick – SCA7 Program Manager
- Morag MacLennan – Operations Manager
- Dave Martin – Manager, Darwin Community Services Team
- Rebecca McCue – Manager, Continuous Improvement
- Caitlyn Morrissey – MJD House Manager
- Jennifer Telfer – Chief Finance Officer
- Julie Wunungmurra – Cultural Advisor/Community Worker
- Elah Yunupingu – Cultural Advisor/Community Worker



Elah and
Mitch cooking
kangaroo tail
and root vegetables
in Gundirri – MJD's
Family On
Country Day.

Staff

- Genevieve Agostinelli – Manager, Community Services
- Rebecca Amery – Therapist
- Kayte Bennett – Manager, Community Services
- Adam Brooks – Trainee Finance Officer
- Laylah Bukulatjpi – Community Worker
- Leah Clarke – Manager, Community Services
- Bronwyn Daniels – Community Worker
- Olga Daniels – Community Worker
- Susan Dickie – Manager, Community Services
- Gillian Edmiston – Family Support Worker
- Jayde Freeman – Family Support Worker
- Loretta George – Community Worker
- Joanne Gondarra – Community Worker
- Mitchell Harman – Family Support Worker
- MaryLisa Herbert – Community Worker
- Tina Hebblewhite – Admin/Procurement Officer
- Colleen Kenny – Family Support Worker
- Chris Kenny – Family Support Worker
- Desireé LaGrappe – Research Officer
- Alvina Lalara – Community Worker
- Gwen Lalara – Co-Researcher/Community Worker
- Joyce Lalara – Co-Researcher/Community Worker
- Louise Lethbridge – Family Support Worker
- Nikki Li – Finance Officer

- Brett Mamarika – Community Worker
- Kerstal Mamarika – Community Worker
- Bryan Massey – Family Support Worker
- Kathy Massey – Special Projects Officer
- Jacob McCue – Manager, Community Services
- Jess Meagher – Manager, Community Services
- Wyam Morris – Manager, Community Services
- Vickerina Nganjmirra – Community Worker
- Rebecca Page-Wood – Manager, Community Services
- Kate Pope – Manager, Community Services
- Nancy Raggett – Community Worker
- Stacey Reilly – Senior Administrative Officer
- Dot Roach – Family Support Worker
- Billie Russo – NDIS Client Services Assistant
- Janine Ryan – Genealogist/Research Officer
- Tamara Shepherd – MJD House Coordinator
- Jillian Turner – Manager, Community Services
- Rachael Turner – Manager, Community Services
- Maria Valdivia – Bookkeeper
- Diana Warford – NDIS Client Services Support Officer
- Tommy Weetra – Community Worker
- Liz Willis – Education Officer
- Steve Wurramara – Community Worker
- Lisa Yidawuku – Community Worker

Patrons

- Prof Garth Nicholson
- Bryan Massey OAM
- Kathy Massey OAM

Finance Sub-Committee

- Janice Oake (Chair)
- Greg Creecy
- David Conley
- Nadia Lindop OAM

Research Advisory Committee

- Peter Fisher OAM (Chair)
- Libby Massey OAM
- Desirée La Grappe/Janine Ryan (Secretariat)
- Jennifer Cullen
- Prof Patrick Keyzer
- Prof Jorge Sequeiros
- Prof Garth Nicholson
- Prof Deb Theodoros
- Prof Emma Kowal
- Prof Wieland Huttner
- Dr Howard Flavell

Risk Sub-Committee

- Anne De Salis (Chair)
- Janice Oake
- Nadia Lindop OAM
- Asia Lenard
- Rebecca McCue (Secretariat)

COVID-19 Sub-Committee

- Neil Westbury PSM (Chair)
- Prof Patrick Keyzer
- Anne De Salis
- Janice Oake
- Nadia Lindop OAM (Secretariat)
- Jennifer Cullen

Fundraising & Income Generation Sub-Committee

- Prof Patrick Keyzer (acting Chair)
- Nadia Lindop OAM
- Libby Collins
- Rebecca McCue (Secretariat)

Volunteers

As well as our Board Directors and Subcommittee members who are all volunteers we want to thank our amazing volunteers who continue to support our clients/families.

As at 30th June 2021:

45% Aboriginal

15% Living with Disability

90% Female

33 Full Time Equivalents (FTE)

Our Partners/Sponsors

Partners



Sponsors/Donors



Grants/Funders



MJDF Darwin staff with Minister Selena Uibo, who visited MJD House (Darwin) in May 2021.

Partners

Anindilyakwa Land Council, Miwatj, Yugul Mangi, Danila Dilba, Anglicare NT, VIC Clinical Genetics Services

Sponsor/Donor Organisations

South32 (GEMCO), Groote Eylandt & Bickerton Island Enterprises, Anindilyakwa Land Council, Groote Eylandt Aboriginal Trust, Telstra Foundation, Sea Swift, Groote Eylandt Lodge, Arnhem Land Progress Association (ALPA), Overgrove P/L, Gilbert + Tobin, Hall & Wilcox, Allens Lawyers, Traditional Credit Union, Share the Dignity, Hutsix, AdaptaLift GSE, Mercure Darwin Airport Resort.

Grants/Funding

Federal Department of Health, NT Government Community Benefit Fund, Youngcare, NT Department of Health, NT Department of Industry, Tourism & Trade, NT Primary Health Network, National Disability Insurance Agency (NDIA), Murdoch Children's Research Institute, University of Melbourne.

Donors

Thanks to all our wonderful donors who have generously supported us throughout the year. Special thanks to Anna's Mob; Ten Summits Challenge; Janine Agzarian; Leanne Baird; Janette Culbert; Prof Bart Currie; Anne De Salis; Judy Hanan; WR Hearn; Roger Livsey; Sarah MacMillan; Elizabeth Milewicz-Tyson; John Payne & Janice Oake; Laura Rademaker; Lorraine Richardson; Matthew Stormont; Christine Sullivan; Michael Turbett; James & Isobel Walker; Students Association of Rural & Remote Health.

Sponsors Spotlight

Sea Swift has been a gold sponsor of the MJDF since acquiring Toll Marine Logistics in late 2014. Sea Swift's support has been a key factor in improving the quality of life for Aboriginal Australians and their families living with Machado-Joseph Disease in North East Arnhem Land.

Sea Swift provides the MJDF with in-kind freight support from Darwin to Elcho Island and Groote Eylandt. MJDF CEO Nadia Lindop says 'Our partnership with Sea Swift has been critical in enabling us to overcome many of the barriers faced in delivering remote community services. Without the support of Sea Swift over so many years, we would simply not be able to do the things that are so critically important to our clients'.

Some of the recent activities Sea Swift has supported through in-kind freight include:

- Supporting a young client's Kin Connect back to Galiwin'ku (Elcho Island) by freighting the essential equipment she needed for her visit. Kin Connects are one of our most important programs, providing an ongoing connection for clients who have moved into Darwin due to their MJD progression and can no longer live in their remote community.
- Shipment of trial assistive technology such as motorised scooters/wheelchairs so that a Groote Eylandt client could trial this equipment in their home community.
- Freighting a new Wheelchair Accessible bus to Groote Eylandt.



MJDF Darwin staff, clients and family join Sea Swift staff at the Sea Swift barge, Francis Bay, Darwin.

Money Story



Mel Asendorf, Selvia Sharpe, Zeng Jones and Billie Russo,
enjoying the Darwin dry season.

STATEMENT OF PROFIT OR LOSS AND OTHER COMPREHENSIVE INCOME FOR THE YEAR ENDED 30 JUNE 2021

	Note	2021	2020
		\$	\$
REVENUE	7	7,569,563	4,266,580
Administration Fees		(66,030)	(51,008)
Advertising & Marketing		(57,755)	(19,490)
Bank Charges		(1,974)	(2,334)
Bad Debts		–	(74)
Computers & Office Supplies		(33,669)	(27,875)
Clients Care & Support		(1,823,265)	(841,061)
Depreciation Expenses	8	(212,451)	(183,785)
Employment Expenses		(2,684,586)	(1,928,904)
Freight, Print & Postage		(9,641)	(7,793)
Insurance		(15,232)	(9,651)
Interest		(5,735)	(6,913)
Legal & Accounting		(37,190)	(13,088)
Assets Written Off		(564)	–
Medical Research & Resources		(52,582)	(54,668)
Motor Vehicle Expenses		(89,374)	(79,219)
Office Building Expenses		(26,902)	(28,454)
Rent & Storage		7,573	9,767
Repairs & Maintenance		(10,110)	(12,534)
Travel		(357,012)	(360,921)
Other Expenses		(167,845)	(180,301)
Total Expenses		(5,644,344)	(3,798,305)
Profit for the year		1,925,219	468,274
Other Comprehensive income for the year		–	–
Total comprehensive income for the year		1,925,219	468,274
Total comprehensive income attributable to the entity		1,925,219	468,274

STATEMENT OF FINANCIAL POSITION AS AT 30 JUNE 2021

	Note	2021	2020
		\$	\$
CURRENT ASSETS			
Cash & Cash Equivalents	15(a)	623,283	1,059,082
Receivables	9	1,209,246	937,864
Other Assets	10	25,548	40,045
Investments	11,4	21,877,082	19,910,815
TOTAL CURRENT ASSETS		23,735,159	21,947,805
NON-CURRENT ASSETS			
Property, Plant and Equipment	12(a)	987,410	950,664
Right of Use Asset	12(b)	140,581	175,836
TOTAL NON-CURRENT ASSETS		1,127,991	1,126,500
TOTAL ASSETS		24,863,150	23,074,305
CURRENT LIABILITIES			
Trade & Other Payables	13 (a)	301,078	357,907
Contract Liabilities	13(b)	80,085	135,322
Lease Liability		69,604	66,810
Provisions	14	257,611	240,611
TOTAL CURRENT LIABILITIES		708,377	800,651
NON-CURRENT LIABILITIES			
Lease Liability		72,819	106,099
Provisions	14	16,797	27,617
TOTAL NON-CURRENT LIABILITIES		89,616	133,717
TOTAL LIABILITIES		797,994	934,368
NET ASSETS		24,065,156	22,139,937
EQUITY			
Retained Earnings		24,065,156	22,139,937
		24,065,156	22,139,937

STATEMENT OF CHANGES IN EQUITY FOR THE YEAR ENDING 30 JUNE 2021

	Note	Retained Earnings
		\$
Balance at 1 July 2019		21,671,663
Profit attributable to the entity		468,274
Total other comprehensive income for the year		-
Balance at 30 June 2020		22,139,937
Balance at 1st July 2020		22,139,937
Profit after income tax expense attributable to the entity		1,925,219
Total other comprehensive income for the year		-
Balance at 30 June 2020		24,065,156

STATEMENT OF CASH FLOWS FOR YEAR ENDED 30 JUNE 2021

	Note	2021	2020
		\$	\$
Cash Flows from Operating Activities			
Grants, sponsorships and donations received		1,187,634	1,577,934
Receipts from operations		3,569,498	1,798,484
Payments to suppliers and employees		(5,639,104)	(3,288,575)
Interest received		30,077	60,070
Dividends received		763,571	761,097
Interest on leases		(5,735)	(6,913)
Net cash (used in)/provided by operating activities	15(b)	(94,059)	902,097
Cash Flow from Investing Activities			
Payment for property, plant and equipment		(165,186)	(317,352)
Proceeds from sale of investments		(2,770,305)	(85,666)
Payment for purchase of investments		2,672,995	-
Net cash used in investing activities		(262,496)	(403,018)
Cash Flow from Financing Activities			
Repayment of leases		(79,244)	(53,059)
Net cash used in financing activities		(79,244)	(53,059)
Net (decrease)/increase in cash held		(435,799)	446,020
Cash at beginning of the year		1,059,082	613,062
Cash at end of the year	15(a)	623,283	1,059,082

For full Financial Statements including notes, please visit the Resources tab of www.mjd.org.au



Nexia Sydney Audit Pty Ltd
Level 16, 1 Market Street
Sydney NSW 2000
PO Box H195
Australia Square NSW 1215
P +61 2 9251 4600
F +61 2 9251 7138
E info@nexiasydney.com.au
W nexia.com.au

Independent Auditor's Report to the Members of MJD Foundation Limited

Report on the Audit of the Financial Report

Opinion

We have audited the financial report, being a special purpose financial report, of MJD Foundation Limited (the Company), which comprises the statement of financial position as at 30 June 2021, the statement of profit or loss and other comprehensive income, statement of changes in equity and statement of cash flows for the year then ended, and notes to the financial statements, including a summary of significant accounting policies, and the directors' declaration.

In our opinion, the accompanying financial report of the Company is in accordance with the Australian Charities and Not-for-profits Commission Act 2012, including:

- i) giving a true and fair view of the Company's financial position as at 30 June 2021 and of its financial performance for the year then ended; and
- ii) complying with Australian Accounting Standards to the extent described in Note 2, and Division 60 of the Australian Charities and Not-for-profits Commission Regulation 2013.

Basis for opinion

We conducted our audit in accordance with Australian Auditing Standards. Our responsibilities under those standards are further described in the 'auditor's responsibilities for the audit of the financial report' section of our report. We are independent of the Company in accordance with the ethical requirements of the Accounting Professional & Ethical Standards Board's APES 110 *Code of Ethics for Professional Accountants (including Independence Standards)* (the Code) that are relevant to our audit of the financial report in Australia. We have also fulfilled our other ethical responsibilities in accordance with the Code.

We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our opinion.

Emphasis of matter regarding basis of accounting

Without modifying our opinion, we draw attention to Note 2 to the financial report, which describes the basis of accounting. The financial report has been prepared for the purpose of fulfilling the directors' financial reporting responsibilities under the Australian Charities and Not-for-profits Commission Act 2012. As a result, the financial report may not be suitable for another purpose. Our opinion is not modified in respect of this matter.

Directors' responsibility for the financial report

The directors of the Company are responsible for the preparation of the financial report that gives a true and fair view and have determined that the basis of preparation described in Note 2 to the financial statements is appropriate to meet the requirements of the Australian Charities and Not-for-profits Commission Act 2012 and is appropriate to meet the needs of the members. The directors are also responsible for such internal control as the directors determine is necessary to enable the preparation of

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the financial report that gives a true and fair view and is free from material misstatement, whether due to fraud or error.

In preparing the financial report, the directors are responsible for assessing the Company's ability to continue as a going concern, disclosing, as applicable, matters related to going concern and using the going concern basis of accounting unless the directors either intend to liquidate the Company or to cease operations, or have no realistic alternative but to do so.

Auditor's responsibility for the audit of the financial report

Our objectives are to obtain reasonable assurance about whether the financial report as a whole is free from material misstatement, whether due to fraud or error, and to issue an auditor's report that includes our opinion. Reasonable assurance is a high level of assurance, but is not a guarantee that an audit conducted in accordance with the Australian Auditing Standards will always detect a material misstatement when it exists. Misstatements can arise from fraud or error and are considered material if, individually or in the aggregate, they could reasonably be expected to influence the economic decisions of users taken on the basis of this financial report.

A further description of our responsibilities for the audit of the financial report is located at The Australian Auditing and Assurance Standards Board website at: www.ausab.gov.au/auditors_files/ar4.pdf. This description forms part of our auditor's report.

Nexia Sydney Audit Pty Ltd

Brett Hanger
Director

Dated at Sydney, this 30th day of October 2021

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staying stronger for longer



MJD Foundation's Nadia Lindop and Gayangwa Lalara discuss COVID-19 vaccination options.

COVID-19 Vaccine Roll out

Darwin team COVID vax compilation.



There is no doubt that the communities that saw a larger initial uptake of vaccinations by our clients were the ones where MJDF staff and clients shared the experience of COVID-19 vaccinations together. By supporting clients to be able to access the vaccination hubs, talking about the vaccinations in English and first languages, and building on our ethos of trusted relationships and two-way learning/working, this had direct outcomes on vaccination numbers. And we had a bit of fun too!

The MJDF's Board and Executive Management Team are committed to ensuring the safety of our clients, and should COVID-19 make its way to remote communities, we want to ensure we've done everything we can to support our clients/families to be vaccinated. We are mobilising our workforce where possible to prioritise support to get the vaccination, and in some cases varying our community visit schedules (to those communities we fly-in-fly-out to) to align with vaccination hub timetables. It has been challenging to access information on the vaccination hub schedules per community, and we will continue to work collaboratively with Government, Aboriginal Medical Services and other organisations to receive this information.



Alison Yunupingu –
Physiotherapy in Galiwin'ku.

Our stories



Young Carer Pamper Day

Often our young mob don't get the recognition they deserve, and so for 'National Carers Week' in October 2020, MJDF decided to celebrate our young carers by having a pamper day in the Darwin Office. Multiple different stations were set up, and there was a hair salon, a nail station, some foot spas, and a make-up zone. There was also lots of music, dancing and laughter! Many young people attended the event, and everyone left feeling relaxed and rejuvenated. Claudius said about the day: 'Yow manymak! It made me feel happy and I enjoyed it'.



Certificate II in Health Research

MJD Foundation's staff Laylah, Vicky and Jess have completed 75% of a Certificate II in Health Research at Menzie School of Health Research. To complete the course, and to put their newly learnt research skills to work, the three students are designing an informative poster to put up in Centrelink staff rooms about 'Wobbly Walking and MJD'.



Bininj Kunwok Language Lessons

Caitlyn and Leah have started their Bininj Kunwok language online short course, with help from teacher Vicky — 'the best teacher ever!', both Caitlyn and Leah have said.

Bininj Kunwok means the 'people's language'. It is the name given to a family of Indigenous languages spoken by around 2000 people in West Arnhem Land, Northern Territory. This includes Gunbalanya, where Vicky is from. Leah said: The word I have been practising is not big, does not look hard: 'mah bonj', which means 'that's it, finished', but Vicky is very particular about us pronouncing the 'nj' sound correctly and well — ask Vicky, but my pronunciation is still maybe 6/10. My next word I want to master is: 'yiyawooyhyimen', which means 'say it again'.



Steve (Bakala) Wurramara, the inspiration for the character of Sam in Trent Dalton's 'All our Shimmering Skies', alongside Nadia Lindop.



Daniel Lalara joining the MJDF team 'On Country' at Buffalo Creek, Darwin.

Improving Beach Access

The MJDF purchased a beach roll out mat/ramp in Darwin to ensure our clients can enjoy the experience of getting onto the beach and getting their feet in the sand.



Billie, fifth from the right, at the GTNT Awards Ceremony with her family and MJDF staff.

Congratulations Billie Russo!

Congratulations to our NDIS Client Services Assistant, Billie Russo, on completing her Certificate III in Business at Charles Darwin University, and for being nominated as a GTNT Award Finalist 2021. We are so proud of you, Billie!



Seena, Dot, Nancy and Becky out On Country at Honeymoon Gap, 20km west of Alice Springs.

A New Office in Alice Springs!

We welcomed our first Manager, Community Services who is permanently located in Alice Springs (Becky Page-Wood), enabling us to increase the supports we provide to our clients/families living in Alice Springs, Papunya, Ntaria (Hermannsburg) and Ltyentye Apurte (Santa Teresa).

Tributes

Tribute to Brian 'Blue'

12 February 1948 — 13 April 2021 (73 years)

NICK KENNY

Brian was born in the old hospital at Roper Mission on 12th Feb 1948. He spent his childhood playing with his siblings out bush. His older brother always looked after Brian, and he used to carry him around on his back. Brian always looked up to his brother, and followed him around everywhere. They were best mates right up until they were both old men.

Brian met Holly in his 20's, and they quickly fell in love. Brian and Holly married in the St Matthew Ngukurr church. They had their first daughter, Dawn, in 1965. Three years later Bronwyn was born.

Bronwyn says that he was the best father. He used to say 'come on Bronwyn, we gotta go', and he used to put her on his shoulders and take her wherever he had to go. When Bronwyn was 7, Holly left and Brian brought the girls up by himself. He taught Dawn and Bronwyn many things, like how to cook damper, how to play the guitar and harmonica, and how to sing. He used to sing lots of Torres Strait Island songs, and he was a base player for the local community gospel band.

At about 30, Brian had a bad horse-riding accident, and he stopped working as a Jackaroo and started working as a teacher. He was a great teacher, and he taught many kids in the community and out in the bush at Ngalawan. He used to teach them maths by counting stones and sticks. All the kids loved being taught by Brian. He enjoyed teaching the kids too, and he went to Batchelor College to become a qualified teacher.



Brian also helped John Sentifer translate the bible into local language. Later he went to QLD to preach the gospel to other communities. He also went to Singapore, Bali, Thailand and Kuala Lumpur to continue teaching kids overseas who didn't have access to good teachers. Brian was the first registered Indigenous teacher from the NT to travel overseas and work as a teacher.

When Brian returned, he retired from teaching and spent his time with his family in Ngukurr and his new granddaughter Danielle. He kept on helping young people with their education, right up to when he was an old man.

As his MJD got worse, he needed to use a wheelchair but that didn't stop him getting around. He would drive the wheelchair everywhere – to the shops, to the billabongs and throughout the streets asking everyone he passed for smokes. Brian's wheelchair had a life of its own – it was always breaking down, and he was always trying to fix it with his bush skills. It was always covered in tape, rope and fishing line trying to keep it together. It was like a wild horse that never got tamed.

Brian was a great man; a kind man and he never said a bad word about anyone. He accepted and loved everyone in his family which is a life lesson we could all learn from him.

We will miss you old Blue Sea. You have left us lots of good memories and we love you.

Tribute to Ngalwakadj - S.Thompson



18 May 1967 — 19 June 2021 (54 years)

VICKIRINA NGANJMIRRA

Unfortunately this year our MJD family lost a very lovely, kind, determined and strong woman that always loved going on outings and being with me (her daughter) at Bagot Community.

She always wanted to go visiting families at Ngukurr for her next Kin Connect trip, but sadly this did not happen.

She loved to have a laugh/make fun in a good way being around with families in Bagot. Even though she lived at Alawa House, she always came to Bagot to relax, catching up on gossip and seeing other families from Gunbalanya when they were in town.

She had close relationships with her carers, especially Ashley at Alawa House, who worked and spent time with her over many years.

We will always remember this strong woman who taught us how to be resilient and determined over the years of her life.

She and her sisters, Stephanie and Una, were very close to each other. Growing up until now, they lost their little sister, which has left them broken hearted.

I will always remember my mum as a strong, determined woman that always wanted to go do stuff on her own, even though I was worried for her. I told her there is no one there to push you/help you. She would do that angry face and might even yell at me. That was her. But she was loving, kind and always helped me and my son out with food or power for my house in Bagot.

When she went for Kin connect, she always remembered to take stuff (like lollies/salty plums/KFC) for her two grandkids and sister in Gunbalanya.

We will miss her dearly and remember her.

MJD family will remember her always, and we feel sad for those that never got the chance to meet her and see her lovely smile.

Ngalwakadj – S.Thompson at Umbakumba shops, Groote Eylandt NT (circa 1990s)



Tribute to Wamutjan

14 May 1998 — 21 August 2021 (23 years)

JULIE WUNUNGMURRA

This year we lost our lovely young woman who we all knew by her nickname 'Barbie Girl', because she loved that song so much.

Barbie Girl was the only daughter for Peter Garrawurra and Katrina Burarrwanga and much loved sister of Jordan, Delf, Samuel & Matthew Garrawurra.



Barbie Girl will be remembered as a loving, kind and always smiling young woman who loved her family with all of her heart.

Barbie Girl especially loved her Grandfather and one of her last memories was being able to go home to Echo Island and pay her final respects to him.

We will miss your smile, and we will miss you so much beautiful Nyoka.

'Gudbinji'

— a Kriol Word from Ngukurr

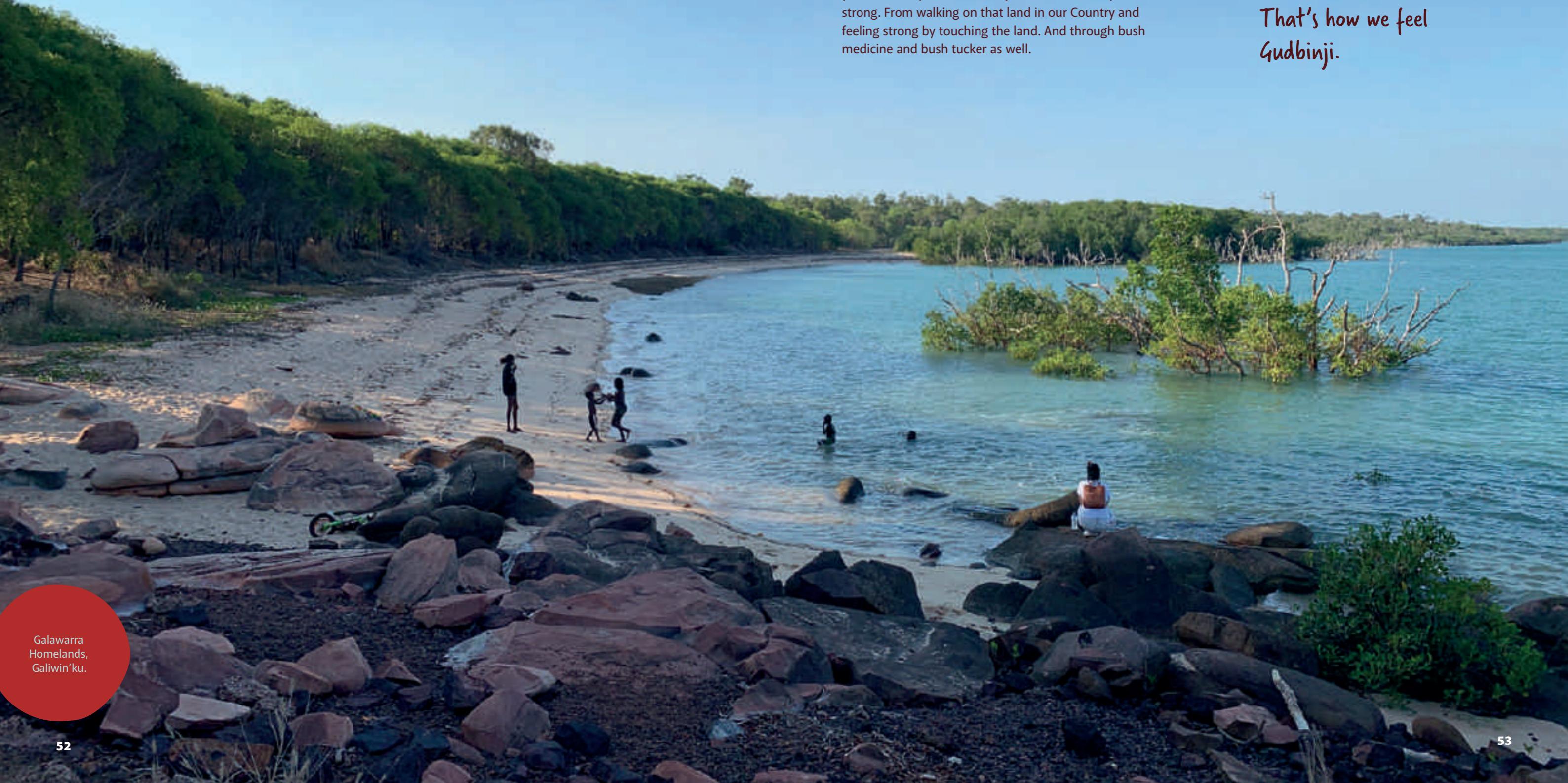
— BOWEY DANIELS, AND HER COUSIN YVETTE

Gudbinji makes you feel good inside: the spiritual feeling when you go back to Country, and you want to stay there. By cooking damper and fish in the fire, the smell from the fish comes out from the fire, and long neck turtle too, and even the damper.

You feel at home, that you are in your own country. Happy inside. Like when you haven't seen someone for a long time and you reconnect with them. You go and lie down next to the river, when you go to your Country you feel free: you feel Gudbinji, and that makes you feel strong. From walking on that land in our Country and feeling strong by touching the land. And through bush medicine and bush tucker as well.

Gudbinji is like a medicine — when you feel sick you go to Gudbinji. You feel proud of where you come from and who you are.

That's how we feel Gudbinji.



In June 2021, Kathy joined Bryan in retirement after working for the MJDF since its inception in 2008. They won't be able to stay away though — they're already volunteering to support clients on Groote!

Kathy Massey OAM and Bryan Massey OAM have worked with Groote Eylandt families living with MJD for over 50 years.



Kathy & Bryan Massey A Lifelong Dedication



Thanks to South32/
GEMCO for funding the
publication of this
annual report.



DONATE HERE

BACK COVER
Steve (Bakala) Wurramara.

FRONT COVER
Melinda's visit to MJD House,
with a stop-in at the office
with Mog.
INSIDE FRONT COVER
Bush Medicine – Ngukurr.

Thank You

Thank you to everyone who has supported the MJD Foundation to enable us to continue to make a positive impact on the lives of people living with MJD and SCA7.



MJDF October 2020 Staff Workshops —
on Zoom with 43 staff, and across 5 locations.



MJD Foundation

DARWIN

PO Box 1745
Nightcliff
NT 0814

GROOTE EYLANDT

PO Box 414
Alyangula
NT 0885

CAIRNS

PO Box 606
North Cairns
QLD 4870

www.mjd.org.au
1300-584-122
ABN: 65 159 208 867

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