



ANNUAL REPORT
2019 -2020



TABLE OF CONTENTS

Key Achievements	01-02
Message from the Chair	03-04
<hr/>	
About Us	05-06
What is MJD?	07
Epidemiology	08
<hr/>	
Our Strategy	09-10
Strategic Overview	11-12
CEO Report	13-14
<hr/>	
Our Work	15-16
Research	17-18
Education	19
Genetic Counselling	20
Community Services	21-22
<hr/>	
People and Partners	23-24
Our Team	25-26
Our Stories	27-32
Tribute to Anna Michael	33-34
<hr/>	
Money Story	35
Financials	36-39
Audit Report	40
<hr/>	
Acknowledgements	41-42



STAYING STRONGER,
FOR LONGER

Talisha with a long-necked turtle, Gunbalanya

KEY ACHIEVEMENTS

- Establishment of MJD HOUSE wellbeing hub in Darwin
- USA International MJD Conference
- Shared stories with Disability Royal Commission
- Opening of MJDF Cairns office
- MJDF CEO elected to National Disability Services (NDS) Board
- Youngcare visit to Groote Eylandt
- Wheelchair maintenance workshop ATLab
- Establishment of our Fundraising & Income Generation Subcommittee (FIGS)
- Board visit to Yarrabah (FNQ) meeting with families affected by SCA7



MESSAGE FROM THE CHAIR

In one way or another, everyone has had their lives impacted in facing the challenges of the world-wide spread of COVID-19. The people at MJDF are no different except in one crucial aspect, that being the well-publicised potential catastrophic consequences if the virus had spread into remote communities.



The fact that this has not occurred (to this point) is largely to the credit of Indigenous leaders such as Patricia Turner AM, the CEO of NACCHO, who along with a number of others pressured governments to enforce an effective lock down in remote communities at the earliest opportunity.

I am particularly proud of the MJDF's response as well. This included adoption of an effective risk management strategy oversighted by a Board Sub-Committee which convened weekly to support and provide guidance to the CEO. As the CEO highlights in her report, that MJDF was able to adapt its operations and retain all its staff throughout the NT and QLD lock down period is testament to its sound governance and effective risk management plan implementation, committed staff and a highly capable CEO. Notwithstanding, MJDF remains on continuing alert regarding the potential re-emergence of the virus in remote Australia. The Board will also be evaluating the lessons learnt and seek to ensure MJDF maintains effective planning for this and other likely pandemic events in the future.

Turning to other highlights, in November 2019, on the back of the International Ataxia Conference held in Washington DC, the MJD Foundation hosted an International MJD conference, bringing researchers and MJD clients from around the world to share progress in current and potential treatments and directly hear the views of clients.

The latter conference highlighted MJDF's growing worldwide leadership role in supporting practical and theoretical research into the disease and in coordinating its own efforts with other international researchers. It also shed further light on the exciting yet challenging impact of the explosion of genomics research both current and projected.

Many presentations highlighted the real progress being made in relation to genetics related treatment of a number of ataxias. The issue is no longer if but when interventions will become available that can either slow the impacts of MJD or result in an eventual cure.

Of particular note at both conferences were presentations by MJDF clients, staff and MJDF funded researchers which drew considerable interest, including from pharmaceutical companies. A key theme that also emerged was the importance of those organisations that represent individuals and families living with rare genetic diseases in ensuring research is focused on the priorities identified by the clients most directly affected and likely to benefit. MJDF attended an initial meeting of 'patient organisations' with this issue in mind and established a number of further valuable contacts. Finally, MJDF didn't secure any government support for this initiative, so we are again particularly grateful to the Anindilyakwa Land Council, Telstra, Groote Eylandt Aboriginal Trust and South32/GEMCO that enabled MJDF's hosting and participation in both conferences. I also want to specifically acknowledge the efforts of Desirée LaGrappe in leading the planning and execution of the conference.

A further year's highlight was a visit by the MJDF Board to the community of Yarrabah in Far North Queensland which resulted in agreement to the community's request that MJDF establish a new Spinocerebellar Ataxia Type 7 program, supporting Aboriginal and Torres Strait Islander families living with SCA7 in and around the community. The opportunity to meet with families and share each other's experiences in living with both these genetic diseases (SCA7 is very similar to MJD but can



also include the added complication in the onset of Macular Degeneration) was a deeply moving experience for all involved. As Board members Tony Wurramarrba AO and Gayangwa Lalara OAM reminded us, it was also an important reaffirmation of what MJDF is all about. MJDF Board members and staff also jointly participated in Australian Institute of Company Directors Not-For-Profit Directors Governance course in early 2020 which provided an important opportunity for Directors to not only enhance their knowledge and skills but also invest in building a better understanding by staff of the various duties and legally binding responsibilities required of Directors.

The only major disappointment of the year was the Federal Department of Health's decision to discontinue funding of MJDF's Genetics Education and Primary Health Education Programs which deliver on the ground culturally informed genetic education to affected individuals and families. This program also

provides vital education to health professionals about MJD itself and the needs of people living with the disease. There are currently no alternative services delivered in remote communities by either the NT or Commonwealth to address this critical need and we plan to again take this matter up with the Federal Minister given his previously stated commitment to supporting those living with rare genetic conditions.

In conclusion, I again thank all our funding partners and supporters without whose continued support the work of MJDF just couldn't continue. Nor would it be maintained without the support of our wonderful clients and their families.

The Board also continues to be supported by a skilled and committed staff superbly led by our CEO Nadia Lindop OAM.


Neil Westbury PSM

ABOUT US

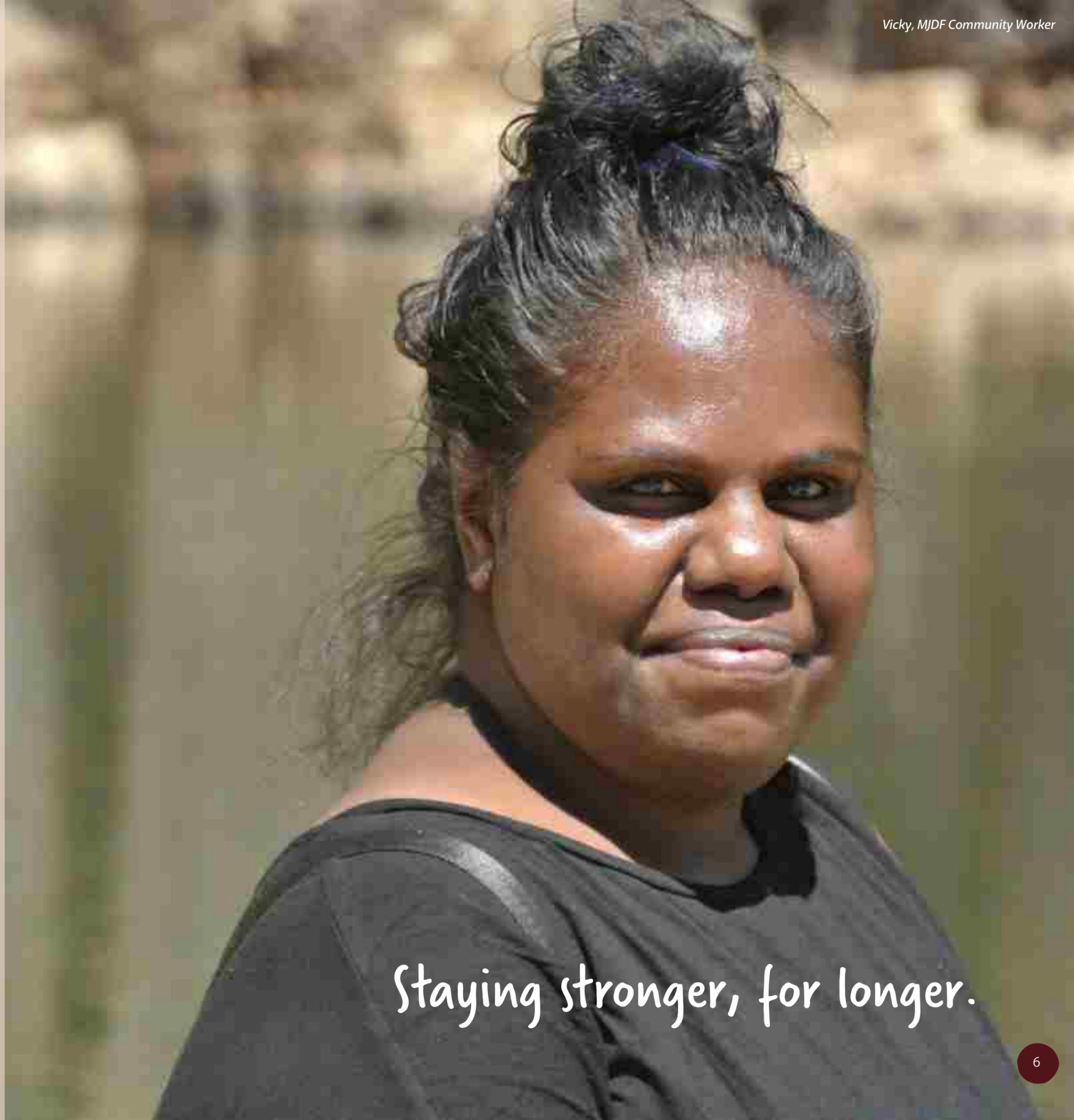
The MJD Foundation works in partnership with Aboriginal Australians*, their families and communities living with Machado-Joseph Disease and other closely associated Ataxias. We provide comprehensive supports and engage in research, increasing understanding of the disease and providing hope for the future.

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), Santa Teresa, Gunbalanya (Oenpelli) and Far North Queensland.

The MJD Foundation prides itself in 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.

The MJD Foundation is a registered Charity with Deductible Gift Recipient status.

*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.



Staying stronger, for longer.

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.

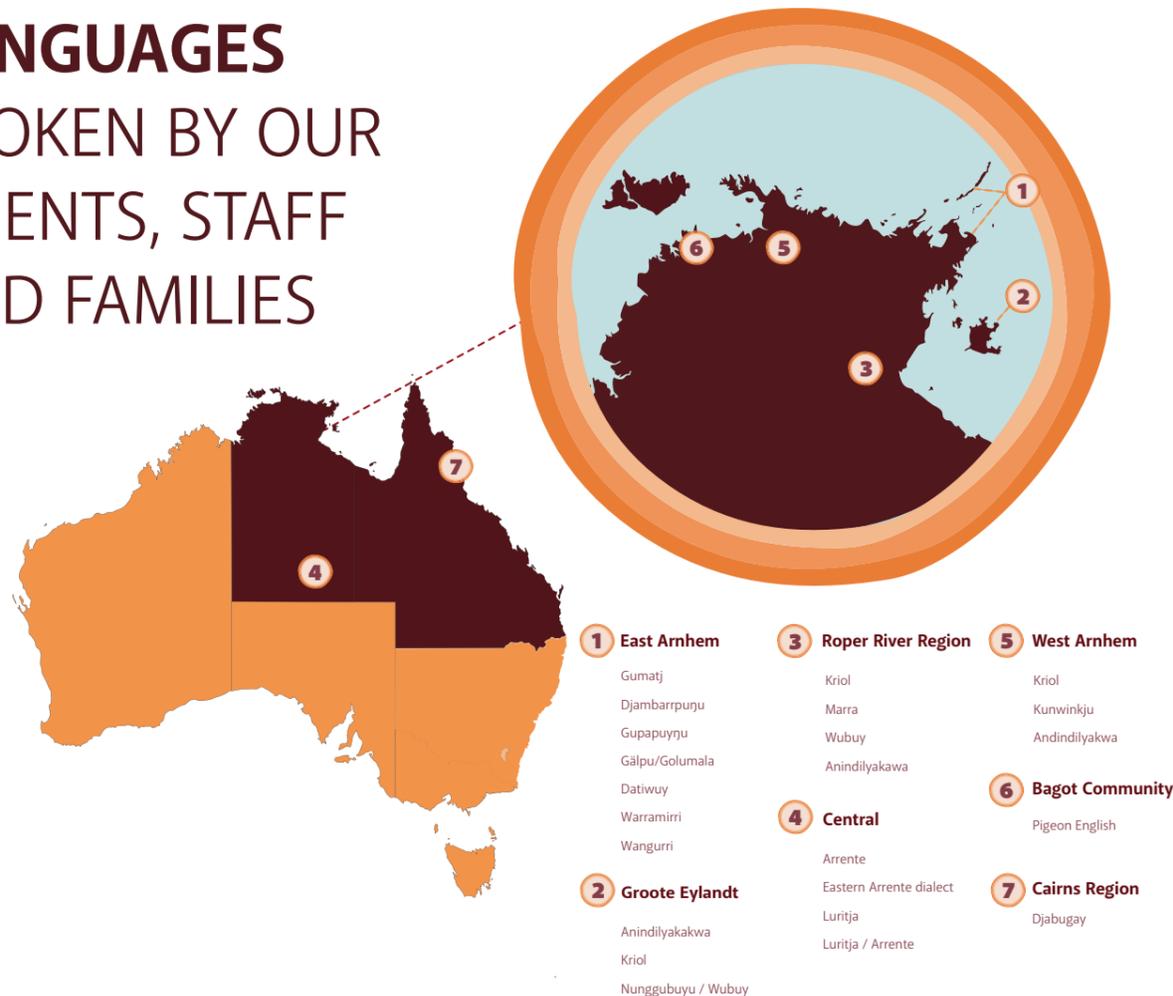
MJD is an inherited, autosomal dominant disorder, meaning that each child of a person who carries the

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 for all activities of daily living within 10 to 15 years of the first symptoms emerging.

LANGUAGES SPOKEN BY OUR CLIENTS, STAFF AND FAMILIES

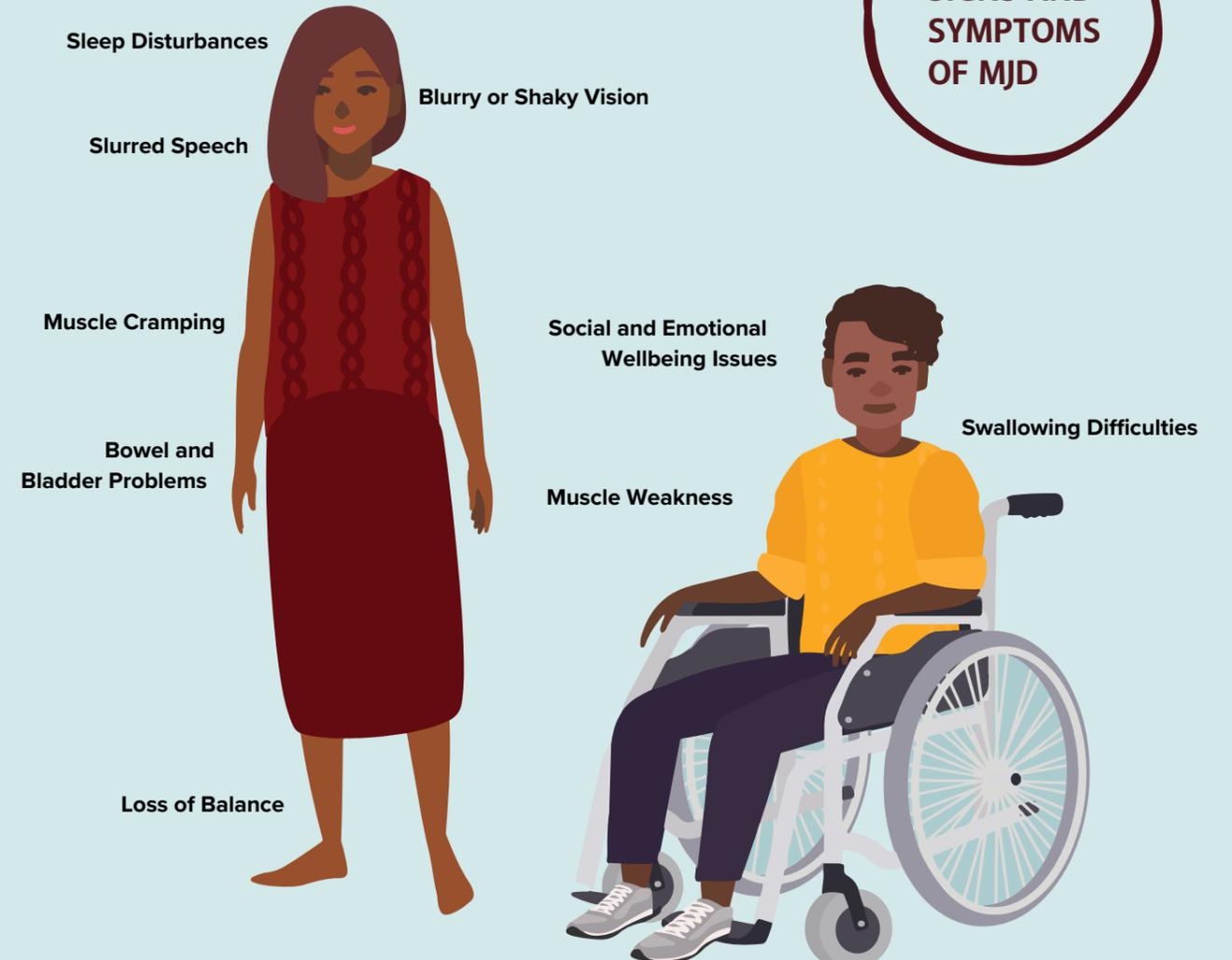


MJD IN ARNHEM LAND AND BEYOND

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

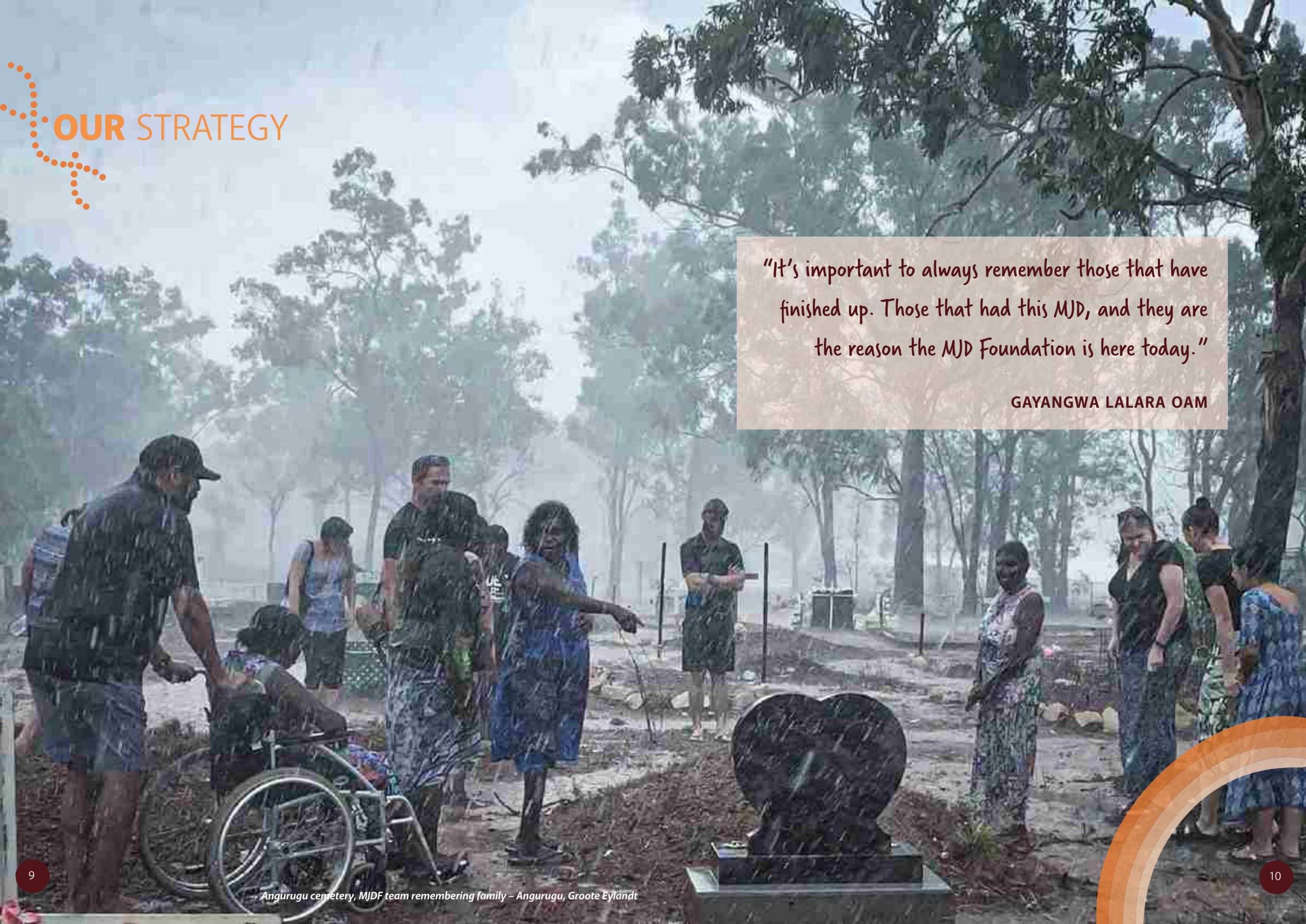
over 700 Aboriginal Australians thought to be "at-risk" of developing the disease across the top end. (At-risk individuals are individuals alive today, who are direct descendants of those with the disease. If a parent has MJD, their child has a 50% chance of being born with MJD and therefore developing the symptoms at some stage in their life).

SIGNS AND SYMPTOMS OF MJD



"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

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.

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).

COMMUNITY SERVICES

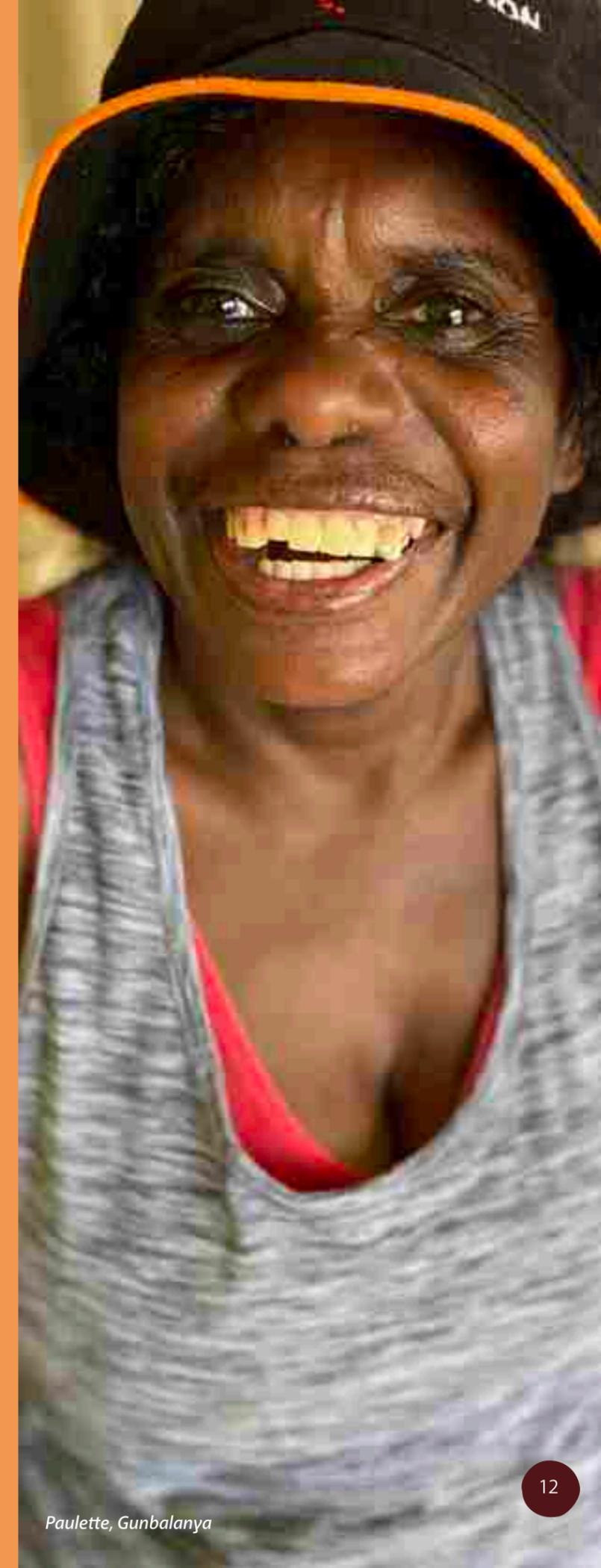
- 1 Map and increase our capacity to deliver equitable supports across all communities where Aboriginal Australians live with MJD.
- 2 Ensure National Disability Insurance Scheme (NDIS) planning and implementation remains a priority to ensure best possible plans for clients.
- 3 Prioritise community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

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 MJD 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.



HIGHLIGHTS FROM OUR CEO



In discussing the 2019-2020 year, and the impacts of COVID-19 in the latter half, at the risk of duplicating the comments of millions of CEOs internationally, I will try to avoid the words pandemic, quarantine, shutdown, isolation, social distancing, unprecedented, pivot. Instead, acknowledging what a challenging 6 months it has been, I want to pay tribute to our staff members, Board Directors, subcommittee members, clients and families. I am very proud to be part of a team that has shown so much resilience in working to ensure our clients and families understood information about the virus (as we became more aware of the facts), and remained calm and focussed on supporting our clients living with MJD.

WORKFORCE

We are proud that the MJD Foundation not only maintained our workforce without having to stand anyone down through the period of COVID-19 restrictions, but our workforce grew to 45 staff members. Currently, 49% of our staff are Aboriginal Australians, and 18% of staff are living with a disability. We are committed to our goal of increasing our Aboriginal Workforce with meaningful employment, and opportunities for ongoing education & training. This year, this included recruiting 2 Aboriginal trainees in our administrative/ operations teams, and supporting our Aboriginal workforce to undertake qualifications and continued development in interpreting/translating (NAATI certified), business administration, personal protective equipment (PPE), MS Office skills, NDIS Worker module, manual handling, wheelchair maintenance, first aid and health research.

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 a forum 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.

A free market economic approach with eventual price deregulation will never work in remote communities where there are, at best, thin markets. We are extremely grateful to wonderful supporters like the

Anindilyakwa Land Council, South32/GEMCO, GEAT, GEBIE, Youngcare and Sea Swift, who enable us to be sustainable under the NDIS despite these challenges.

HIGHLIGHTS

- MJD HOUSE kicked off in earnest in September 2019. MJD HOUSE is a wellbeing hub comprising 2 residences located in Darwin, providing our clients with 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. MJD HOUSE is now operating at full capacity.
- International MJD Conference (USA). In November 2019, the MJD Foundation hosted the Washington DC International MJD conference, bringing researchers and MJD patients from around the world to share emerging research results, and hear from patients about what's important to them. This conference followed on from our highly successful 2015 International conference (Cairns QLD), attracting many of the same researchers, plus new colleagues from USA, China, Israel, Germany, Belgium, Peru, Brazil, Portugal, United Kingdom and Australia.
- This year we opened our Cairns office in preparation of the commencement of our SCA7 (Spinocerebellar Ataxia Type 7) program, supporting families living with SCA7 in and around Yarrabah. SCA7 is a closely related ataxia to Machado Joseph Disease (SCA3). We are thrilled to be co-located with Spinal Life Australia at their state-of-the-art facility in Cairns.



James and family - a visit home (Kin Connect), Santa Teresa

LOOKING AHEAD

- We were honoured to host Disability Royal Commissioners The Hon Roslyn Atkinson AO, Alastair McEwin AM and Andrea Mason OAM in Darwin to talk to them more about the work of the MJD Foundation, and in particular the challenges of delivering supports in remote communities.
- We also expanded our options for clients living in remote communities to receive physiotherapy and other supports (if they choose) through Telehealth utilising mainstream solutions like Zoom and Facetime.
- In December 2019, I had the pleasure of being elected to the National Disability Services (NDS) National Board. NDS is the peak body for disability providers across Australia.
- In March 2020, it was great to host the Hon Bill Shorten MP (Shadow Minister for the NDIS) and Senator Malarndirri McCarthy. They spent time with MJDF staff and clients at MJD HOUSE.
- 2019-2020 saw the launch of our Fundraising & Income Generating Subcommittee (FIGS) reporting to the Board, as part of our renewal of our Fundraising strategy for the coming years.
- Anna's Mob raised over \$10,000! We've been so moved by Anna Michael's generosity and her love for our clients/families. Anna passed away peacefully on 1st January 2020. Read more about her moving story on our tributes page.
- It was our pleasure to host Youngcare Australia on a visit to Groote Eylandt in late 2019 so that they could meet some of the clients they have supported over the years and learn more about the work of the MJDF.
- SCA7 - in 2020/2021, MJDF will launch our Spinocerebellar Ataxia Type 7 program, supporting Aboriginal & Torres Strait Islander families living with SCA7 in and around Yarrabah in Far North QLD. We are super excited to welcome back ex-staff member Mark Kilpatrick who used to work for us on Groote Eylandt, and will return to lead this important new program.
- MJD School (Umbakumba) - in the coming year, we will be establishing a multipurpose facility on Groote Eylandt to support intensive therapy for our clients, student education and research opportunities.

THANK YOU

Thank you so much to our sponsors and partners who enable us to deliver supports to our clients and to collaborate with researchers and conduct our own research into MJD. Thank you also to our very dedicated staff members who are passionate about the work we do for our clients and families.

Nadia Lindop OAM
CEO

“Learning about the work that has been developed in Australia with MJD communities was an incredible opportunity”

International MJD Research Conference attendee



MJDF researchers, staff and volunteers – Washington D.C., USA

RESEARCH

In a 12 month period marked by massive social change we feel very fortunate to have been able to continue to grow the MJDF Foundation research agenda, as well as successfully host an international research meeting in Washington DC.

The international MJD meeting was conducted on November 11th and 12th as a satellite of the larger International Ataxia Research Conference (IARC). The aims were two fold; -to advance international research in Machado-Joseph Disease (MJD), and to foster international collaborations. It was attended by 69 delegates from 10 countries and included researchers, industry representatives (pharma and biotech companies) and people living with MJD and their caregivers.

Contextual care and innovation in MJD care in low resourced and culturally complex contexts; pre-clinical research: drug and gene therapies; disease mechanisms, pathogenesis and biomarkers; and clinical research and practice were addressed. A special thanks to Desireé LaGrappe and the team of volunteers from the John Hopkins School of Nursing, Public Health & Medicine along with volunteers Nicola Rangeley, Alexandra Roginski and Carl Oates for their help in making it happen.

Highlights of the conference included the first Aboriginal international speakers from the MJDF, including Aboriginal researchers living with MJD (go Joycea!), 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. Delegates expressed thanks to the MJDF for hosting a focused, close meeting and for facilitating patient and family participation, describing the real human connection as a motivating factor to progress research in the hope of discovering effective MJD treatments. Scientific presentations showcased that these are 'unprecedented and exciting times' in the field of MJD research. **As the science moves toward human clinical trials, there is reason to hope.**

A number of existing and new projects have also progressed this year with our researchers proving their adaptability and resilience despite changed circumstances, global conference cancellations and widespread publication delays.

Our research into keeping families walking and moving around, conducted by community researchers Joyce Lalara, Gayangwa Lalara, Gwen Lalara and PhD candidate/physiotherapist Jen Carr, continued to produce exceptional work. The team have published two articles in peer reviewed journals and have developed the Staying Strong Toolbox program alongside families with MJD. The physical activity and lifestyle program was piloted on Groote Eylandt and in Ngukurr, was found to be feasible and to keep families stronger, healthier and happier. Despite being officially on maternity leave, Charles Darwin PhD candidate and Speech Pathologist Rebecca Amery, along with a team of Yolŋu researchers have had their phase 1 results describing the **communication strengths and needs of Yolŋu people living with MJD** published, completed data analysis for phase 2, developed 4 Yolŋu communication aids this year – and produced baby Harriet.

'Yolŋu Matha - English Keyboard' for iOS. This app is the first high-tech Augmentative and Alternative Communication (AAC) aid for Yolŋu with complex communication needs, collaboratively designed with our clients and their families living with MJD and the Telstra Foundation.

Dr Angela Laird and her team at Macquarie University continue to move the **molecular work begun with zebrafish** into new and innovative directions. Their presentations at the MJD and IARC conferences were exceptionally well received and they engage regularly with the MJDF community services and research team, keeping their lab work focussed and inspired by people living with MJD. **Sleep research data analysis** has been completed and publication is planned for late 2020.

The **Better Indigenous Genetic (BIG) Health Services** project has resulted in 2 publications considering the specific cultural and social requirements of Aboriginal people living with genetic diseases, one specifically considering the model used by the MJDF – both will be available in late 2020.

The MJDF, University of Melbourne and Synapse project to **evaluate the rollout of the National Disability Insurance Scheme (NDIS)** rollout in remote NT and Queensland communities has produced a policy brief and a publication has been accepted for publication in late 2020.



THE INTERNATIONAL MJD MEETING

"It was very well organised and timed. Great mix of researchers, clients and families."

"Learning about the work that has been developed in Australia with MJD communities was an incredible opportunity to think about ways of improving patient care in our home country (and all around the world) - the Staying Strong Toolbox is certainly a high point in the Conference."

"The conference was very good, had very high quality speakers and posters, and gave rise to fruitful networking opportunities between MJD researchers."

"There was such a vast array of research presented and it was very interesting to hear about the varied cultural environments of patients with MJD."

"I was particularly impressed to listen [to] the work patients, families and healthcare are doing together, and to have the opportunity to listen from families [on] what they expect from clinicians and researchers."

"There are way too few meetings dedicated for MJD research. It is very important to meet and exchange with other researchers and to stay in constant contact."

"The conference was great - extremely motivating and inspiring."

EDUCATION

MJDF Education programs and resources aim to strengthen the capacity of health professionals, family and professional carers and the community in general, to respond appropriately to the needs of people with MJD. During this year we conducted 11 health professional in-services and 8 care worker in-services and workshops and have moved to a recurring schedule for Darwin carer education.

Informal, incidental and ongoing family carer education was provided on a needs basis covering a range of core MJD clinical and high support needs including: PEG, sleep, transfers, safe swallowing and genetics. We were also privileged to once again conduct annual medical student training for Flinders/CDU medical students – a highlight of the year for our dedicated clients who delight in the opportunity to teach the ‘baby doctors’.

A number of additional resources have also been finalised including a suite of aircraft manual handling resources to assist the airline industry in their safe transport of people living with MJD.

Our resource are readily available on the MJD website and include links to previously completed materials such as the:

- Medical Protocols
- Family and Carer Help Sheets
- RAHC e-modules: <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, communication



Jake, sharing knowledge of MJD with careworkers – MJD careworker workshop, Alice Springs



GENETIC COUNSELLING

Sadly, every year brings new confirmations of people in our families beginning their ‘official’ journey with MJD. In many cases the results of genetic testing confirms 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 model is client led; incorporates a shared understanding; involves relationships, continuity

and trust; and incorporates a family approach. All critical elements for genetic care are in this context – because 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.”

This year, despite changed service delivery models and restricted access to communities, our staff were able to provide a combination of face to face and virtual consults into 6 remote communities for 12 individuals and their families. So it was with great regret MJDF received the news that the Federal Department of Health declined funding into 2020, leaving us to investigate alternate funding sources to continue to provide genetic care in this complex environment.

COMMUNITY SERVICES

As a team, we regularly pause and reflect on the sparkling moments, celebrating smiles, relationships, heart and connection. We are privileged and humbled to work in a relationship-based approach that honours Our Way. A quote from one of our beautiful clients, 'this is a shared life', exemplifies this. 'Our Way' approach values and respects a 'two-way' or 'both ways' approach, delivering supports that are flexible and responsive to the needs of our clients, and reflecting the diverse cultural and linguistic needs of families.

Ever important to celebrate the sparkling moments, it goes without saying that the impact of COVID-19 has challenged us in so many ways.

We remained vigilant and flexible in our service delivery, continuing to provide essential supports with best practice. We adapted. It was and is still challenging.

We made the heartbreakingly difficult decision to suspend the Kin Connect and MJD HOUSE program, which deeply saddened clients and families. We suspended travel between our urban and remote communities. We adapted, creating innovative ways

to support connection to family, culture and country, continuously improving.

The Community Services family has many sparkling moments to celebrate in the 2019-2020 period. Continuing to grow in capacity, providing best-practice, holistic disability-care that includes targeted therapeutic support, complex care coordination and social and emotional wellbeing support. We do this by listening from the heart and working in partnership with families living with MJD.

A continued challenge with organisational growth is the consolidation of working Our Way. Our growth has encompassed increased Aboriginal Community Workers in Darwin, Groote, Elcho and Ngukurr. Our Allied Health team includes Nurses, Physiotherapists, Occupational Therapists, Social Workers and a Speech Pathologist; and we have Family Support Workers supporting Darwin, Ngukurr, Groote and now Cairns. The MJD HOUSE program is now supported by an MJD HOUSE Program Manager in recognition of this vibrant program.

MJD HOUSE is a Wellness Hub located in Darwin with the aim of keeping our clients and families stronger

for longer so they remain living in, and cared for in their communities. The MJD HOUSE program launched in September 2019, providing respite for clients and families to rest and access a range of supports (including therapy and specialist supports) that contribute to their wellbeing and their ability to live their best possible lives. The program was suspended, due to COVID-19, in April 2020 with hopes of restarting later in the year. Feedback from the first client stays have been positive: clients and carers loved the house, accessed specialist supports, enjoyed the rest and especially the recreational activities.

Staying Stronger for Longer is a vital program that encompasses best practice therapeutic interventions across our communities and with our clients. Our 'On Country' model engages experts from both cultures, combining traditional knowledge and priorities with best practice therapy, including a range of speech, occupational therapy and physiotherapy.

Our Occupational Therapists, Speech Pathologists and Physiotherapists deliver therapy through NDIS plans and individualised support packages supporting clients across the Northern Territory and Far North Queensland. Weekly physiotherapy is currently being accessed in Groote, Darwin, Cairns, Nhulunbuy and Alice Springs. Guided by our clients and Aboriginal staff, therapies that combine meaningful goals as defined by individuals, families, and carers with clinical best practice in allied health management of MJD symptoms has the power to greatly influence client wellbeing.

Ensuring our clients living in remote communities have access to therapists and specialist supports to remain living at home in their community is important to maintaining quality of life. Through the NDIS, clients living in Ngukurr, Gunbalanya, Galiwin'ku, Yirrkala, Ltyentye Apurte, Papunya and Groote Eylandt have accessed specialist allied health including Occupational Therapy, Speech Pathology, Specialist Continence Nursing and Physiotherapy services in their home community.

MJDF continues to work to improve community transport options and accessibility. We provide innovative assistive technology solutions to meet individual and community needs, supporting people to stay at home and in their community.

Our Kin Connect program supports clients living away from home to maintain cultural connection and to return to country. This provides experiences for clients that increase wellbeing, community and cultural participation.

This year MJD Foundation delivered four Kin Connect trips to Elcho Island, Gunbalanya and Groote. There is significant preparation, planning and collaboration that goes into a Kin Connect trip. The value of supporting a client to return home to family, culture and community is immeasurable.

Accessing all parts of Australia is made possible through our Holiday of a Lifetime program. Also requiring immense planning and team work, this year we supported a client and family to create memorable moments and adventures in Darwin. In Far North Queensland, the MJDF was approached by an Aboriginal Medical Service to assist them with investigating a rare genetic condition similar to MJD called Spinocerebellar Ataxia Type 7 (SCA7). MJDF continues to be guided by families and community living with SCA7. In December 2019, MJDF Board members met with families living with SCA7. Stories of grief, sadness, hope and strength were shared that day about the journey living with MJD and SCA7, the similarities and shared understanding. In the coming year, we will launch our SCA7 Program to support families living in and around Yarrabah who are living with SCA7.

In March 2020, MJDF opened a Cairns office in the Spinal Life Healthy Living Centre, with a vision to expand supports to families living with MJD and SCA7 in Far North Queensland.



Roseanne reunited with family – Kin Connect trip, Groote Eylandt

PEOPLE AND PARTNERS

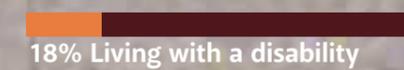
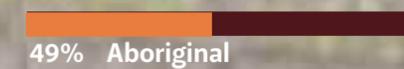


OUR PEOPLE

BOARD



STAFF



OUR TEAM

Nadia Lindop OAM - Chief Executive Officer
 Libby Massey OAM - Director, Research & Education
 Melinda Fajerman - Director, Community Services
 Jennifer Telfer - Chief Finance Officer
 Morag MacLennan - Operations Manager
 Gayangwa Lalara OAM - Senior Cultural Advisor

- Rebecca Amery - Therapist
- Mel Asendorf - Client Services Coordinator
- Elizabeth Bukulatjpi - Community Worker
- Jennifer Carr - Therapist
- Leah Clarke - Manager, Community Services
- Jasmine Cook - Admin trainee
- Olga Daniels - Co-Researcher/Community Worker
- Bronwyn Daniels - Community Worker
- Gillian Edmiston - Family Support Worker
- Loretta George - Community Worker
- Alison Grootendorst - Clinical Team Lead/Manager, Community Services
- Farrah Gumbala - Co-Researcher
- Tina Hebblewhite - Admin/Procurement Officer
- Zeng Jones - Finance Officer
- Colleen Kenny - Family Support Worker
- Chris Kenny - Family Support Worker
- Lena Kuznetsova - Bookkeeper
- Desireé LaGrappe - Manager Integrated Services
- Gayangwa Lalara OAM - Senior Cultural Advisor
- Gwen Lalara - Co-Researcher
- Joyce Lalara - Co-Researcher/Community Worker
- Louise Lethbridge - Family Support Worker

- Brett Mamarika - Community Worker
- Clarissa Mamarika - Community Worker
- Hilroy Mangurra - Community Worker
- Bryan Massey - Family Support Worker
- Kathy Massey - Special Projects Officer
- Jacob McCue - Manager, Community Services
- Rebecca McCue - Project Manager/Family Support Worker
- Jess Meagher - Manager, Community Services
- Wyam Morris - Manager, Community Services
- Vickerina Nganjmirra - Community Worker
- Mich Peters - MJD House Coordinator
- Kate Pope - Manager, Community Services
- Nancy Raggett - Community Worker
- Stacey Reilly - Senior Administrative Officer
- Billie Russo - Client Services Assistant
- Janine Ryan - Genealogist
- Tommy Weetra - Community Worker
- Liz Willis - Team Lead, Darwin Community Services
- Julie Wunungmurra - Co-Researcher/Community Worker
- Steve Wurramara - Community Worker
- Djapu Yunupingu - Co-Researcher
- Elah Yunupingu - Community Worker



Ali and Barbara (Rarrapul) – trialling powered mobility aides, Darwin

Board

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

Patrons

- Professor Garth Nicholson
- Bryan Massey OAM
- Kathy Massey OAM

Finance Sub-Committee

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

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
- Desireé LaGrappe (Secretariat)
- Rebecca McCue

Research Advisory Committee

- Peter Fisher OAM (Chair)
- Libby Massey OAM
- Desireé LaGrappe (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)

Volunteers

As well as our Board members and Subcommittee members who are all volunteers, we want to thank our amazing volunteers who continue to support our clients/families, especially on Holidays of a Lifetime and Kin Connect trips, which are such important programs.



OUR PARTNERS/SPONSORS

Partners

Anindilyakwa Land Council, First People’s Disability Network, 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, Telstra Corporation, Overgrove P/L, Sea Swift, Groote Eylandt Lodge, Gilbert + Tobin, Hall & Wilcox, Traditional Credit Union, Adaptalift GSE, Darwin Airport Corporate Giving Committee, Mercure Darwin Airport Resort.

Grants and Donations

Federal Department of Health, QLD Government Community Benefit Fund, NT Government Community Benefit Fund, Youngcare, NT Department of Health, NT Department of Trade, Business & Innovation, NT Primary Health Network, National Disability Insurance Agency (NDIA), Boosting the Local Workforce (EY), 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; Prof Bart Currie; Anne De Salis; Marcus Fever; WR Hearn; Roger Livsey; Sarah MacMillan; John Payne & Janice Oake; Lorraine Richardson; Matthew Stormont; Christine Sullivan; James & Isobel Walker.

PARTNERS



SPONSORS/DONORS



GRANTS/FUNDERS



OUR STORIES



Ernie and Simon, Cairns

ERNIE REACHES 160 STEPS!

I've been lucky enough to work with Ernest now for three years. He is one of the most inspirational people I have met. He has a sheer determination to push himself with his exercise programs and continually strives to break his records. In 2018 Ernest achieved a total of 2000 steps walking assisted with myself. His initial goal in 2019 was to match this number. However, so true is his determination that he pushed out an incredible 3,000 steps.

Whilst 2020 has been greatly interrupted by COVID-19 restrictions and unfortunately cost him a couple of months of walking, it hasn't stopped his courage. Despite the break in continuity he has still managed an amazing 1,180 steps thus far and found another way to keep breaking records.

On the 20th of August 2020 he did an incredible 160 steps in one physio session over only two legs (100 steps and 60 steps). His previous greatest total for one session was 140 steps in four legs. Ernest certainly is a crowd pleaser and always punches out the big numbers when there are spectators and when we are down by the creek. He sets a high standard and continues to deliver. I have no doubt he will continue to break records and I look forward to every session with Ernest and the energy he brings to the table.

Simon Morris



BoyBoy following Michael home, Santa Teresa

MICHAEL AND BOYBOY

Michael is an Eastern Arrernte man from Santa Teresa community, located 80 odd kilometres south-east of Alice Springs. Santa Teresa is also known as Ltyentye Apurte in the local Eastern Arrernte language, which is pronounced more closely to "ginger porta" – a throwback to earlier linguists' attempts to alphabetise the desert language that has been spoken in this region for thousands of years.

Michael is a strong and resilient man and any questions around what might be done to further support his situation are usually met with a big broad smile that spreads across his face. This is despite living with all the challenges and complexities that come with having MJD and chronic kidney disease. As a part of Michael's ongoing medical treatment he attends the Purple House dialysis clinic located on community three times a week. Each treatment goes for four to five hours at a time.

On these days Michael drives his sun yellow electric scooter up the red desert dust layered streets of Ltyentye Apurte community to the Purple House clinic. Trailing a few safe metres behind Michael's scooter (and a few extra metres on hot days) is Michael's four legged loyal companion BoyBoy. BoyBoy, Michael's dog, follows Michael to the clinic and sits directly under his dialysis chair while the hours pass waiting patiently. When the treatment is finished the procession, lead by Michael in his scooter and followed by his safety support team of the Purple House truck and BoyBoy, make their way back along the roads to Michael's house. Michael is often a little tired after these treatments but BoyBoy is usually more than happy to sit with him on the family verandah to watch the afternoon pass.

Jake McCue



Brian and Bowie, Ngukurr

BLUE'S STORY

Brian Daniels is the most senior man and elder of the Daniels family in Ngukurr – a little community on the bank of the Roper River in South East Arnhem Land. Since Brian's older brother and best mate, David, passed away several years ago, Brian has assumed an important position of leadership within the community. However, due to the progressive physical decline of his MJD, it has become increasingly difficult for Brian to fulfil his role in community as his ability to mobilise, communicate and access meetings, ceremony and homelands has been limited.

Brian has always been very close with his daughter Bronwyn who lived at home with him for many years along with his niece Elaine as carers. Both Bronwyn and Elaine also have MJD and due to their increased needs and family commitments they have both had to move out of home to access the increased supports they require.

Consequently, Brian was left without his long term carers and all other family in community were committed to other housing and family responsibilities. It was a major concern for the MJD Foundation that Brian was left without trusted family carers who were able to provide the live in 24/7 support he required.

This is when Hilroy Mangurra, his wife Yvette and his three sons (17, 15 and 3) volunteered to move in with Brian to look after him. This was an incredible act of respect, kindness and sacrifice for the family to make, considering that Hilroy also has MJD and although distantly related, the Mangurras are not immediate relatives of Brian.

Hilroy, Yvette and his sons have been amazing carers for Brian -- patient, respectful and very attentive. Considering Brian's care needs are significant, the family work together to share the daily tasks of cooking, cleaning, helping Brian with personal hygiene activities



Brian and Hilroy, Ngukurr



Nick, Brian and Hilroy, Ngukurr

and ensuring he takes his daily medication. When Brian asks for a tea, a light of his smoke and to be pushed around the community to visit family, Hilroy and his family oblige with a smile on their face.

Brian knows how lucky he is and he often says that his new adopted son, daughter and grandsons are the best carers he has ever had. "This boy here, he's a real good boy, his sons too they always look after me. This one here, Yvette, she is always looking after me like a daughter. They are all real good to me."

The bond is strong between Hilroy and Brian and there is plenty of mutual respect between them. As Hilroy explains, "It does get really stressful at times and you don't get much sleep at night because he is always awake yelling out for help or to turn the fan on or off. He needs help with personal care, eating, drinking tea and taking medicine. I have to get him and push him home when his wheelchair runs out of battery and he is stuck in community. Sometimes I have to try and fix his wheelchair when it gets broken and I have to do it quickly so he can keep using it. It's hard on me and my wife and my sons and sometimes it feels like we can't go on, but we need to keep looking after him because there is no one else and he is an important man who deserved to be well looked after."

Thanks to Hilroy and his family, Brian is still living in his beloved hometown Ngukurr, in his own home and surrounded by the family and community that he never wants to be parted from.

The story of Hilroy and Brian is a seldom told narrative that plays out in many communities within many families where local carers show incredible commitment and love to ensure that old sick people are looked after and supported to continue living in their community to the end.

Nick Kenny

THE CHALLENGES OF COVID-19 AND BOWIE'S MESSAGE

This year began like any other year, but by mid-March it was clear that 2020 would be anything but "normal." The 2019 coronavirus pandemic, or COVID-19, has changed many of the ways we live and work. For families living with disability and for the disability sector there have been added layers of challenges.

While the public health emergency has been challenging, it has also been an opportunity for organisations and the clients they support to draw on their immense strengths like their resilience and vast support networks.

This experience has been shared by many families living with MJD and the MJD Foundation. Aboriginal communities have been some of the most affected by COVID-19 related restrictions because of bio-security zones, which meant many people were separated from their families and unable to visit or return to their home communities. This also cut off many communities from regular, visiting services.

It was hard for clients and staff when we were not able to see each other in-person as much and when we had to pause some activities to keep everyone safe. While MJD clients living in residential care and supported living accommodation were especially isolated physically during this time, together with staff they found new ways of staying connected to their families and to continue to care for each other. As restrictions have lifted in some parts of the country, many clients have enjoyed getting back to the things they love that are important to them and make them happy. At the MJD Foundation, these are the types of supports we really enjoy helping people to do. Things like group 'on country' days to get exercise, spend

time together with families, walk on the beach, look for 'bush medicine,' or hunt for yams.

One of the biggest challenges, like many other organisations, was getting access to Personal Protective Equipment, or PPE, and cleaning supplies for both staff and clients – not to mention toilet paper! Through an incredible effort by our team to advocate to the National Stockpile and to the National Disability Services in addition to search suppliers far and wide we were able to get what we needed to protect clients and staff. This was followed by a big effort to train everyone in the extra infection-control precautions and safe use of PPE to prevent COVID-19. This was no easy task at the time. With staff spread across Australia and, importantly, the need to comply with public health guidance – like physical distancing and travel restrictions – we all had to be flexible. With the help of a telehealth grant, everyone had to quickly upskill in the use of technology and virtual meetings. This helped us to get there in the end with a few laughs and fun along the way. We were reminded of how dedicated our staff are to the work they do and how well we work together as a team, even during a crisis.

Bronwyn Daniels, an MJD Foundation Community Worker, has found it helpful to reflect outwardly and think about others during this time. For people around the country and the world who are in isolation or impacted by COVID-19 in other ways, Bronwyn shares her painting of a lotus flower and lily pad (pictured) to bring a little joy during a challenging time. She wants others to know there are people thinking of them, hoping for their good health and happiness, and to share a simple message: "Be safe, wash your hands."

- Desireé LaGrappe



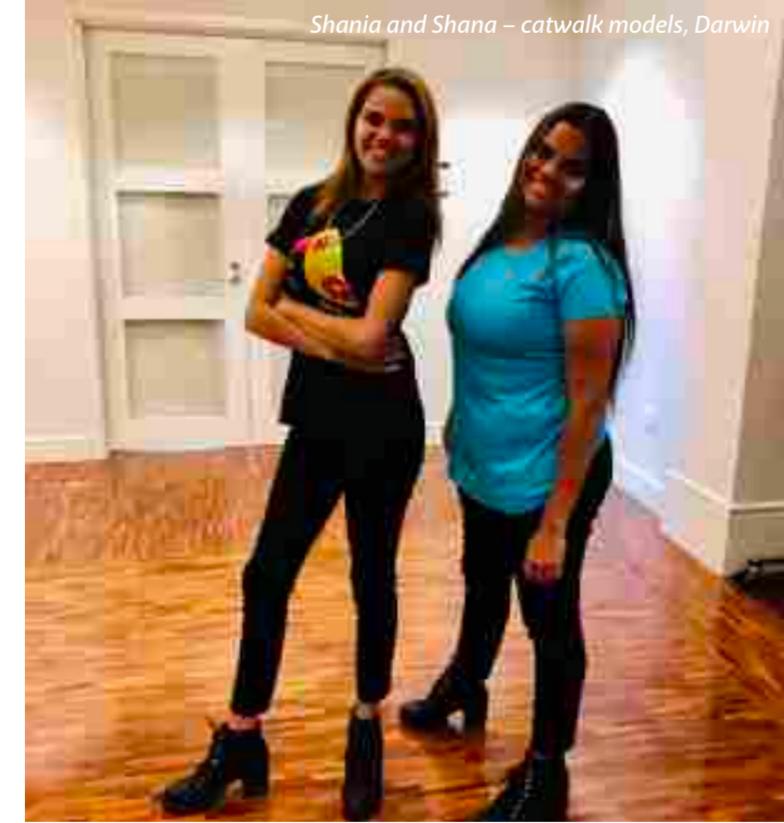
Desireé, Liz, Leah, Gillian and Vicky – COVID-19 PPE training, Darwin



Bowie, Katherine

2019 NT DISABILITY SERVICES AND INCLUSION AWARDS

MJDF were very excited to participate in the launch of the 2019 NT Disability & Inclusion Awards at Parliament House in Darwin. We were also thrilled to facilitate the involvement of Shania and Shana – the girls were amazing catwalk models, modelling local Territory fashion as part of the fashion parade at the event. The girls did a really great job, and we were very proud of them.



Shania and Shana – catwalk models, Darwin

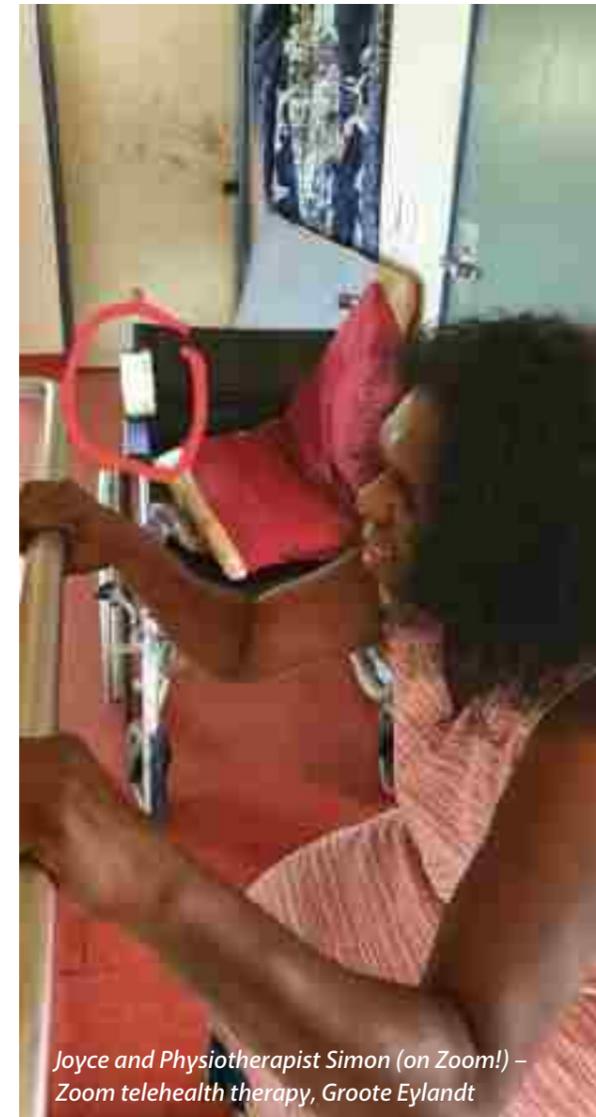
TELEHEALTH

Around the world, much of this year has been dictated by the COVID-19 pandemic. Service delivery as we knew it was significantly disrupted. As the situation evolved and restrictions were put in place regarding travel and limiting direct contact with families living with MJD, we were challenged to consider new ways of working to help MJDF clients continue to have access to support to stay stronger for longer.

For the MJDF therapy team, this meant getting creative. Through the use of online platforms – videos and stories were shared to help us stay connected and motivated. In Cairns, Groote Eylandt, Elcho Island and Darwin, therapists trialed using online platforms to engage with clients and deliver physiotherapy, speech pathology and occupational therapy services. Despite not being about to connect in person, many remained highly motivated to continue to do therapy at home to help keep their minds and bodies strong. We all learnt a lot about both the opportunities and challenges associated with telehealth during this time.

As we continue to journey with the pandemic, transition to a 'new normal' and reflect on this experience with our clients – our new challenge is to consider how we can use what we learnt to creatively and courageously continue to advocate for improved access to therapy for families living with MJD, and engage in conversations around what role telehealth has to play in how we work moving forward.

- Ali Grootendorst



Joyce and Physiotherapist Simon (on Zoom!) – Zoom telehealth therapy, Groote Eylandt

TRIBUTE – ANNA MICHAEL

In June 2019 we received a phone call from Anna's friend Sally. Sally was calling on behalf of Anna to find out more about the MJD Foundation.

This is Anna's story about setting up Anna's Mob:

Why I set up this fundraiser?

The idea for Anna's Mob began one night when I couldn't sleep. There was a massive thunderstorm, with so much lightning that it fried my landline and modem! But I also had a "lightning bolt moment" as my brain refused to let me sleep... thinking, thinking, thinking.

For the past 2 years I have been dealing with ovarian cancer. This is a tricky cancer at the best of times due to its absence of obvious symptoms, and its tendency to recur, but I have also inherited the BRACA 1 gene mutation from my father's side of the family... no fault, no blame, just rotten luck. This gave me a high probability of developing both ovarian and breast cancer, like my paternal Grandmother.

The BRACA1 gene mutation (BR=breast, CA=cancer) is a dominant gene mutation, which has a 50-50 chance of being passed to the next generation. Men can be carriers, like my father. Until 18 months ago I had no idea that I had inherited it. If I had known, there are preventative measures I could have taken, such as a hysterectomy after having had my children and/or mastectomy. These would have dramatically reduced my likelihood of cancer... like by around 80% However, we didn't know that it was in our family.

Why the MJD Foundation?

I was recently in the Oncology waiting room when I read an article that touched me deeply. It was about the Machado-Joseph Disease, which is a hereditary neuro degenerative condition, and has a high prevalence in Arnhem Land. They think that it was introduced to the local Aboriginal people by traders many centuries ago. MJD begins by affecting walking and speech, and progresses to swallowing problems. Like BRACA1, it is a dominant genetic disorder, with a 50% likelihood of affecting members in the next generation, but MJD also shows its symptoms in younger patients with each presentation.

I really felt for these people, with this genetic time-bomb inside them. Like me. Uncertain of who would

be affected in the family... when and how to tell those affected... and I wondered why their story was not more widely known.

So, that night of my lightning bolt moment, I decided to tell their story along with mine, and to see if my mob could rally some support for their mob. And even to set up a Facebook page and group... something I had resisted for years! Hilarious irony for those who know my IT skills! With no immediate internet after the storm, I enlisted the help of friend Sal and my brother Kim to investigate MJD. We contacted the MJD Foundation, and my son Emile and Sal helped me to navigate Facebook and set up a group page.

The MJD Foundation told us of 2 respite houses that they are currently setting up in Darwin, and any funds my mob sends to the Foundation are well appreciated to furnish and modify the houses, to support rehab, and for recreational and medical stays. So, instead of bringing me a bunch of flowers or chocolates, maybe you would like to join Anna's Mob in donating and reading about MJD?

I think that this will be an empowering thing to see for my mob, now that I am getting sicker.

Thanks to all my wonderful family and friends. I am so blessed to be surrounded by my mob, and to have had nearly 60 years of extremely good health.

And a huge amount of love to the MJD mob, with wishes for speedy research to understand this condition better, for continuing treatment, and hopefully, for a cure in the future.

Xxxxx Anna.

Anna Michael - Anna's Mob

<https://chuffed.org/project/annas-mob-for-mjdf>



Thank you Anna – MJD HOUSE, Darwin



Anna Michael

Anna's Mob has raised over \$10,000! We've been so moved by Anna's generosity and her love for our clients/families. I never met Anna face to face but we spoke on the phone several times and I was touched by her graciousness and outlook on life. Anna passed away peacefully on 1st January 2020. We continue to think of all of Anna's family and friends and will always remember her.

MONEY STORY

'We are proud that the MJD Foundation not only maintained our workforce without having to stand anyone down through the period of COVID-19 restrictions, but our workforce grew to 45 staff members.'

- Nadia Lindop OAM, CEO

OUR FINANCIALS

STATEMENT OF PROFIT OR LOSS AND OTHER COMPREHENSIVE INCOME FOR THE YEAR ENDED 30 June 2020

	Note	2020	2019
		\$	\$
REVENUE	7	4,266,580	4,201,731
Administration Fees		(51,008)	(41,386)
Advertising & Marketing		(19,490)	(29,254)
Bank Charges		(2,334)	(1,057)
Bad Debts		(74)	-
Computers & Office Supplies		(27,875)	(22,859)
Clients Care & Support		(841,061)	(645,720)
Depreciation Expenses	8	(183,785)	(76,244)
Employment Expenses		(1,928,904)	(1,507,959)
Freight, Print & Postage		(7,793)	(8,006)
Insurance		(9,651)	(7,689)
Interest		(6,913)	-
Legal & Accounting		(13,088)	(6,000)
Medical Research & Resources		(54,668)	(97,162)
Motor Vehicle Expenses		(79,219)	(67,311)
Office Building Expenses		(28,454)	(33,014)
Rent & Storage		9,767	(28,354)
Repairs & Maintenance		(12,534)	(6,102)
Travel		(360,921)	(330,053)
Other Expenses		(180,301)	(264,394)
Total Expenses		(3,798,305)	(3,172,564)
Profit/(Loss) for the year		468,274	1,029,167
Other Comprehensive income for the year		-	-
Total comprehensive income for the year		468,274	1,029,167
Total comprehensive income attributable to the entity		468,274	1,029,167

OUR FINANCIALS

OUR FINANCIALS

STATEMENT OF FINANCIAL POSITION AS AT 30 JUNE 2020

	Note	2020	2019
		\$	\$
CURRENT ASSETS			
Cash & Cash Equivalents	15(a)	1,059,082	613,062
Receivables	9	937,864	580,422
Other Assets	10	40,045	42,378
Investments	11,4	19,910,815	20,111,264
TOTAL CURRENT ASSETS		21,947,805	21,347,126
NON-CURRENT ASSETS			
Property, Plant and Equipment	12(a)	950,664	756,964
Right of Use Asset	12(b)	175,836	-
TOTAL NON-CURRENT ASSETS		1,126,500	756,964
TOTAL ASSETS		23,074,305	22,104,090
CURRENT LIABILITIES			
Trade & Other Payables	13 (a)	357,907	243,936
Contract Liabilities	13(b)	135,322	-
Lease Liability		66,810	-
Provisions	14	240,611	173,385
TOTAL CURRENT LIABILITIES		800,651	417,321
NON-CURRENT LIABILITIES			
Lease Liability		106,099	
Provisions	14	27,617	15,106
TOTAL NON-CURRENT LIABILITIES		133,717	15,106
TOTAL LIABILITIES		934,368	432,427
NET ASSETS		22,139,937	21,671,663
EQUITY			
Retained Earnings		22,139,937	21,671,663
		22,139,937	21,671,663

STATEMENT OF CHANGES IN EQUITY FOR THE YEAR ENDING 30 JUNE 2020

	Note	Retained Earnings
		\$
Balance at 1 July 2018		19,992,591
Profit/(Loss) after income tax expense attributable to the entity		1,029,167
Adjustment for change in accounting policy		649,905
Total other comprehensive income for the year		-
Balance at 30 June 2019		21,671,663
Balance at 1st July 2019		21,671,663
Profit/(Loss) attributable to the entity		468,274
Total other comprehensive income for the year		-
Balance at 30 June 2020		22,139,937

Responsibilities of the Directors 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 in accordance with Australian Accounting Standards – Reduced Disclosure Requirements and the Australian Charities and Not-for-profits Commission Act 2012 and for such internal control as the directors determine is necessary to enable the preparation of the financial report that is free from material misstatement, whether due to fraud or error.

In preparing the financial report, the Board is responsible for assessing the entity'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 Board either intends to cease operations or have no realistic alternative but to do so.

Auditor's Responsibilities 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 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 the financial report.

As part of an audit in accordance with the Australian Auditing Standards, we exercise professional judgment and maintain professional scepticism throughout the audit. We also:

- Identify and assess the risks of material misstatement of the financial report, whether due to fraud or error, design and perform audit procedures responsive to those risks, and obtain audit evidence that is sufficient and appropriate to provide a basis for our opinion. The risk of not detecting a material misstatement resulting from fraud is higher than for one resulting from error, as fraud may involve collusion, forgery, intentional omissions, misrepresentations, or the override of internal control.
- Obtain an understanding of internal control relevant to the audit in order to design audit procedures that are appropriate in the circumstances, but not for the purpose of expressing an opinion on the effectiveness of the Entity's internal control.
- Evaluate the appropriateness of accounting policies used and the reasonableness of accounting estimates and related disclosures made by the directors.
- Conclude on the appropriateness of the directors' use of the going concern basis of accounting and, based on the audit evidence obtained, whether a material uncertainty exists related to events or conditions that may cast significant doubt on the Entity's ability to continue as a going concern. If we conclude that a material uncertainty exists, we are required to draw attention in our auditor's report to the related disclosures in the financial report or, if such disclosures are inadequate, to modify our opinion. Our conclusions are based on the audit evidence obtained up to the date of our auditor's report. However, future events or conditions may cause the Entity to cease to continue as a going concern.
- Evaluate the overall presentation, structure and content of the financial report, including the disclosures, and whether the financial report represents the underlying transactions and events in a manner that achieves fair presentation.

We communicate with the directors regarding, among other matters, the planned scope and timing of the audit and significant audit findings, including any significant deficiencies in internal control that we identify during our audit.

Nexia Sydney Audit Pty Ltd



Brett Hanger
Director

Dated at Sydney, this 16th day of November 2020.

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 Machado-Joseph Disease.



THANKS TO SOUTH32/GEMCO
FOR FUNDING THE PUBLICATION
OF THIS ANNUAL REPORT.



Staying stronger, for longer.

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