

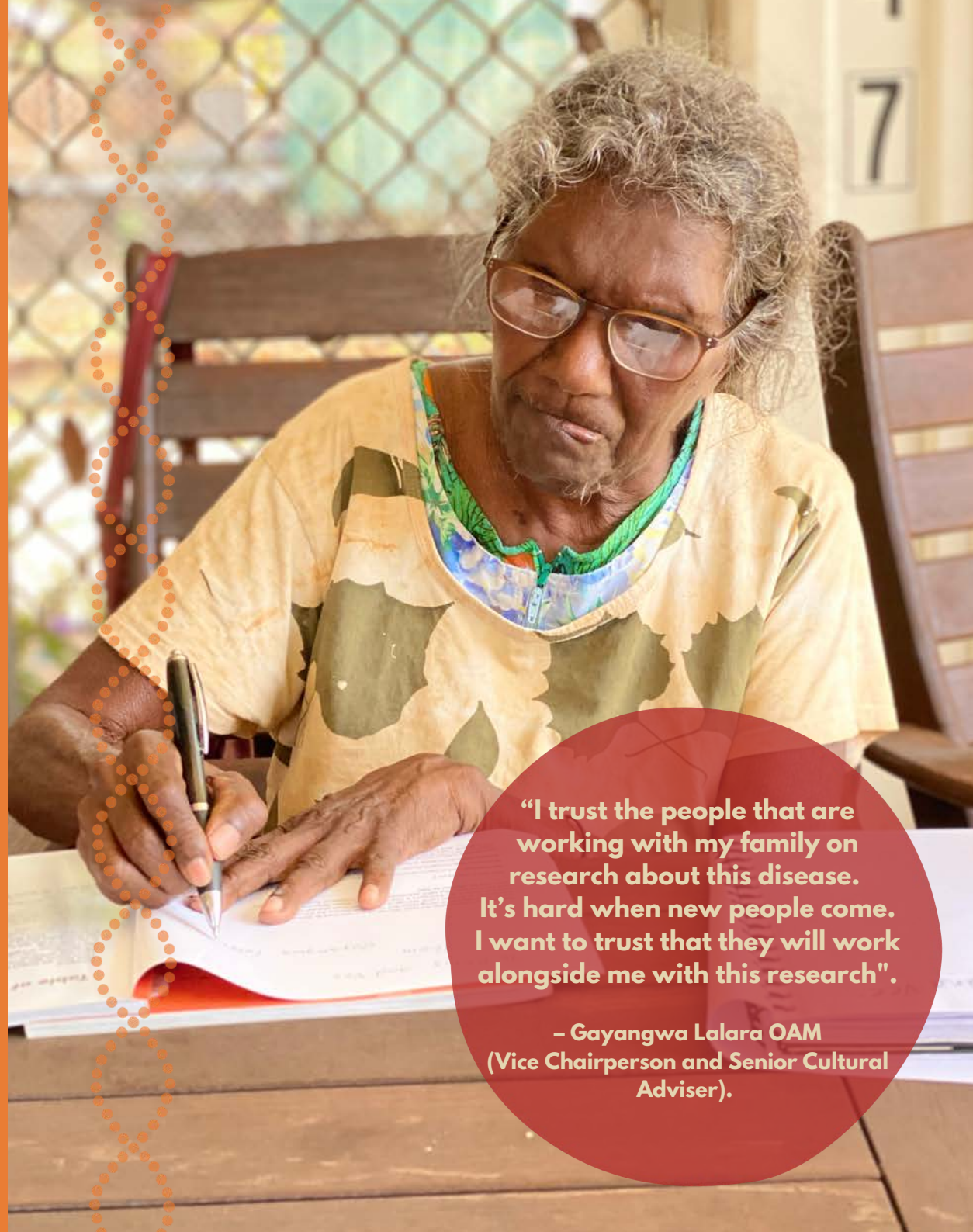


# FUTURE WAY 2022-2027 OUR STRATEGIC PLAN



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**“I trust the people that are working with my family on research about this disease. It’s hard when new people come. I want to trust that they will work alongside me with this research”.**

**– Gayangwa Lalara OAM  
(Vice Chairperson and Senior Cultural Adviser).**

## OUR MISSION

The MJD Foundation partners with Aboriginal & Torres Strait Islander communities to support families living with Machado-Joseph Disease (MJD) and Spinocerebellar Ataxia Type 7 (SCA7) by providing specialised knowledge and supports. We collaborate to conduct research providing hope for the future, and use our influence for change, so people living with MJD and related conditions can live stronger for longer.

## OUR VISION

A future free from  
MJD and SCA7.



STAYING STRONGER FOR LONGER

## OUR WAY

The MJD Foundation commenced in 2008 as a community driven response to families overwhelmed by Machado-Joseph Disease (MJD) and its devastating impacts. From grassroots on Groote Eylandt, and under the guidance of remarkable leadership from senior Aboriginal community members, we developed the principles for the development of our programs, the way we structure our workforce, how we deliver our services, and our model of engaging in other communities – we call this model 'Our Way'.

'Our Way' is a self-determination approach based on the Aboriginal & Torres Strait Islander way of experiencing the world and preferred practices. These include the centrality of family and kinship relationships, and prioritising collective decision-making and place-based responses.

'Our Way' governs all that we do in research, education, clinical and community services as well as the MJD Foundation's governance.

'Our Way' means we are family and client led.



## TWO-WAY APPROACH

To deliver health and disability services effectively in a non-dominant culture displaced for centuries, it is critical to prioritise and genuinely value the cultural and social issues that may constitute barriers to accessing these services.

This requires a 'two-way' approach, where staff members from different cultures (Aboriginal and non-Aboriginal) work side-by-side and learn from each other, partnering and sharing skills and knowledge to develop solutions tailored to meet the needs of people living with MJD and SCA7 and minimising workforce power imbalances.

Local members of the communities have the intimate knowledge held only by those in the correct relationships to each other which is necessary for MJDF to understand the needs of our clients. Therefore, in response to moiety divisions, avoidance relationship structures, and the hereditary nature of the disease, Aboriginal Community Workers are employed from within affected families. Many are also people living with MJD, which has assisted in mitigating the 'shame' that may be felt by people with MJD when seeking assistance.

This 'two-way' workforce model reflects the consistently expressed preference of MJD families for developing a trusted relationship with those providing support. Capacity in individuals and local community is also enhanced as culture, language and kinship relationships are taught alongside health and disability information.

# OUR VALUES

Our values are the things we believe are important in the way we work and live. We show up in our values, they guide **WHAT** we do and **HOW** we do what we do.

## TRUST

Trust is the foundation of our relationships. We do what we say we will do.



## TEAMWORK

We find joy in working together. It makes us stronger. We bring our best every day.



## FAMILY

Family is everything. We are connected by genetics, experience and our service to each other. Our relationships shape our growth.



## RESPECT

We listen to each other, take our time and honour our differences. In doing so we grow stronger.



# OVERARCHING STRATEGIC GOALS 2022 - 2027

1

**Our programs and services are designed and delivered following “Our Way”, being client/family led, with “Our Way” being embedded throughout all parts of the organisation.**

2

**Our service provision is equitable across locations, with a focus on overcoming the barriers of remote service delivery so that our clients can choose to stay living in, and cared for in their community.**

3

**The clinical and community services we deliver to our clients/families are best practice, based on evidence through robust research.**

4

**Our clients are prepared and eligible to participate in clinical trials.**

# OUR WORK AREAS

## RESEARCH



Our 'Research Cycle of Knowing' ensures MJD and SCA7 families have the best information about the disease and the ways to manage it. We listen to families to find out what's important to them. We both lead research and collaborate with experts, embedding 'Our Way' to ensure cultures and values are respected. We talk with MJD researchers around the world and share the latest news with our families. We are always looking to make life better for people with MJD and SCA7. We know that it is important to keep searching for a treatment and cure.

## EDUCATION



We believe that our clients and families receive better support if people in their lives understand more about MJD and SCA7, and are confident, capable and knowledgeable. We provide education to clients, their families, health professionals, careworkers and other support organisations.

## CLINICAL SERVICES



We provide specialist clinical services including:

- Genetic Care – providing culturally safe genetic education and counselling so that families better understand how MJD and SCA7 are passed down through families and have the knowledge they need to make decisions about their future.
- Neurology clinics – ensuring our clients have access to a specialist neurologist to track their disease progression and direct best practice interventions.
- Therapy program – delivering multidisciplinary, specialised knowledge and therapeutic services.

## COMMUNITY SERVICES



Our families are supported by a highly skilled multidisciplinary team comprised of Aboriginal Health and Community Workers, Health Professionals and Family Support Workers. Our team listens from the heart and responds with holistic family-centred practice working in partnership with families living with MJD and SCA7, by valuing and respecting an "Our Way" approach. We provide supports under the National Disability Insurance Scheme (NDIS), but do not limit our support to NDIS constraints.

## ADVOCACY



We strive to improve outcomes for our clients by ensuring the people who can make a difference, understand about MJD and SCA7, and understand how policies impact people's lives. We use our influence to encourage meaningful and practical changes to relevant policies and practices. We raise awareness of the impacts of MJD and SCA7 on families and communities.

## GOVERNANCE/ MANAGEMENT



We are an Aboriginal controlled organisation. We have a strong and dedicated Board who support the Strategic goals of the MJDF. Our staff strive for excellence bringing their best every day in: teamwork, the delivery of our programs, financial & legal regulatory compliance, fundraising & income generation. Our workforce strategy honours "Our Way" working, partnering Aboriginal and non-Aboriginal staff across MJDF activities.

# WHAT DOES SUCCESS LOOK LIKE?

**“I don’t want to move into Darwin, but I can’t get help with showering and getting dressed and going out. I want to stay living here on my country”**

**“I want to keep doing physio ‘on country’. It helps me be strong on the inside, so I can stay strong on the outside”**

**“It’s unique that we aren’t constrained by the NDIS in how we can support our clients, and we can also support the whole family. Other organisations are not like this. We need to keep this”**



**“I feel like I can talk to anyone in the MJD Foundation about genetics and they will help me”**

**“When it comes time for clinical drug trials, to be eligible our clients need to have been seeing a Neurologist to have accurate biomarker data available. Having this as a regular and expanded program is going to be a critically important for our clients”**

**“I used to only get help with emergency respite when things got really hard. I felt shamed. Now we know we have MJD House, and we look forward to it, and it keeps us stronger”**

**“Our submissions to government focus on solutions with strong evidence to support our recommendations”**



**“We hold a lot of knowledge about MJD and it’s so important that we put resources into ensuring our clients, families and staff understand the latest research and how it might impact our practice”**

**“Having family education in language is important so that our families truly understand”**

**“Collaboration and sharing of information is key. If we support other Disability support providers in training and building confidence in their support workers about how to care for people with MJD, we have better outcomes for clients, and we strengthen the sector”**

**“We want our own place in our community where MJD clients can go to rest, do our therapy, and maybe have a shower”**

**“Our funders feel that their support is well placed, with demonstrable outcomes and impact for our clients/families”**

**“That ‘Kin Connect’ program, bringing people home to their community when they have to live in Darwin. It’s so important. It makes their heart strong”**



**“What I really want to see is a tablet to help with that disease”**



# RESEARCH

STRATEGIC PRIORITIES AND KEY PERFORMANCE MEASURES

## WHAT WE WILL DO - OUR STRATEGIC PRIORITIES

### We will:

- A.1 Strengthen our research 'Cycle of Knowing' by facilitating knowledge transfer to clients/families about current research findings and listening to clients/families about what is important to them. ● ●
- A.2 Strengthen our national and international research linkages and partnerships to position us to lead and collaborate on research projects. ● ● ●
- A.3 Undertake activities to ensure our clients are eligible and able to make informed decisions when relevant clinical trials present. ● ● ●
- A.4 Ensure research findings are translated into best practice within our education, clinical and community services practices. ● ●

## KEY PERFORMANCE MEASURES

1. Completed 'Cycle of Knowing' occurs across each cohort\* over each 12-month period.
2. We are positioned to, and participate in, research initiatives as research leads or collaborators.
3. Our clients are eligible for and can participate in clinical trials as they occur.
4. Our research builds on the body of evidence that informs treatments and improvements for MJD and SCA7.

*\*a cohort is 'a group of people with shared characteristics'. For example, a cohort can be comprised of a group of people that share similar genetics and/or characteristics of disease, or that live in the same location, or that share service delivery issues, etc. People can also be a part of more than one cohort.*





## EDUCATION

### We will:

- B.1 Support those who provide care to people living with MJD and SCA7 to be confident, capable and hold the knowledge they need to meet their complex needs. ● ● ●
- B.2 Ensure our clients/families living with MJD and SCA7 feel well supported in their journey with the disease and are able to make informed decisions. ● ● ●
- B.3 Enhance our Education Resource Hub with resources that address clinical, disability care, genetic, social and cultural issues for individuals and their families who live with MJD and SCA7. ● ● ●

## KEY PERFORMANCE MEASURES

1. People who support those living with MJD and SCA7 report improved knowledge and confidence in caring for those with the disease.
2. Family-focused education workshops are delivered annually for each cohort.
3. People who support those living with MJD and SCA7 access the Education Resource Hub and complete training.



# WHAT WE WILL DO - OUR STRATEGIC PRIORITIES



## CLINICAL SERVICES

### We will:

- C.1 Ensure our clients/families living with, or at risk of, MJD or SCA7 can access and effectively engage with culturally accessible genetic services. ● ● ●
- C.2 Provide culturally safe, competent and best practice therapy to keep clients strong, inside and out, enabling our clients to stay stronger for longer. ● ● ●
- C.3 Support our clients to receive regular access to specialist neurological primary health care supports to track disease progression and direct best practice interventions. ● ● ● ●

## KEY PERFORMANCE MEASURES

1. Clients and families actively engage in genetic services.
2. Staff feel confident in their knowledge and ability to engage with clients of genetic services in a culturally safe way.
3. Clients have access to specialist, multidisciplinary therapy across communities.
4. The Therapy Program is contributing to trial readiness for our clients.
5. MJDF Therapy Program is recognised as a leader, utilising evidence to deliver 'best practice' services.
6. Every client can obtain a neurological assessment at least once per year.



## We will:

- D.1 Work to meet the critical and unmet needs of our clients no matter where they live. ● ● ●
- D.2 Allocate resources to implement 'in-place' services into remote communities (including client wellbeing and therapy hubs) to support our clients to remain living in and cared for in their remote community. ● ● ●
- D.3 Support our clients/families with holistic supports throughout their journey with MJD and SCA7, focused on staying strong on the inside and outside. ● ● ●

## COMMUNITY SERVICES

### KEY PERFORMANCE MEASURES

1. Clients can access shelter, food security, personal care, transport, access community, therapy and general support in their own communities.
2. 'In-place' services are established in identified priority communities.
3. We value and respect an 'Our Way' approach with our clients and do not limit our supports to NDIS constraints.



## WHAT WE WILL DO - OUR STRATEGIC PRIORITIES

1 2 3 4



### ADVOCACY/ INFLUENCE

#### We will:

- E.1 Raise awareness of MJD and SCA7, including the high prevalence and need among Aboriginal & Torres Strait Islander families living in the Northern Territory and Far North Queensland. ● ● ●
- E.2 Allocate resources to ensuring NDIS delivers for all our clients living with MJD and SCA7 by participating in opportunities to provide evidence and solution focused feedback. ● ● ●
- E.3 Focus advocacy efforts and influence on Aboriginal & Torres Strait Islander access to services; degenerative conditions; remote service delivery; NDIS improvements; social determinants of health. ●

### KEY PERFORMANCE MEASURES

1. MJDF expertise and advice is sought by government and non-government agencies in relation to MJD, SCA7 and disability support servicing in remote and very remote Australia.
2. Quality of NDIS plans improve over time with MJDF recommended principles being adopted.
3. We develop and deliver on an annual Advocacy Plan.



# WHAT WE WILL DO - OUR STRATEGIC PRIORITIES



## GOVERNANCE/ MANAGEMENT

### We will:

- F.1 **Maintain high levels of excellence in governance and accountability as an Aboriginal Controlled Organisation, and actively seek opportunities for continuous improvement in meeting our legal and regulatory compliance requirements.** ● ●
- F.2 **Maintain and expand government, philanthropic and corporate support via carefully targeted fundraising strategies and continued engagement with existing supporters.** ● ●
- F.3 **Strengthen and showcase 'Our Way' through embedding of our workforce strategy.** ●
- F.4 **Strengthen partnerships with organisations to support delivery of client services into communities and increases opportunity for 'in-place' supports.** ● ●
- F.5 **Consider impacts of climate change and be responsible across the organisation.** ● ●

## KEY PERFORMANCE MEASURES

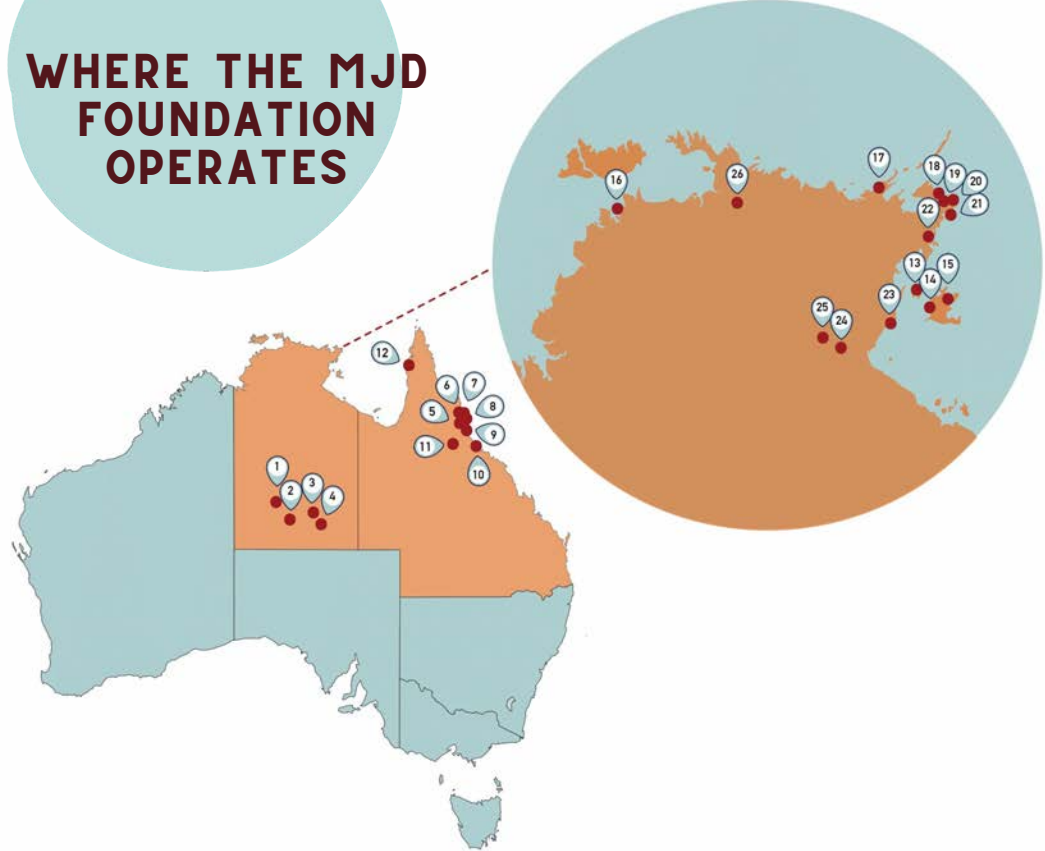
1. Our compliance register is current, complete and consistently of a high standard.
2. We have a Board endorsed Funding and Income Generation Strategy with agreed targets that are met annually.
3. Our Aboriginal workforce are engaged and our non-Aboriginal workforce are confident in working 'Our Way'.
4. We demonstrate strong relationships with community based organisations and actively seek opportunities for partnership.
5. We demonstrate environmentally sustainable practices in our work.



# MJD FOUNDATION

WWW.MJD.ORG.AU  
1300-584-122  
ABN: 65 159 208 867

## WHERE THE MJD FOUNDATION OPERATES



**DARWIN**  
PO BOX 1745  
NIGHTCLIFF  
NT 0814

**CAIRNS**  
PO BOX 606  
CAIRNS NORTH  
QLD 4870

**GROOTE EYLANDT**  
PO BOX 414  
ALYANGULA  
NT 0885

|  |   |  |   |   |
|--|---|--|---|---|
| <b>Central Australia</b><br>1. Papunya<br>2. Ntaria (Hermannsburg)<br>3. Mparntwe (Alice Springs)<br>4. Ltyentye Apurte (Santa Teresa) | <b>Far North Queensland</b><br>5. Atherton<br>6. Kowrova<br>7. Ngoonbi (Kuranda)<br>8. Gimuy (Cairns)<br>9. Yarrabah<br>10. Townsville<br>11. Mareeba<br>12. Napranum | <b>Groote Archipelago</b><br>13. Milyakburra<br>14. Angurugu<br>15. Umbakumba<br><br><b>Darwin</b><br>16. Darwin | <b>East Arnhem Land</b><br>17. Galiwin'ku (Elcho Island)<br>18. Birritjimi (Wallaby Beach)<br>19. Gunyangara (Ski Beach)<br>20. Nhulunbuy (Gove)<br>21. Yirrkala<br>22. Birany Birany | <b>South East Arnhem Land</b><br>23. Numbulwar<br>24. Ngukurr<br>25. Urapunga<br><br><b>West Arnhem Land</b><br>26. Gunbalanya (Oenpelli) |
|--|---|--|---|---|



The MJD Foundation proudly acknowledges the Traditional Owners of the many lands on which we work and the clients/families we serve living across the Northern Territory and Far North Queensland. We recognise the continued connection to these lands, waters and communities and the critical importance to our clients in maintaining these connections throughout their journey with MJD and SCA7.

We particularly acknowledge all our Aboriginal & Torres Strait Islander families, paying respect to their culture and language, and appreciating the wisdom and guidance from elders both past and present.