



## **Governance Statement to declare MJD Foundation Limited as an Aboriginal<sup>1</sup> Controlled organisation.**

Last updated: 16/06/2023

The MJD Foundation Limited (MJDF) is a Public Company limited by Guarantee and is registered with ASIC under the Corporations Act. The MJDF is also registered with the Australian Charities and Not-for-Profit Commission (ACNC) under the Charities Act.

The MJDF 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 SCA7 live stronger for longer.

The MJDF is a grantee of the Aboriginals Benefit Account (Commonwealth) and Anindilyakwa Land Council.

The MJDF aligns with a key outcome under the *Northern Territory Disability Strategy 2022 – 2032*, (Outcome 3: People with disability can access the places, information and services they need). MJDF increases the choice of quality, culturally competent disability service providers across the Territory, through an enhanced role for Aboriginal Community Controlled Organisations in the provision of disability services. The MJDF as an Aboriginal Community Controlled Organisation through its Governance structure actively contributes to this priority.

The MJDF is an Aboriginal organisation that adheres to the Principles and Standards as set down in the Articles of the *United Nations Declaration on the Rights of Indigenous Peoples* (the Declaration) of which Australia endorsed on 3 April 2009.

The following Articles underpin the operation of the MJDF.

- Article 3 – Self Determination
- Article 5 – Our Own Institutions
- Article 18 – Decision-Making
- Article 22 – Special needs (reference to disability)
- Article 24 – Health and Traditional Medicines
- Article 31 – Cultural Heritage and Traditional Knowledge
- Article 33 – Determining our Identities

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<sup>1</sup> If the MJDF uses the term Aboriginal in preference to Aboriginal and Torres Strait Islander it is to recognise 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 or other closely associated Ataxias.



**Article 3 – Self-Determination**  
**Article 18 – Decision Making**  
**Article 22 – Special Needs**

Principle: Self-Determination and participation

Standard: Organisation created by Aboriginal Australians, for Aboriginal Australians

The establishment of the MJD Foundation in 2008 was led by Groote Eylandt Traditional Owners who wanted more support for their family members living with Machado-Joseph Disease.

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). (MJDF. 2021, p8)

The MJD Foundation has now expanded to provide supports to other communities across the Northern Territory and Far North QLD where Aboriginal Australians live with Machado-Joseph Disease.

The MJDF works in partnership with Aboriginal Australians, their families and communities affected by Machado-Joseph Disease, providing specialised supports, engages in research providing hope for the future, and uses our influence to advocate for improved outcomes for people living with MJD.

The MJDF has substantial and unique experience in Aboriginal very remote non-government disability service provision.

Principle: Aboriginal representation in Governance and workforce

Standard: The MJD Foundation is governed by a Board of Directors – with a minimum of 51% of positions held by Aboriginal Australians.

The MJD Foundation's employees are – 46% Aboriginal Australians.

Aboriginal people affected by MJDF, their families, their communities and the Aboriginal Workforce lead and guide through input in the MJD Foundation's Strategic Plan.

['Ngeniyerriya – The History of Machado-Joseph Disease on Groote Eylandt'](#). This is a story of strength, and honours the lives of Groote Eylandters who have passed away from MJD (MJDF 2021 14)

**Article 5 – Our Own Institutions**  
**Article 33 – Determining Our Identities**

Principle: Control and Ownership

Standard: Beneficiaries of an organisation are Aboriginal

The MJD Foundation's clients/beneficiaries are only Aboriginal Australians

Standard: Aboriginal stakeholder support

The Anindilyakwa Land Council on Groote Eylandt remain the largest financial supporter of the MJD Foundation.



**Article 24 – Health and Traditional Medicines**  
**Article 31 – Cultural Heritage and Traditional Knowledge**

Principle: Inform and Consent

Standard: Through the MJDF Research program

Facilitate best practice research towards discovery of a treatment for MJD and encourage excellence in the interface between Aboriginal people living with MJD and researchers. (Strategic Plan 2018 – 2021).

The research agenda is designed by Aboriginal people living with MJD, their families and their communities through the MJDF's 'Cycle of Knowing'.

Treatment options are prioritised, and MJDF researchers conduct research in an ethically sound and culturally informed manner. Research findings are properly documented, published, and translated into practice. (Strategic Plan 2018 – 2021)

Dr Angela Laird and her team at Macquarie University focus on the search for treatments to help people living with MJD. Dr 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.



## REFERENCES:

MJD Foundation Limited: (2018). *MJD Foundation – Disability Service Delivery Model – A review of the MJD Foundation’s disability service delivery model: contrast and comparison to traditional disability service models.*

MJD Foundation (2021) *Annual Report 2020/21*

MJD Foundation (2018) *Strategic Plan 2018 – 2021*

MJD Foundation (2021) *Ngeniyerriya – The story of Machado-Joseph Disease on Groote Eylandt*

MJD Foundation (2022) *Annual Report 2021/22*

MJD Foundation (2022) *Future Way (2022-2027) – Our Strategic Plan*