

A photograph of two women high-fiving outdoors. The woman on the left is an older Black woman with her hair in a bun, wearing a yellow shirt, and she is smiling broadly. The woman on the right is a younger white woman with short brown hair, wearing a light blue t-shirt and a watch, looking towards the older woman. The background is a blurred outdoor setting with a wooden fence and greenery.

**LET OUR HOPE
BECOME YOUR WILL**

A FUTURE FREE FROM
MACHADO-JOSEPH DISEASE

A FUTURE FREE FROM MJD

We believe the impossible is possible and strive to create a future free from Machado-Joseph Disease (MJD). A treatment to slow the effects of MJD would have far reaching affects on Aboriginal communities and families globally. We're investing in that possibility and invite you to join us.



MJD Foundation

PO Box 414

Alyangula NT 0885

www.mjd.org.au

1300-584-122

ABN: 65 159 208 867



TOGETHER WE CAN...

Machado-Joseph Disease is a neurodegenerative disease that impacts the lives of individuals, families and their communities internationally. The disease affects adults and children, slowly reducing their muscular control. The majority of Australians with the disease are Aboriginal people living in some of the most remote and inaccessible parts of the country. This makes service delivery challenging.

The MJD Foundation is a charitable organisation. It provides comprehensive supports in partnership with Aboriginal¹ Australians, their families and communities living with Machado-Joseph Disease and engages in research providing hope for the future. The MJD Foundation works directly with communities listening to their needs. Aboriginal Australians are employed by the MJD Foundation to work in partnership with non-Aboriginal staff for all activities, including client support and co-research.

In the business of making change, going the extra mile is something that makes this work possible. The gift of a volunteer's time, the effort to raise funds, or a bequest in your will to the MJD Foundation are the everyday acts of heroes. We hope you can join us on this here journey.

¹ The MJD Foundation 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 referred to in the national context. No disrespect is intended to our Torres Strait Islander families and communities. The MJD Foundation acknowledges the inclusion of Torres Strait Islanders who may be affected by MJD.

BAKALA'S STORY

Steve (Bakala) Wurramara first noticed signs of Machado-Joseph Disease in his late teens and has spent his entire adult life challenging the progressive effects of the disease.

Driven by a desire for a better future for himself and his family, Bakala is searching for a cure. He explores the land and the sea of the Grootte Archipelago, making balms from plants, testing bush medicines and using ceremony in the hope for an answer - and he has got scientists interested. With the support of Macquarie University's Zebrafish research lab, which is leading the search for a treatment for MJD, his findings are being tested alongside western medicine. He believes that his dream for a future free from MJD will become a reality for his people and all people living with MJD.





**LET OUR HOPE
BECOME YOUR WILL**

LEAVE A LEGACY, CHANGE THE WORLD...

We would like to ask you to consider leaving a bequest to the MJD Foundation in your will. We at the MJD Foundation are passionate about supporting Aboriginal Australians and their families living with Machado-Joseph Disease.

Your support will help deliver services directly to Aboriginal Australians and support the research needed to find an effective treatment. Together we could change the lives of people living with Machado-Joseph Disease.

We all hope to look after our families and loved ones to ensure they have the best possible lives. Supporting the work of the MJD Foundation will enable this to happen.

Neil Westbury PSM

MJD Foundation Chairperson



**TOGETHER WE CAN
MAKE A DIFFERENCE**





WHAT IS MACHADO JOSEPH DISEASE?

MJD is a hereditary neurodegenerative condition and there is no known cure. The effects of the disease have been known to the Aboriginal people of Arnhem Land for many generations. Within 5 to 10 years after the onset of symptoms most people are wheelchair bound and fully dependent for all activities of daily living. There are over 650 people alive today in the Northern Territory and Far North Queensland who are at risk of having the disease.

THE MJD FOUNDATION is a charity, established in 2008 to support Aboriginal Australians and their families living with Machado-Joseph Disease (MJD) in Arnhem Land and beyond. The MJD Foundation works in partnership with Aboriginal Australians, their families and communities living with Machado Joseph Disease to provide comprehensive supports and engage in research providing hope for the future. These services include:



EDUCATION

Training health professionals, careworkers and family carers.
Providing genetic education/counselling



RESEARCH

Searching for a treatment and cure for MJD.
Ensuring health professionals are aware of the latest research.



EQUIPMENT

Providing equipment and assistive technology to improve activities of daily living and increase mobility.



ADVOCACY

Being a voice for clients to affect policy.
Fundraising
Raising awareness of MJD.



COMMUNITY SERVICES

Coordinating supports.
Staying stronger for longer.
Providing therapy
Improving wellbeing.

An aerial photograph of a coastal landscape. The foreground shows a rocky, brownish terrain with sparse green vegetation. In the middle ground, there is a large body of turquoise water, possibly a bay or a large lake, surrounded by more land. The background shows a hazy horizon under a cloudy sky.

CHANGING LIVES

John MacMillian left a legacy, a lasting impact on the lives of hundreds of Aboriginal Australians. He dedicated time, passion and academic rigour to explaining the genetics of MJD.

He empowered Aboriginal Australian families affected by the disease to make more informed decisions. His work with the MJD Foundation was a fundamental step in decreasing the shame previously associated with the disease in these communities. His legacy lives on today

Associate Professor John MacMillan was a medical geneticist. Grounded by nature and driven by a desire to create social change, he found a deep passion providing genetic education and counselling to Aboriginal Australian families affected by MJD. He established the MJD Foundation genetic counselling and education program and was instrumental in developing education resources and genetic counselling guidelines.

John passed prematurely, aged 55 years in Dec 2014, but his contribution and legacy continues. "He was resilient and resolute, leading others to focus on what matters in the face of adversity".

The **"John MacMillan Indigenous Australian Genetic Education Program"** fund was established upon his death to continue his crucial work of providing genetic counselling to Aboriginal Australians.

John's work continues to change the lives of Aboriginal Australians and their families living with MJD in Arnhem land and beyond.



WHAT IS A BEQUEST?

By providing a gift to the MJD Foundation in your will through a bequest, you make a powerful commitment that will change the future, for the better, for generations to come.

Your bequest

will be used to support Aboriginal Australians and their families living with Machado Joseph Disease into the future.



It's the chance to improve lives and change the future for Aboriginal Australians living with MJD and their families.





Passion & Commitment

A bequest is the ultimate statement of your commitment to a lifelong passion.



MAKING A GIFT IN YOUR WILL TO THE MJD FOUNDATION

Including a bequest to the MJD Foundation is easy. When you make a Will, or update your existing one, simply ask your Solicitor to include a bequest to the MJD Foundation Ltd.

Here are three options for including a bequest in your will.

A percentage of my estate



You may choose to give any percentage of your estate. The correct wording to bequeath a percentage of your total estate is as follows: *"I give and bequeath ___ per cent of my estate to the MJD Foundation, PO Box 414, Alyangula NT 0885 and declare that the receipt of an executive officer at the time, shall be sufficient discharge of my executor's duty."*



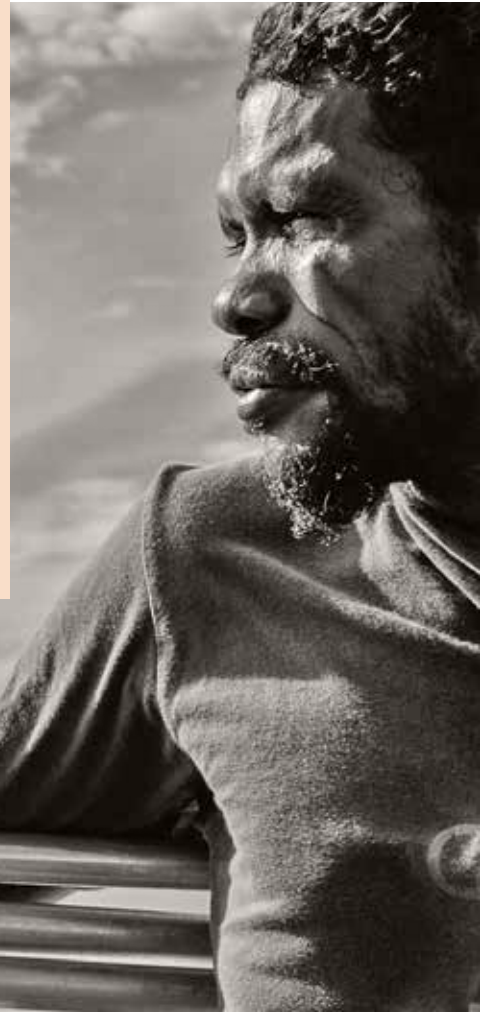
A specific amount from my estate

You may choose to leave a specific amount of money from your estate. In that case, the correct wording is as follows: *"I give and bequeath \$___ from my estate to the MJD Foundation, PO Box 414, Alyangula NT 0885 for its Endowment Fund and declare that the receipt of an executive officer at the time, shall be sufficient discharge of my executor's duty."*

The residue from my estate



After you have taken care of your family, friends and any debts, you may choose to leave the remainder from your estate. In that case, the correct wording is as follows: *"I give and bequeath the rest and residue from my estate to the MJD Foundation, PO Box 414, Alyangula NT 0885 for its Endowment Fund and declare that the receipt of an executive officer at the time, shall be sufficient discharge of my executor's duty."*



WHERE WILL MY MONEY BE SPENT?

We believe that your money should be spent providing services directly to Aboriginal Australians or used to further research.

It is important to us that you feel your contribution is making a difference to the people you care about.

100%

We have the administrative and organisation costs covered, which means we can guarantee that every dollar you bequest goes directly to services or research for Aboriginal Australians living with MJD.





WE ARE HERE TO HELP

Not sure what to do next or have some question about making a bequest – then we're here to help. No matter what your question, we'd love to talk to you.



THANK YOU

It makes me more comfortable now to know that there are people helping my family and other families with this disease. I am proud of the MJD Foundation and when I finish up I will know that the MJD Foundation will be around for a long time to keep helping.

Gayangwa Lalara
Vice Chairperson



**THANK YOU FOR BEING
PART OF THE CHANGE
& WORKING TOWARDS
CREATING A FUTURE
FREE OF MJD DISEASE**





REACH OUT TO US

Please contact:

Nadia Lindop
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Ph: 1300-584-122
Email: nadia.lindop@mjd.org.au

Or write to us at:

MJD Foundation
PO Box 414
Alyangula NT 0885