

The MiNDAUS Registry is supported by:



"Advocacy, research and support for people living with MND"



Learn more and join the Registry at:

www.mindaus.org

Or scan the QR code:



If you have any questions about the Registry please email:

mindaus@mndaustralia.org.au

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MiNDAUS REGISTRY

The Australian Motor
Neurone Disease Registry

manage • share • contribute



Why do we have the MiNDAUS Registry?

There is still a lot we don't know about MND, including its causes and why it affects people in different ways.

The MiNDAUS Registry collects health information during your normal clinic visits as well as any information you may choose to enter. By allowing us to collect your health information you will become part of the bigger picture, helping us to understand MND and to develop better treatments and improve care and services.



The MiNDAUS Registry:

- ✓ Is Australian, voluntary, and highly secure
- ✓ Allows you to see the information collected about you
- ✓ Offers a free, ready to use personal MND Health Record which you or a carer or family member can edit, change, or share at any time
- ✓ Is quick and easy – you can register yourself or ask your clinic to register you

Taking part in clinical trials and research

If you agree, your information can be used to determine if you are suitable for a clinical trial or linked to approved research.

The MiNDAUS Registry team may contact you about potential clinical trials, but we will never share any information that will identify you.

By joining the Registry, we're working together to:

- ✓ Develop a single source of information about people with MND in Australia
- ✓ Know how many people live with MND in Australia and where they live, so we can better target services to support them
- ✓ Improve research into better treatments, improved care and one day a cure for MND

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