

Medical Research Future Fund



Accelerated Research Investment – Motor Neurone Disease

INVESTMENT

The Australian Government will invest **\$2 million** in new targeted clinical trial activity for adults with Motor Neurone Disease (MND).

KEY ELEMENTS

Investment will facilitate new clinical trial activity, and provide vital access to trials for Australian adults with MND, to test whether existing medicines can improve treatments and outcomes for these patients.

RATIONALE

- Every day in Australia, two people are diagnosed with MND, and two people die because of MND.
- Incidence of MND appears to have more than doubled over the last twenty years.
- The cause of MND is not yet understood and there is no known cure. The average survival rate is three to five years.
- Clinical research is crucial in determining the next generation of clinical interventions and best practice care for patients with MND.
- Australians living with MND have poor access to clinical research.
- This investment will enable up to 200 Australian adults with MND to participate in a clinical trial, subject to trial inclusion/exclusion criteria.

DESIRED OUTCOMES

- New opportunities for clinical trial participation and associated benefits for the latest research.
- Rapid patient trial recruitment.
- Access to new interventions and treatment options.
- Purposeful collaboration with researchers across health services and institutions, and with the private sector.
- Translation of scientific discovery into best practice treatment and therapies, and greater sector capacity in trial collaboration and delivery.
- Reinforcement of Australia's position as a preferred destination for clinical trials.

MEDICAL RESEARCH FUTURE FUND

The Medical Research Future Fund (MRFF) demonstrates the Government's strong commitment to research and innovation. The MRFF provides a long term sustainable source of funding for endeavours that aim to improve health outcomes, quality of life and health system sustainability.

The MRFF will double direct Australian Government funding for health and medical research.

The MRFF is a dedicated vehicle for priority investment in health and medical research.

The MRFF, established under the *Medical Research Future Fund Act 2015*, provides grants of financial assistance to support health and medical research and innovation in improving the health and wellbeing of Australians. It operates as an endowment fund with the capital preserved in perpetuity. At maturity, the MRFF will reach \$20 billion.

The first disbursements from the MRFF focus on translating research into real health benefits, breakthrough investments in new technologies and challenges, and enhancing Australia's reputation for research excellence and leadership.

Over \$65 million will be injected into a range of programs that cut across the research pipeline – fuelling new discoveries and the translation and commercialisation of great Australian ideas.





KEY FACTS

- Clinical trials are research investigations that explore whether a medical strategy, treatment or device is safe and effective for humans.
- Trials are important tools that contribute to knowledge, generate best practice, prove the efficacy of new treatments and change clinical practice and policy.
- MND refers to a group of diseases in which the nerve cells (neurons) controlling the muscles that enable movement, speech, swallowing and breathing fail to work normally. As the disease progresses these important cells eventually die. With no nerves to activate them the muscles gradually weaken and waste.
- With no residual muscles or strength, MND patients are often left motionless, mute and trapped in once active bodies. In the majority of cases, the mind and intellect are left intact.
- MND is a progressive and fatal disease (the average life expectancy from diagnosis is 27 months) and affects more than 2,000 people in Australia.
- MND is also known as Amyotrophic Lateral Sclerosis (ALS) or Lou Gehrig's Disease, after the famous American baseball player who succumbed to the disease.
- The incidence of MND appears to be increasing with more than 700 deaths in 2013 in Australia, compared with only 330 deaths in 1993.
- There are no available treatments that prevent, or stop, disease progression for MND.
- Currently, less than 100 MND patients are enrolled in clinical trials in Australia.
- The Cure for MND Foundation is a not-for-profit charity that aims to raise awareness about MND, improve care for those affected by the disease, and increase vital research funding to find a cure.
- Cure for MND is Australia's largest and independent funder of MND research and clinical trials.

IMPLEMENTATION

- Cure for MND Foundation will administer this research program.
- Trials investment will be based on scientific rigour with the focus on pre-clinical work to test the viability of re-purposed drugs for those who suffer from MND.
- Where possible, private sector co-investment opportunities will be explored and international researcher collaborations established.

ADVISORY BOARD

The Australian Medical Research Advisory Board, established in accordance with the *MRFF Act*, is responsible for consulting on and developing a five-yearly Strategy that sets out the vision, aims and objectives for the MRFF and an accompanying two-yearly list of Priorities. The Government must consider the Strategy and Priorities in making MRFF investment decisions.

STRATEGY 2016-2021

VISION: A health system fully informed by quality health and medical research.

Identifies key strategic investment platforms that set to position Australia to meet future healthcare challenges:

- Strategic and international horizons
- Data and infrastructure
- Health services and systems research
- Capacity and collaboration
- Trials and translation
- Commercialisation

PRIORITIES 2016-2018

The first MRFF disbursements address identified Priorities under each strategic platform, are a mix of strategic investments, and use a range of administrative mechanisms to maximise impact. More disbursements will occur in 2017-18.

FOR MORE INFORMATION

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