



Senate Standing Committee on Community Affairs

Legislative responses to Recommendations of the Lockhart Review

September 2006

Legislative responses to Recommendations of the Lockhart Review

Submitted via email

to:

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On:

3 October 2006

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The Motor Neurone Disease Association of Australia (MNDAA)

congratulates the Government and the Prime Minister on the selection of the members of the Lockhart Review Committee who, we understand, were selected because of their pre-eminent expertise, particularly related to science and ethics. MNDAA appreciates this opportunity to make a submission to the Senate Standing Committee on Community Affairs concerning the exposure draft *Somatic Cell Nuclear Transfer and Related Research Amendment Bill 2006*.

1,400 people in Australia today are living with motor neurone disease (MND). Each day at least one Australian dies of MND and a new person is diagnosed with this progressive and inevitably fatal disease.

Average life expectancy is 2 to 3 years. During this time people with MND become progressively more paralysed and have increasing difficulties with their speech, swallowing and breathing. Generally people with MND remain mentally alert as they face a series of losses and become more and more dependent on their families and service providers for care.

Although MND was first described nearly 150 years ago there is still no known cause and no known cure. Research provides hope for people living with MND and their families that the cause or causes of this devastating disease will soon be discovered, hope for a treatment to extend life expectancy and quality of life and hope for an eventual cure. The Motor Neurone Disease Association of Australia (MNDAA) therefore supports and promotes all forms of scientifically and ethically reputable research.

The Motor Neurone Disease Association of Australia (MNDAA) is the national peak body for MND in Australia. During 2005/06 **404** people newly diagnosed with MND registered with MND Associations across Australia and the state/territory Associations were informed of 315 people who had had lost their fight with MND. 958 people were registered with State/Territory Associations as of 1/7/06.

MNDAA's Research Policy (October, 2005) states that:

"MNDAA supports research which is legal, has sound scientific rationale and has the potential to bring us closer to finding the cause, treatment or cure for MND."

MNDAA recognises that research on embryonic stem cells poses ethical dilemmas for some Australians; however, we believe that the only way to fulfill our vision of ***a world free from the impact of MND*** is to investigate all legal and ethical research avenues.

For this reason The Motor Neurone Disease Association of Australia supports the recommendations of the Lockhart Review.

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MNDAA therefore agrees with the legislation on the basis of the recommendations of the Lockhart Review.

The Lockhart Review Committee's recommendations dramatically broaden avenues for scientific research into spinal cord injuries and diseases such as motor neurone disease, particularly options relating to somatic cell nuclear transfer (SCNT).

Concluding comments in the Lockhart Review's 54 recommendations are "that the creation of human embryos by nuclear transfer should be permitted, according to strict regulatory guidelines, including strong ethical guidelines for egg donation" (Section 11.2)

Importantly The Lockhart Review distinguishes between the reproductive and therapeutic cloning below:

- While reproductive cloning aims to copy a person, SCNT only aims to copy a person's cells; therefore, provided the person consents, there is no objection to this.

Research with SCNT is now legal in Great Britain, Sweden, Belgium, Singapore and Israel.

The potential for the recommendations of the Legislative Review Committee to increase our understanding of the causes of motor neurone disease and to help lead to treatments and eventually a cure, cannot be underestimated.

MNDAA supports the substance and purpose of the bill presented to the President of the Senate Community Affairs Committee. People with MND, their families and friends hope the Committee also supports the bill.

MNDAA would welcome the opportunity to participate in the proposed public hearings during October.

A handwritten signature in blue ink, appearing to read 'Carol Birks', with a horizontal line underneath.

Carol Birks
National Executive Director

Motor Neurone Disease Association of Australia

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