mnd
New South Wales

26 September 2006

President
Senate Community Affairs Committee
community.affairs@aph.gov.au

Submission to the Inquiry into the Legislative responses to Recommendations of the Lockhart Review

The Motor Neurone Disease Association of NSW (MNDA NSW) represents people living with motor neurone disease (MND), their families and carers across NSW. MNDA NSW provides ongoing support, information, education and equipment for people with MND as soon as the need arises wherever possible. Our Regional Advisors help clients navigate the health and disability system and make referrals to the relevant services.

MNDA NSW currently has 346 people with MND registered. In 2005/2006 173 new members joined the Association and 128 members died from MND during that period. The median life expectancy for our members is 27 months from diagnosis to death.[1]

At present there is no known cause and no known cure for motor neurone disease. 90% of cases are sporadic and the other 10% of cases are familial 20% of whom carry the identified SOD1 gene.

The disease is terminal leading to progressive paralysis of limbs and increasing difficulties with speech and swallowing. Generally the person remains astute and mentally alert, however eventually people with MND are unable to breathe without assistance. In most cases people rely entirely on their families for care and in many cases the person has young children.

Whilst we understand that there are a broad range of views within our membership we believe that the only way to fulfil our vision of *a world free from MND* is to investigate all legal and ethical research avenues.

For this reason MNDA NSW supports the recommendations of the Lockhart Review.

MNDA NSW congratulates the Government on its selection of the members of the

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[1] MNDA NSW client database

Motor Neurone Disease Association of New South Wales Inc.
Building 4, Gladesville Hospital Victoria Road Gladesville NSW 2111
Locked Bag 5005 Gladesville NSW 1675
Phone: 02 8877 0999 Freecall: 1800 640 144 Fax: 02 9816 2077
admin@mndnsw.asn.au www.mndnsw.asn.au
ABN 12 387 503 221 CFN 11154

Lockhart Review Committee and we realise that each Committee member's selection was supported by the Prime Minister because of their pre-eminent expertise, particularly relating to science and ethics.

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.

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

MNDA NSW 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.

If you require any further information please feel free to contact me.

Sincerely

Graham Opie
Chief Executive Officer