MND

MOTOR NEURONE DISEASE
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The Secretary
Standing Committee on Community Affairs
Parliament House
Canberra ACT 2600

By email: community.affairs.sen@aph.gov.au

Dear Secretary

RE: Legislative responses to recommendations of the Lockhart Review

The MND Association of Victoria (MND Victoria) supports the proposed legislative responses to the recommendations of the Lockhart Review to create and expand opportunity to find cause, treatment and cure for motor neurone disease and many other cruel and heartless diseases that affect our community.

Motor Neurone Disease is a progressive neurological disease that kills people. More than one person every day dies from motor neurone disease, and another person is diagnosed. This disease strips away people's abilities to walk, talk, swallow, breath and speak. It removes their capacity to influence their environment. It takes away their capacity to touch, hug, cuddle and kiss – yet it leaves an active mind, aware of what is happening but powerless to do anything about it. Attached is a background paper on MND for your information.

MND Victoria has a broad membership and works in a community of diverse views and opinions, and a wide range of underlying moral and ethical positions.

MND Victoria supports the recommendations of the Lockhart Review.

MND Victoria believes that the pursuit of cause, treatment and cure for motor neurone disease requires exploration of the broadest possible opportunities for research. These opportunities must be legal, have a clear scientific rationale, and potential to bring us closer to finding cause, treatment and cure for motor neurone disease.

The Government created an eminently qualified review committee to review these Acts and make recommendations. The Lockhart Review recommendations create a supportive and empowering framework for scientific research that incorporates legislative approval with strict, effective controls and limitations. It maintains the prohibition on human reproductive cloning.

MND Victoria believes that opportunity exists for advances in the study of motor neurone disease through the use of stem cells. It also believes that differently sourced stem cells provide different opportunities. In particular, MND Victoria believes that somatic cell nuclear transfer (SCNT), to create stem cells of a person diagnosed with motor neurone disease, creates some unique opportunities in research into motor neurone disease that are not available through stem cells derived from other sources.

People living with MND, and those that will be diagnosed in the future, need the potential that comes from stem cell research to find cause, treatment and cure. They need recognition of the different opportunities adult and embryonic stem cells offer. They need the unique opportunity that SCNT offers to examine neurons of and from a person living with MND to learn about the disease progression and to identify potential treatments.

We want to rid the world of MND. People living with the disease want that too.

If you require any further information please contact me on 03 9830 2122 or 1800 80 6632.

Yours faithfully

Rodney Harris

Rodney Harris
Chief Executive Officer

BACKGROUND INFORMATION

ON

MOTOR NEURONE DISEASE

September 2006

MOTOR NEURONE DISEASE

Some background

General

- Motor Neurone Disease is the name given to a group of diseases in which damage to motor neurones occurs. Motor neurones are nerve cells that control the movement of voluntary muscles, that is, muscles that are under conscious control. These include all the muscles of the trunk and limbs, and of speech and swallowing.

- With no nerves to activate them, muscles gradually weaken and waste, and paralysis ensues. Weakness is often seen first in the hands or feet, or the first sign may be swallowing difficulty or slurred speech. Muscle twitching and/or cramps may also occur. In the majority of cases the senses, intellect and memory are not affected.

- MND affects each person differently in respect of initial symptoms, rate and pattern of progression, and survival time; there are no remissions. Average survival time after diagnosis is 2 to 3 years or less, with a few people surviving over 5 or more years.

- Progression of MND is rapid, creating high levels of disability and consequent needs for support. Support needed includes assistance with feeding, communication, movement, transferring, toiletting, day activities etc. MND has a comprehensive impact on all activities of daily living.

- The key feature of the disease is the speed of progression, which poses huge problems of adjustment for people who have MND; an escalating burden on carers and families; and a challenge to those who are involved in meeting the variable and complex care needs.

- The cause of MND is not known, except that in a small percentage of cases it is hereditary. It is not contagious.

- Research taking place around the world includes genetic factors, the study of toxic factors and the chemicals by which nerve cells are controlled and communicate, and the growth, repair and aging of motor neurones.

- Stem cell research offers new and different opportunities, particularly using adult and embryonic stem cells, and stem cells derived from somatic cell nuclear transfer

The World

- Incidence is around 2 per 100,000 of population per year, and prevalence 6 per 100,000 (International Alliance of ALS/MND Associations, 2005).

- MND occurs in all countries of the world, usually in people over the age of forty, but there have been many cases of younger people being affected. Peak ages of onset are the fifties and sixties, and men are affected slightly more often than women.

- Riluzole, developed by sanofi aventis, has been demonstrated in trials to extend life expectancy in people living with MND. It is registered in Australia and is included in the Pharmaceutical Benefits Scheme.

In Australia

- In Australia over 1,300 people are suffering from its devastating effects.
- In 2002, 508 people died from MND while 111 death were attributed to HIV/Aids (Australian Institute of Health and Welfare, 2004)
- In 2003, the Australian Institute of Health and Welfare reported 530 deaths
- More than one person dies from MND every day, and another person is diagnosed

Outcomes of MND

- creates a body with increasing losses of ability, while leaving the mind and senses intact

- removes the ability of people to influence their external environment
- aware of what is happening but unable to do anything about it
- one carer commented “I feel more paralysed by MND than my husband”
- families and carers live with the impact of MND forever

Needs Arise From

- rapidly changing physical ability of client, and decreasing capacity of carer
- increasing levels of support required for carer and client
- emotional demands of caring and being cared for

Summary of Needs

- counselling and support at and following diagnosis
- accurate information
- respite for carers and ongoing support in day activities for client
- support from volunteers when appropriate
- equipment and activities to maintain independence, including communication
- a focus for supported access to services
- coordinated support from a team of professionals
- early intervention which often reduces overall service needs
- need urgent response - waiting lists are not appropriate

Care

- Most people with MND remain at home throughout the course of their illness, and in most cases the person with MND will have been independent and capable of making his/her own decisions - only the physical element of that independence is eroded.

- An extensive network exists within the community of people who will assist in accessing appropriate support services, preserving independence and maintaining quality of life. Such services are important not only for the person with MND, but also for their carers; the MND Association plays a pivotal role in ensuring that people living with MND are linked into such services in their own neighbourhood.

- People living with MND are not traditional service users, and have rarely had involvement with the disability or community services sector.

- Research by Sach (1995 and 1997) indicates that people living with MND **will not access services** unless they are confident in the knowledge of the provider about MND and its impact.

- People living with MND need counselling, support, needs assessment, referral to appropriate services, monitoring, reassessment, and ongoing support. Service providers who have people living with MND as clients need training, education, support and backup.

Some well known people who have died from MND include:

- Actor David Niven
- Australian Parliamentarian Dr Harry Jenkins
- Painter Pro Hart
- Lord Leonard Cheshire, VC
- Jazz pianist Charlie Mingus
- Australian athletics coach Percy Cerutty
- Russian composer Dimitri Shostakovich
- Mao Tse Tung Revolutionary leader of China
- Morrie Schwartz American Professor of Sociology, media personality and author, who was the subject of the International best-selling book, “Tuesdays with Morrie.”