

## MEDIA RELEASE – Immediate

### **Breakthrough research signal new era for Australians living with motor neurone disease**

After decades in the shadows, motor neurone disease (MND) has received a major boost with a series of research breakthroughs that give clearer direction for finding a cure to this baffling disease.

Findings in a recent study have shone light on a mistake in the recycling process within cells that is key to MND. Researchers at North Western University in Chicago have announced discovery of a second gene that links motor neurone disease to protein recycling and disposal. This follows the identification of a common chromosome in 40% of inherited cases of the disease by a multinational research team in September.

‘For the first time, scientists have seen proof of a common biological process in MND. Not only that, scientists are starting to identify the actual genes involved in this process,’ says Carol Birks, Executive Director at Motor Neurone Disease Australia.

‘Similar problems appear to occur in other neurodegenerative conditions, such as Parkinson’s disease and Huntington’s disease. This should encourage pharmaceutical companies to pursue treatments to improve protein processing and hopefully prevent neurones from dying,’ says Carol.

Dr Paul Brock AM has been living with motor neurone disease for 15 years. ‘This still incurable, inevitably terminal disease kills more Australians every year than does AIDS, but so few people have even heard of it. About 10% of people afflicted with MND have inherited the disease from within the family line – this is referred to as the ‘familial’ form of MND. The remaining 90% are said to be afflicted with the ‘sporadic’ form – which it might be said is medical jargon for ‘we do not understand the cause’. We desperately need more research into understanding the cause, slowing the progression, and finding a cure for this mongrel disease.’

Carol Birks, Executive Director at Motor Neurone Disease Australia says, ‘It’s the nature of this disease that people are desperate for information and news of research breakthroughs. Despite being described over 140 years ago, there remains no known cause or cure for this terminal disease that affects 1,400 Australians.’

‘Motor neurone disease touches people’s hearts. In 2011 Australians donated a record \$1.4 million for research into a cause, control and cure of MND. I think the generosity of donations is a reflection of how much this awful disease affects people,’ says Carol.

Recent MND research grants to the value of just over \$2.6 million from the National Health and Medical Research Council (NHMRC) have further boosted momentum for research and ensure Australia continues to play a key role in fighting this disease.

MND is a rapidly progressing, terminal disease in which nerves weaken and waste, causing near-total paralysis of the body. The mind is usually unaffected, leaving people trapped in their body. Average survival time after diagnosis is just 2-3 years.

Australians with MND are gathering in Sydney today to hear about the latest research from leading international experts at the 22<sup>nd</sup> International ALS/MND symposium.

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#### **For more information or to interview Dr Paul Brock, contact:**

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**Dr Paul Brock AM**

Dr Paul Brock was diagnosed with motor neurone disease in 1996. He was then given an expected life span of 3 - 5 years. Fifteen years later most of his body is paralysed, but he continues to live life as fully as he can with his wife and daughters. Paul has been an education advisor to both state and federal governments, written 130 publications and is currently Director of Learning and Development Research with the NSW Department of Education and Communities. He is also an Adjunct Professor in the Faculty of Education and Social Work at The University of Sydney. Paul is Vice-Patron of the Motor Neurone Disease Association of NSW.

Paul is available for interview about the experience of living with MND and the urgent need for research into finding a cure and providing greater support for people with MND and their families.