



**SPEECH TO THE SENATE**  
**MPI**  
**MOTOR NEURONE DISEASE**

**By Senator Guy Barnett, 18 June 2008**

[Senator BARNETT](#) (Tasmania) (1.44 p.m.)—I rise today to mark a special day in the calendar of this nation—the global day in honour of motor neurone disease, 21 June. Every year since 1997 the International Alliance of Motor Neurone Disease Associations around the world has celebrated 21 June as the global day of recognition of ALS and motor neurone disease, a disease that affects people in every country of the globe. The solstice is on 21 June; it is a turning point. Each year the ALS and motor neurone disease community undertake a range of activities to express their hope that this day will be another turning point in the search for cause, treatment and cure of this awful disease. Members of the international alliance undertake a range of activities to recognise this disease. Many organise meetings of people diagnosed with motor neurone disease and carers, and some organise social events. Meetings of boards of directors undertake fundraising activities or simply reflect on being part of the worldwide fight against motor neurone disease.

The global day is important because it is one day that every member of the international alliance has in common to reflect their dedication and their role in the global fight against motor neurone disease. Many countries already have awareness days, weeks and even a month of recognising motor neurone disease. And in Australia we have the Motor Neurone Disease Awareness Week. That was celebrated just recently in Tasmania and across the country. It stimulates a period of intense effort to promote awareness of the disease.

At this juncture, I would like to pay a tribute to the Motor Neurone Disease Association in Tasmania, to its president, Tim Hynes, and specifically to its former president, Bill Braithwaite, who died recently. He was a wonderful advocate and leader for the Motor Neurone Disease Association in Tasmania over many years. Sue, his wife, was also a wonderful support and helper, and has been very kind and generous in her support not just for her husband Bill but also for the association more generally. Sue is still remembered by all members of the association. We recognise her today and thank her for her support of the association and, of course, for dear Bill over so many years. Bill was a strong advocate for people with motor neurone disease in Tasmania. In the north of Tasmania, in Launceston, we have a monthly get-together where people with motor neurone disease or their family and friends can come. My mother, Lady Sally Ferrall, is involved, and my wife is a member of the committee. My wife, Kate, regularly attends during those special monthly occasions.

I want to acknowledge that this week the global day of recognising motor neurone disease will be celebrated in the parliament. The launch of the global day will be held

tomorrow morning, Thursday, 19 June, in the House of Representatives alcove. I want to note that this cruel disease affects 1,300 people across the nation and I will share some more statistics shortly. The Motor Neurone Disease Association of Australia will present the Living Better for Longer campaign at tomorrow's breakfast and they will outline some of the ways in which the Australian government can help people living with motor neurone disease and their families. Tomorrow morning, I will welcome and launch the event together with Carol Birks, the National Executive Director of the Living Better for Longer campaign for the Motor Neurone Disease Association. Dr Robert Henderson will be speaking on the multidisciplinary clinics and Ralph Warren, who is the President of Motor Neurone Disease Australia, will share a message. We will also hear a message from the world renowned Professor, Stephen Hawking, and we will have a film clip to hear his message for the breakfast participants.

In terms of the statistics, the incidence of mortality demonstrates an increase in the number of deaths from motor neurone disease in Australia during the last decade. The ageing population and interventions that improve life expectancy for sufferers of motor neurone disease are likely to result in a steady increase in the number of people living with motor neurone disease in Australia. But each day at least one person dies from motor neurone disease and another is diagnosed in this country. The average life expectancy for a person with motor neurone disease is two to three years from diagnosis. But that can vary, and in the case of Bill Braithwaite it was for much longer—many years. For others it is shorter, but that is the average—two to three years. As I have indicated, 1,300 people are living with motor neurone disease in Australia at any given time, and 971 people were registered with the motor neurone disease associations as at 30 June 2007. In 2006-07, the motor neurone disease associations loaned 2,187 items of equipment. You might ask what sort of equipment and what type of things?

Before I do that I just want to explain what motor neurone disease is. It is a name given to a group of diseases in which the nerve cells or the neurones controlling the muscles that enable us to move around, speak, swallow and breath fail to work normally. So with no nerves to activate them, the muscles gradually weaken and waste. The patterns of weakness and rate of progression vary from person to person. It is a debilitating disease and at times—certainly right now for me—it is hard to even describe it because it has affected me personally. My father, John Barnett, died of the disease in 1985. It was first described by Jean Martin Charkot in 1869, and there is still no known cause or cure. That is a tough position to be in with such a devastating disease, and treatment options are very limited. Effective management of the disease by a variety of specialist health professionals is vital to maintaining quality of life and assisting with symptom control. In terms of the equipment: yes, there is a range of equipment, including speech devices, wheelchairs and devices that assist in the communication of one's intentions. My wife is a speech pathologist and she has spent a good deal of time in her career offering assistance to people with motor neurone disease and with communication needs more generally.

As I said, Motor Neurone Disease is a debilitating disease that results in the deterioration and wastage of muscles over a period of time, gradually leading to death. This week, with Global Day coming up on 21 June, it is important that we recognise the work of Motor Neurone Disease Australia, which is the peak body, and of the state motor neurone disease associations around the country. Motor Neurone Disease Australia was formed in 1991 in response to the increasing number of people and their families and carers living with motor neurone disease in Australia. I am a former board member of Motor Neurone Disease Australia and was president of the association in Tasmania prior to my entry into the Senate, and obviously our family has a special interest in it. In fact, my

mother was a founding member of the association in Tasmania. She got it started all those years ago in the mid-1980s when my father had motor neurone disease. I pay tribute to Mum for the care, support and love that she demonstrated to my father during those three years when he had this dreadful disease.

The Motor Neurone Disease Australia network comprises six state associations, representing all states and territories, and the Motor Neurone Disease Research Institute of Australia. Motor Neurone Disease Australia members work together to advance, promote and influence local and national efforts to achieve the vision of a world free from the impact of motor neurone disease. By providing a national peak body for motor neurone disease in Australia, MND Australia is committed to lobbying for excellence in all services provided to all people affected by motor neurone disease, facilitating and coordinating the dissemination of information, creating reciprocal supportive and informative links with research organisations, ensuring increased awareness of the issues facing people living with motor neurone disease and enhancing the quality of life of people living with motor neurone disease. As I indicated earlier, MND Australia is a member of the international alliance of ALS/MND associations, the peak body for national organisations who support people living with ALS/MND.

Stephen Smith, the Minister for Foreign Affairs, is very supportive of people with motor neurone disease and has been an advocate for them in this parliament and I know that other members and senators likewise join together with the objective of helping wherever possible people with this disease, at both a state and a federal level. I commend the breakfast tomorrow to members, senators and the general public and place on the record that we can all do something on Global Day, 21 June, the winter solstice. You could talk about it with your friends. You could have a function or indeed donate funds to your local Motor Neurone Disease Association. You could write to your local newspaper and tell your story or that of others relating to this disease. We want people to stand up and say yes, there is no known cause and there is no known cure, but it is a disease that is worth standing up for because there are 1,300 Australians with this disease.

Sitting suspended from 1.56 pm to 2.00 pm.