



1 May 2016

Guy Barnett, Parliamentary Secretary to the Premier

Motor Neurone Disease week

Motor Neurone Disease week is held during the first week of May every year to raise awareness of this debilitating disease and the impact it has on people living with MND and their family.

MND week offers time to remember those who have died from the disease and provide support for those living with the disease and their family and friends.

I am honoured to be Ambassador for Motor Neurone Disease Australia, thankful for the opportunity to raise awareness and be a voice for the MND community.

My father died in 1985 after battling with the disease for three years. My late mother, Lady Sallie Ferrall, with the support of many wonderful locals and our family, supported the establishment of MND Tasmania and she was its Patron.

Motor Neurone Disease affects the body's motor neurone nerve cells, which control the movement of voluntary muscles. The disease causes motor neurone cells to die over a prolonged period, with people slowly losing the ability to control the muscles that control their arms, legs, back, neck and even speech.

It is estimated that there are over 420,000 people in the world that are living with MND, with approximately 140,000 cases diagnosed worldwide each year. In Australia, over 2,000 people are living with MND and in Tasmania over 40. More than 2 Australians die every day from MND.

A special thank you to both MND Australia and MND Tasmania for their wonderful support of people with MND and their families.

To make a donation or for more information go to MND Australia website: www.mndaust.asn.au or call 1 800 806 632.

Note- I moved the attached motion in state parliament last Wednesday

Motor Neurone Disease Global Day 21 June 2016

Mr Guy Barnett MP [*Member for Lyons*] to move—That the House:—

1. Notes that during Motor Neurone Disease (MND) Week, 1 – 7 May, MND Australia is running a new social media campaign, designed to highlight the experiences of MND

from all sectors of the community, helping to raise awareness of the impact of MND in Australia;

2. Notes that MND Australia has officially launched its first Deloitte access Economics Report on the Economic Analysis of Motor Neurone Disease (MND) in Australia;
3. Notes that the Report reveals the total cost of MND in Australia was \$2.37 billion in 2015, this equates to \$1.1 million per person;
4. Recognises that MND affects over 400 000 people globally with over 140 000 people diagnosed with MND each year, that's 384 new cases every day
5. Further notes that an estimated 2 094 Australians are living with MND, including some 45 Tasmanians. MND Australia reports that 752 Australians died from MND in 2015, more than 2 people per day;
6. Recognises that MND not only affects the person with motor neurone disease but also directly or indirectly effects on average 14 other friends and relatives;
7. Congratulates and thanks both MND Australia and MND Tasmania, who for over twenty years, have proved effective advocates, promoted optimal care and support options for those living with MND and tirelessly raised funds for research into the cause and, ultimately, cure for MND.
8. Notes that, 21 June 2016, is Motor Neurone Disease Global Day, a global day of recognition for Amyotrophic Lateral Sclerosis (ALS) and Motor Neurone Disease (MND)—a disease that affects every country on the globe;