

Spotlight on MND – [Blog](#)

Promoting awareness as MND Ambassador by Guy Barnett

It is such an honour to support people with motor neurone disease and their families and to promote the cause for a cure.

Being ambassador for motor neurone disease Australia allows me to stand up and speak to decision-makers in the national arena and in my home state of Tasmania.

When my father died of MND in 1985, my late mother Lady Sallie Ferrall, with the support of many wonderful locals and our family, supported the establishment of MND Tasmania. I was more involved in the Tassie association on my return to Tasmania from the US in the late 80's and became president.

Promoting MND as a senator was also a great opportunity to showcase not just the work of the association but the important role of research to find a cure and also to improve care and management of people with MND.

It seems research is now very much on the agenda of our political decision makers as is the need for improved care. For every person with MND in Australia – and that is over 2000 people – another 14 people are directly affected. Sadly, more than two Australians die with MND every day.

Every year, MND week provides a real boost to understanding and awareness. Around the globe there are 400,000 people with this disease, including over 2000 in Australia and more than 40 in Tasmania.

It's also a chance to tell the decision makers that the cost of MND based on the most recent report by Deloitte is \$2.37 billion each year or for every person with MND it costs \$1.1 million.

It was so much fun attending a party for Mrs Pat Stafford and her husband Harry as they celebrated their 70th wedding anniversary on March 21. Pat has been on a 20 year plus journey with MND. I was so pleased to help organise special birthday cards from the Queen, Governor General, Prime Minister, the Governor and the Premier. What a special day!

Pat Stafford is just one Tasmanian who is supported by the local MND support group in Launceston. MND Tasmania has some 45 members. President Tim Hynes is an excellent leader and well supported in this role by an able committee.

My dear mother Lady Sallie Ferrall was patron for MND in Tasmania and she hosted the first public meeting of the MND association at her home at Quamby on 15 October 1985. As patron for MND Tasmania, she enjoyed helping and supporting people with MND and their families. Mum died on 15 September last year and will be missed.

So, we all have a part to play in promoting helping and supporting people with MND and their families and the cause that we are all committed to. MND awareness week is a wonderful opportunity for all of us! I am pleased to have been able to raise MND issues in the state parliament here in Tasmania and I encourage all those involved to continue actively promoting and raise MND awareness wherever you are.

Guy Barnett MP

Parliamentary Secretary to the Premier
Liberal Member for Lyons
Ambassador for MND Australia

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Thank you for your support!