Cornwall Branch of the Motor Neurone Disease (MND) Association highlights rights for people living with MND at Westminster reception
By the MND Association with addendum by Emma Bungay

Hilary Rogers, Treasurer of the Cornwall Branch of the Motor Neurone Disease Association was invited as a guest at a reception which heard from author Dr Jane Hawking. The first wife of Professor Stephen Hawking, Jane wrote the book behind the Oscar-winning film *The Theory of Everything* and remains an ardent campaigner for people affected by motor neurone disease (MND).

She told those present that she hoped the film had drawn attention to the silent, often isolated despair of many patients and their carers.

She concluded: "I hope it will encourage politicians, amongst other audiences, to ensure that people living with MND, and their carers, can access the financial support they are entitled to through the benefits system. That is the least we can do for motor neurone disease sufferers and their hard-pressed partners and families who face the daily challenge of living with this devastating condition".

More than 100 MND Association volunteers from England, Wales and Northern Ireland met with some 55 MPs and Peers at the VIP reception at Church House, Dean's Yard (Tuesday 18 October).

The reception increased MPs' understanding of MND and the issues that affect people living with the disease, their families and carers. Attendees also heard from Penny Mordaunt MP, Minister for Disabled People, Work and Health who said "it's incredibly important for members of Parliament whether we're ministers or whether we're backbenchers to hear your stories. It helps us make better policy. The anecdotes and stories you tell us, we can talk about on the floor of the House of Commons and in the House of Lords. It really does help us tremendously make better laws, make better policy and get you what you need."

Hilary Rogers from the Cornwall Branch said: "It was great to be at the reception and to speak with MPs about the importance of support for those living with MND. The speeches were excellent and pointed out the problems people and their carers and families experience from day to day and how they need these benefits as they are not going to get better."

Sally Light, Chief Executive of the MND Association, said: "It was wonderful to see so many of our amazing volunteers gathered together and for them to have the opportunity to share their personal experience of MND with MPs and Peers present. It is a devastating disease and people affected need to have the support and awareness of decision makers at Westminster. In particular the day was an opportunity to talk about the importance of Attendance Allowance [a disability benefit for people over 65] and why it should be retained in its current form.

"We also talked to MPs about the Government's recent announcement to scrap re-assessments for Employment and Support Allowance [ESA - a benefit for those unable to work due to a disability or health conditions] for those with severe, life-time conditions. We hope that people with MND will be exempt from these highly inappropriate re-assessments. The financial impact of MND and the

extra costs of living with a disability can be immense for families so it is vital that people with MND have access to the disability benefits they are entitled to."

Photo Captions -

1. Sally Light, Chief Executive, spoke about the NICE guidelines for MND and the financial impact on the family of a person living with MND.
2. Jane Hawking spoke about her book, the film, and how those with MND and their carers often have to give up their paid jobs so they need ESA. Then Sarah Ezekiel, winner of the Third Sector Award for Volunteer of the Year 2016, spoke of how she was diagnosed aged 34, when she was 7 months pregnant with child number two.
3. Alison Aviss, Chair and Association Visitor of North Wiltshire branch; Sally Light; Hilary Rogers.
4. Penny Mordaunt, Minister of State for Department for Work and Pensions.
5. Madeleine Moon, Chair of All-Party Parliamentary Group for MND.