

PE1723/E

Petitioner submission of 8 January

My name is Mary Ramsay. I have lived with essential tremor all my life, and am currently chair of the Scottish Tremor Society (two *Ts* for *Scottish*, one *T* for *tremor*). I am writing in support of the provision of Focussed Ultrasound Scanner in Scotland.

While I've lived with my tremors since birth, I didn't receive a definite diagnosis until I was 48. I went through hell and back as a child, living with a very real condition but not knowing what it was, while suffering physical and mental abuse from others who didn't see my illness. Just something wrong with 'me'. At 20, I was told I would never have children.

Imagine walking in my shoes – something I often imagine too, as very often I can't manage it due to the tremors in my legs, which have worsened significantly over the past four years. Then imagine electrodes wired into your mind, like some modern-day Frankenstein – that's what deep brain stimulation feels like, yet it's my only respite from my tremors. It's exhausting, and that's before the distance travelled to get my treatment. There's nothing for people with tremors in the north and east – it's all centralised in Glasgow, and they rarely accept anyone from the north and east because they have a long waiting list – so I have to travel from Inverness to Glasgow, which is a long journey. I previously had to travel longer, Inverness-Newcastle, which involved an overnight stay. But even now, I'm knackered until what feels like forever.

This has been my life. My tremors, and the lack of understanding surrounding them, has impacted my entire life. Those of us with essential tremor deserve better, and there is a better option.

Focussed ultrasound is a non-invasive treatment that does what it says on the tin – focussing ultrasound on specific parts of the brain identified with tremors, to relieve their onset and progression. Focussed ultrasound is less risky and less traumatic for patients, with full recovery in a matter of hours rather than days. Children can potentially be back at school the next day, saved the trauma of a major medical procedure and protracted recovery and, more importantly, reducing their absences and offering something closer to a 'regular' childhood, one without the abuse I suffered at their age. Adults will be better placed to undertake employment and full-time education, with a wider range of opportunities for their present and future than I was fortunate enough to have when I was younger.

This will not benefit me personally. I am ineligible for focussed ultrasound treatment, but it will make a huge difference to children and others diagnosed with essential tremor now and in the future. I understand medical concerns that some of the findings on focussed ultrasound are limited, but this is all the more reason for further research – something that will not be possible in this country without the provision of a Focussed Ultrasound Scanner, which Dundee is now very close to obtaining. And, bluntly, medical concerns are not always correct. I said I was told when I was 20 I would not have children, but now I have three children and ten grandchildren.

If there is a will and determination to fight essential tremor, and to understand its causes, it can be overcome for the generations that will come after me. It is for those

determining the outcome of this consultation to decide whether their will, and their determination, is sufficient for Scottish doctors and Scots with essential tremor to have the best opportunity to fight this fight. For me, and my part, if focussed ultrasound helps someone avoid what I went through, I will fight to my last breath to get it.