

## **PE1723/B**

National Tremor Foundation submission of 17 October 2019

As a charity which represents over 1 million people in the UK, the National Tremor Foundation supports any research & development into essential tremor.

Essential tremor (ET) is the most common movement disorder. It causes parts of the body to move in an uncontrolled and repetitive manner, most commonly affecting the arms and hands. There are many causes of severe tremor - it is a syndrome rather than a specific condition. There are over one million people with Essential Tremor in Britain and around 250,000 people with the syndrome are severely disabled by their tremor. Current treatments include drug therapies, surgery and deep brain stimulation. These treatments are of limited effectiveness or cannot be used in all sufferers; some have moderate risks and side effects.

The cause of ET is not known, although approximately 50% of people affected have a family history of the condition. ET can have a profound impact on people by impacting on their quality of life, social life and employment.

Drug treatment is the first line therapy for ET; however, this is a condition which does not respond to drug treatment in many patients. This is known as medication-refractory ET. Surgical intervention in ET is offered to patients whose symptoms are significant and severe and have not responded to medication.

Deep Brain stimulation (DBS) is the surgical procedure that is currently commissioned for patients with ET. Electrodes are inserted into a specific area of the brain that is responsible for modifying movements. In ET, the area of the brain targeted to improve tremor is the ventral. DBS is effective at improving people's symptoms, but the benefits of DBS tend to diminish over time. This is an invasive procedure and the main risks are bleeding within the skull, stroke and infection.

MRgFUS thalamotomy is a new procedure for the treatment of ET. This procedure uses focused ultrasound waves generated externally to the body that are directed to, and alter the function of, the VIM nucleus to improve tremor. This is done under magnetic resonance imaging (MRI) guidance.

But the new procedure - MRI-guided focused ultrasound - can be carried out without the need for invasive surgery. It involves using a powerful MRI machine to focus ultrasound waves on a specific area of brain tissue. At that point, molecules are vibrated extremely quickly, which creates intense heat to destroy only the targeted tissue and break the abnormal electrical circuits causing the tremor.

This is a non-invasive procedure that does not require the introduction or maintenance of hardware into the brain, avoiding the maintenance of the inserted hardware (i.e. battery replacement) and minimising the risk of bleeding within the skull, stroke and infection. This can be done as a day-case procedure.

There is a growing body of clinical evidence from around the world that this procedure is safe and effective, and it has been shown recently to have very successful outcomes in the treatment of Essential Tremor, with many fewer risks than deep brain stimulation and at a substantially decreased cost per patient treated.

The MRI-guided focused ultrasound machinery at St Marys hospital in Paddington is currently the only one in the UK. Dundee University are campaigning to get a similar machine installed at their hospital in Scotland & the National Tremor Foundation were delighted to gain a £40K grant towards this campaign in July 2018.

The first UK clinical trial of the treatment took place at St Mary's Hospital, London in 2016, using the £1.1 million MRI machine funded by Imperial Health Charity. During the trial, the procedure was used to treat 13 patients. All experienced significant improvements in the severity of their tremor.

As you may be aware Essential Tremor is 8 times more common than Parkinson's and in June 2018, NICE issued a positive guidance for this innovative procedure to treat Essential Tremor. MRgFUS is a life changing treatment with approval for use from NICE, yet is not currently available on the NHS, meaning that only patients who can afford to pay for it can be treated. NHS England has started the process to develop a commissioning policy for this treatment, but without certainty on outcome or timeframe

As an organisation which has many support group's we see every day the effect that living with essential tremor can have on people. Seemingly normal everyday tasks become a chore or a burden. Furthermore, the anxiety in thinking about performing those tasks increases the tremor. Carrying a cup, eating in public, lifting a spoon, writing a signature, holding a newspaper, giving a presentation, etc, etc. In turn this affects your everyday lives & your interactions with your family, friends, schoolmates, fellow students, work colleagues and general public.

The list of everyday events affecting people with essential tremor are endless but we are heartened by the incredible research that has been undertaken in this field, and would really urge the Scottish parliament to seize the opportunity this life changing equipment & treatment could bring to people, and the benefits socially & economically we are certain it would bring.