Template Letter to Send to Members of Parliament Re: Virtual Parliamentary Roundtable

[Name of Member of Parliament] House of Commons London SW1A 0AA

June 2020

[Dear Name of Member of Parliament]

Help Patients in Your Constituency like Me Access Life Changing Treatment on the NHS

I am contacting you as a consituent to ask if you would be willing to participate in a virtual Parliamentary Roundtable that is being held on **Monday 13th July from 2.00pm – 3.00pm** and hosted by **The Rt. Hon. Sir Mike Penning MP.** The meeting will discuss why MR-Guided Focused Ultrasound for Essential Tremor (MRgFUS) should be available on the NHS and how you could become involved in the campaign to help achieve this goal. Further details about the event are included at the foot of this letter.

During the virtual private roundtable event for Parliamentarians on 13th July, MPs and Peers will have the opportunity to meet with various people to discuss the benefits of this therapy being available on the NHS. Those who will be speaking at the event are as follows:

- Professor Nandi MBBS, M.Ch., D.Phil., FRCS (SN) Consultant Neurosurgeon
- Geoff Sleight Patient who has benefitted from MRgFUS
- Professor Gedroyc MBBS, MRCP, FRCR Consultant Radiologist, and FUS pioneer
- Kevin Harfoot Chairman of the Board of Trustees, National Tremor Foundation

A patient representative will be at the event to talk about the significant impact the therapy could make on many people's quality of life, as well as the Chair of the National Tremor Foundation (NTF), which provides help, support and advice to all those living with all forms of tremor irrespective of age.

During the discussion you will be able to find out more about how you can support the campaign, as near the end of July a meeting of NHS England's (NHSE) Clinical Priorities Advisory Group (CPAG) will take place and consider this issue. Recently NHSE conducted a public consultation into MRgFUS being available on the NHS and it made a positive recommendation that it should be so.

As someone with Essential Tremor who may be able to benefit from MRgFUS I would like to take this opportunity to explain how the condition affects me: *[Please use this space to explain the impact of the condition on your quality of life].*

As you may be aware Essential Tremor is 8 times more common than Parkinsons and in June 2018, NICE issued a positive guidance for this innovative procedure to treat Essential Tremor - which costs significantly less than the only currently available treatment on the NHS. 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.

Now that NHS England have recommended a positive commissioning policy for this treatment, I would welcome your support as my MP for the campaign. With your help and support, patients in your constituency like me could benefit from this innovative new treatment being available on the NHS. I look forward to hearing from you.

Yours sincerely, (please provide contact email address and postal address here)





The Rt. Hon. Sir Mike Penning MP

Invites You to a Virtual Roundtable Event

An Event for Members of Parliament & Members of the House of Lords

Monday 13th July 2020 2.00pm – 3.00pm Zoom details to be circulated in advance

During this private virtual roundtable event Members of both Houses will have the opportunity to find out more how patients could benefit from MR-Guided Focused Ultrasound for Essential Tremor (MRgFUS) being available on the NHS. During the event you will be able to find out about how you can support the campaign and will have the opportunity to listen to:

- Professor Nandi MBBS, M.Ch., D.Phil., FRCS (SN) Consultant Neurosurgeon
 Geoff Sleight Patient who has benefitted from MRgFUS
- Professor Gedroyc MBBS, MRCP, FRCR Consultant Radiologist, and FUS pioneer
- Kevin Harfoot Chairman of the Board of Trustees, National Tremor Foundation

Why Should You Attend This Event?

- ☑ Essential Tremor is 8 times more common than Parkinsons.
- ☑ In June 2018, NICE issued a positive guidance for this innovative incisionless procedure to treat Essential Tremor which costs significantly less than the only currently available treatment on the NHS.
- ☑ Following a public consultation NHS England recently confirmed a positive outcome for its commissioning policy to provide MRgFUS for NHS patients.
- ☑ In late July the Clinical Priorities Advisory Group (CPAG) is expected to meet and make a recommendation as to its availability and timeframe.
- ☑ Essential Tremor has a severe impact on quality of life, patients feel isolated as they unable to do simple things like eat and drink in public. For further information please see this <u>video</u>.
- ☑ This is a life changing treatment yet is not currently available on the NHS, meaning that only patients who can afford to pay for it can be treated.

Please RSVP To Confirm Your Attendance

Email: emma@mailpbconsulting.com