NTF News

National Tremor Foundation

Issue 008

Support groups & more!

PARLIAMENTARY SPECIAL

Contents

NTF
National Tremor Foundation

New groups to be launched for January 2020

Worthing Shakers

To be opened by the Mayor of Worthing, Hazel Thorpe
Saturday 18th January 2020 13:30 to 16:30
Goring Methodist Hall, Bury Drive, BN12 4XB
For details contact Jackie on jackie@tremor.org.uk

Central Scotland Shakers

Further details to follow.

Parliamentary drop-in event for MR-Guided Focused Ultrasound for essential tremor

Prof. Wladyslaw Gedroyc talking to Baroness Golding about MRgFUS at the Pariamentary drop in

Actor Jim Carter with Liz Twist MP and Essential Tremor patient Ann Connolly at the Pariamentary drop in

Shadow Health Secretary of State for Health & Social Care, Jonathan Ashworth MP, signs the pledge to support the campaign for MRgFUS being available on the NHS

The Palriamentary Drop for MRgFUS for essential tremor was an amazing success

Success at Parliamentary drop-in event for MR-Guided Focused Ultrasound for essential tremor

Last month was a turning point for essential tremor (ET) in the UK. Armed with literature on the condition, real-life stories from people living with Essential Tremor, and a couple of familiar faces in the form of National Tremor Foundation Honorary President Lord Julian Fellowes and actor Jim Carter (widely known for playing Carson in Downton Abbey) – the National Tremor Foundation took to the Houses of Parliament.

Working closely with the Rt. Hon Tom Brake MP, Virendra Sharma MP, and INSIGHTEC, the developers of the innovative neurosurgery technology for MR-Guided Focused Ultrasound (MRgFUS), a drop-in session was hosted for Parliamentarians to learn more about essential tremor and how patients within their constituencies and local communities could benefit from MRgFUS. With NHS England currently looking into making this therapy available on the NHS, the aim of the event was to engage with MPs and Peers to secure their support for the campaign. Attendance was a great success with more than 20 MPs and Peers (or their representatives) attending the event.

During the event, Parliamentarians had the opportunity to talk to Prof. Wladyslaw Gedroyc, Consultant Radiologist, St. Mary's Hospital, Imperial College NHS Trust about Essential Tremor, the challenges with the currently available treatment options, and about how MRgFUS could provide a life-changing treatment option for patients. Whilst many MPs and Peers were unaware of essential tremor when they arrived, after speaking to Prof. Gedroyc and people living with the condition, they were significantly more knowledgeable and with a greater understanding when they departed.

Essential tremor has a severe impact on quality of life. For those living with the condition it can be isolating and simple everyday tasks that many take for granted, like preparing meals, eating and drinking and using touchscreen phones can become impossible. Via our support group network, members spoke to Parliamentarians about the significant effect essential tremor has on their day-to-day lives, going a substantial way to bringing this enormously debilitating condition to life.

Talking about why he has a passion for this campaign, the Rt. Hon Tom Brake MP commented, "I'm conscious that the level of understanding of Essential Tremor is very low and there is a significant confusion with Parkinson's disease. We supported the event to help raise awareness and make the distinction between these two diseases, and to ensure that the level of research and funding is there for treatment. When we have the luck or fortune of a treatment that is effective, we should certainly take advantage of it and make sure it is rolled out across the NHS."

National Tremor Foundation Honorary President and essential tremor patient, Lord Julian Fellowes, along with actor Jim Carter, generously gave up their time to support the event, by encouraging

Lord Fellowes talks to National Tremor Foundation coordinator Jackie Farrell and Prof. Gedroyc

Parliamentarians to sign a pledge board supporting the availability of MRgFUS on the NHS, and telling their own experiences of life with essential tremor – either in real-life or on-screen.

Talking about how he has championed his own awareness of essential tremor, Lord Fellowes remarked that in order to make people feel more comfortable about their diagnosis, he felt compelled to put it into a drama on-screen, “Awareness is important; when people get essential tremor they can feel like they are losing their reason and wonder why and what they’ve done wrong, and the answer is nothing, you have a perfectly identifiable condition. But because no one has heard of it, talks about it, or has seen it featured in a character of a TV drama etc, they don’t realise it exists. I felt that was my role to help.”

He continued, “What is particularly odd about essential tremor, is that there are eight times as many people with it as there are with Parkinson’s, yet nobody knows about it. Since I was diagnosed, we now have a new ultrasound technology whereby it focuses on a particular part of the brain and is non-invasive. It is a treatment I’m very keen on and supportive of.”

In addition to listening to stories from guest speakers, Parliamentarians had the opportunity to sign a pledge board, to add their support to the campaign. The board paved the way for MPs and Peers to commit to championing the NHS commissioning policy for MRgFUS, and set the campaigning group on the journey for better patient access to life-changing treatment. In addition, MPs and Peers also had the opportunity to add their support to an open letter to the Chief Executive of NHS England, Simon Stevens requesting that NHS England agrees to the adoption of the therapy on the NHS.

Essential tremor affects a large number of people in the UK. It is often thought of as an adult-onset condition; however, the disorder affects around four out of 100 adults over 40 years of age, and can also start in early childhood, affecting about 5% of children.

We asked essential tremor patient, Merane Todd and her sister Denene Capper, what this treatment would mean for them. Merane commented, “If there was a treatment that could in any way help me get my life back together, to do normal everyday activities, to be able to keep me in work and allow me to dress myself without my partner having to assist me, it would be life-changing.”

Merane’s sister, Denene responded, “It is soul-destroying watching your sister, who is able-bodied, struggling with certain everyday things. We are here today to support Merane because it is of the utmost importance to me to make sure that she gets treatment, to get that quality of life back.”

Conservative MP David Rutley listening to Essential Tremor patient and Leeds support group leader Merane Todd talk about living with the condition

The passion from patients and their families to support the campaign for change for people with essential tremor is very encouraging and the National Tremor Foundation deems it important to say a special ‘thank you’ to the foundation’s Support Group Coordinator, Jackie Farrell. Jackie has lived with essential tremor for decades, but a number of years ago, was forced to give up her dance school due to symptoms of tremor. After a period of grievance, Jackie took action and joined the National Tremor Foundation to help raise awareness of the condition and provide the support so desperately needed by patients. Jackie comments, “Dance had been my life. I worked hard to set up and manage my own dance school, a business that I nurtured for over 40 years. However, sadly, 15 years ago I had to give it all up. You can’t teach classical ballet when your hands shake like mine. It took away my life. But, I decided to use my knowledge positively and joined the NTF and I now coordinate our national support groups, organise awareness days and give talks on essential tremor. If this new treatment is funded on the NHS, it will be a hugely valuable option for patients, so I am glad I can be here to support the campaign.”

The National Tremor Foundation would like to take this opportunity to thank all the Parliamentarians who attended the drop in session and pledged their support, the speakers on the day, the Honorary President, the NTF support coordinators and each of the members and their families who attended, for their role in making the event a success. The foundation would also like to give special thanks to all their supporters who have personally helped the campaign so far by contacting their local MP and encouraging them to attend the event. Your support means that together we continue to raise vital awareness of Essential Tremor, and carry on campaigning for access to effective treatments that will give those who live with essential tremor the chance of a better quality of life.

National Tremor Foundation

Shakers Social

Sunday 24 November 2019

1pm –5pm

Civil Service Club,13–15 Great Scotland Yard, London SW1 2HJ

Do you have or know someone with a neurological movement disorder such as Essential Tremor or Orthostatic Tremor? Why not pop along to meet others for a lighthearted, informal get together.

Complimentary teas and coffees.

Participating activities:

Craft Corner – Quiz – Board games

Café on site at Civil Service Club– 12midday – 3pm

To register interest or see programme, go to www.tremor.org.uk/social

Supported by Civil Service Club

Southerners' Lunch

The first get together of the Orthostatic Tremor Group "Southerners' Lunch" on Saturday 7 September at Riverside Inn, in Amberley West Sussex was a great success.

They very much enjoyed their time chatting over lunch and getting to know each other. Support group member, Lynda Hubbard was brilliant at finding a venue and organising our menu choices.

They are hoping to arrange another date for the next lunch early in the new year and looking forward to others joining them.


A fantastic turn out for the first Southerners' Lunch

Get involved in research into designing a product to aid with makeup application

Hannah Taylor is studying a Masters in Product Design Engineering at Strathclyde University and designing a product to aid with makeup application for those with hand tremors.

She has created an anonymous survey in order to get a better understanding of the difficulties faced when applying makeup with a tremor and how these difficulties are overcome.

To take part go to www.tremor.org.uk/get-involved-in-tremor-research

Or by scanning the QR code on the right with your smart phone.

Launch of new support group

By Merane Todd, Leeds and Shefield Support Group Organiser


A fantastic turn out for the first Southerners' Lunch

After a lot of behind the scenes planning and organising with the team, Ann Collins, Jo Squires, Christine Knowles, David Knowles, Geoff Speight, Merane Todd and the NTF. The launch of the Sheffield Shakers Support Group finally arrived and it couldn't of gone better.

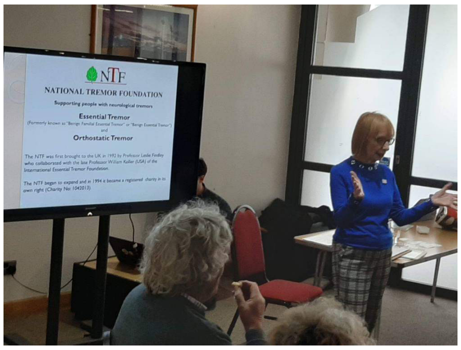
Despite the motorway being closed in both direction around Sheffield and all traffic diverted, people still came. Each time I thought this is a fantastic turn out someone else came through the door.

With donations made from the sale of handmade crafts, cards and body shop items and a raffle. A total of £90 was raised for the Leeds and Sheffield Support Groups.

For further information on the Sheffield Shakers Support Group, please contact lands@tremor.org.uk

Nordic Assisted Walking
Phill Alcock talked about the benefits and demonstrated Nordic Assisted Walking. For anyone wishing to try Nordic Assisted Walking please contact lands@tremor.org

Ann Collins – Sheffield Shakers (below)
Introducing Ann Collins who organised the launch and will be running the Sheffield Shakers Support Group. Ann welcomed everyone and shared her personal experience of living with Essential Tremor.



Jackie Farrell NTF Suppport Group Co-ordinator (above)
Jackie Farrell the National Tremor Foundation (NTF) Group Support Coordinator, introduced the NTF.

GyroGear
Benjamin Koh and Enrica Papi, provided an update on the progress of the GyroGlove.

For further details about the Sheffield Support Group contact .Merane on lands@tremor.org.uk

Events for 2019/2020

November

Leeds Tremor Support Group Meet Up

16 November 1pm - 4pm
Leeds Marriott Hotel, 4 Trevelyan Square Boar Lane, Leeds, LS1 6ET
For further details
lands@tremor.org.uk

Shaking and dining

16 November, 5pm–7pm
Attleborough Arms, Highfield Road,
Nuneaton, CV11 4PL
For further details contact Larz on
nuneatontremor@gmail.com

Shakers Social Get Together, London

24 November 1pm - 5pm
The Civil Service Club, 13-15, Great Scotland Yard, London, SW1A 2HJ
For further details contact Jackie on
jackie@tremor.org.uk

To register interest or see programme, go to www.tremor.org.uk/social

Salisbury Shakers pantomime

30 November
Visit to the Salisbury pantomime, Robin Hood
For further details contact Sheelagh on
salisburyshakers@btinternet.com

January 2020

Salisbury Shakers

11 January
For further details contact Sheelagh on
salisburyshakers@btinternet.com

Worthing Shakers Tremor group launch

18 January 1pm - 4:30pm
Goring Methodist Hall, Bury Drive, BN12 4XB
For further details Jackie on
jackie@tremor.org.uk

Support groups

The NTF currently has a small network of local Support Groups across the United Kingdom. These groups are run by dedicated volunteers who give their time to offer support and information to anyone affected by a tremor condition living in their area.

Contact Support Groups Coordinator Jackie on 07843 777288 or email jackie@tremor.org.uk

Jackie, Support Groups Coodinator

Essential Tremor

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Primary Orthostatic Tremor

Alyson Farr
alyson@tremor.org.uk

Advice for children

Kitty Reilly
kitty@tremor.org.uk

Online support groups

NTF Facebook Support Group
www.facebook.com/national-tremorfoundation

Orthostatic Tremor Support Group
www.facebook.com/groups/299934143841327

In the next newsletter we are looking for young people for editorial. Contact duncan.crossland@tremor.org.uk to get involved.

NTF

National Tremor Foundation

Support for people with neurological tremors

Did you know that the NTF represents over one million people?

To find out more go to www.tremor.org.uk

NationalTremorFoundation
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Charity No: 1042013