

Lord Fellowes visits St. Marys Hospital

Imperial Health Charity launch

The campaign in Scotland

Support groups
& more!

How to start
a support group

-SUMMER EDITION-

Contents

NTF Annual Conference success	p3
Top tips for surviving the hot weather with tremor	p4
NTF secures large donation for campaign in Scotland	p5
Imperial health charity launch	p6
Lord Fellowes visits St. Marys Hospital	p7
Jackie invited as speaker at Disabilities and Neurological Study Day	p8
Raising awareness in Hampshire	p9
Shaking it up in Salisbury	p9
Essential tremor and children	p10
Support Groups	p11



National Tremor Foundation

**Did you know that you can now become a
Friend of the NTF?**

**To find out more go to
www.tremor.org.uk/friend**

NTF Annual Conference success



part of your chromosomes called the telomere. Basically the longer the telomere, the longer you should live.

Gyrogear founder, Faii Ong, presented the latest developments on the GyroGlove. The GyroGlove is a wearable device that is used to treat tremor using a gyroscope. It is designed to avoid the side effects from medications or alternatively the dangers of surgery

Dr. Peter Bain discussed the non-invasive, single treatment, MRI guided ultrasound. He compared the procedure to other treatments, and gave an update on his research and other developments in the field.

Following the success of the Annual Conference we look forward to the NTF's next event.

To find out more about events go to www.tremor.org.uk/events

Dr Peter Bain neurologist & NTF Trustee discusses MRI focussed ultrasound treatment

The Annual Conference held on the 16th June at the Holiday Inn in Brentwood was a huge success.

The event saw over 60 people attend and attracted people come from all around the country.

There were presentations held by Professor Hawkes on 'Do people with familial essential tremor live longer'; Dr Peter Bain on focussed ultrasound; Gyrogear founder, Faii Ong; NTF Support Group Coordinator, Jackie Farrell; and the NTF Chairman Kevin Harfoot.

Before the presentations the Orthostatic Tremor Support Group had a meeting where members were able to share their experiences with orthostatic tremor and support others.

Jackie Farrell, NTF Support Group Coordinator, gave a small talk on support groups and mindfulness and its benefits to those with essential tremor.

During the conference, Professor Hawkes explained the research on long-life, tremor and Oragene Saliva. He explained that it is now possible to estimate your life expectancy by examining the DNA in saliva and specifically the end

Top tips for surviving the hot weather with tremor

1. When inside

Shut windows and pull down the shades when it is hotter outside. You can open the windows for ventilation when it is cooler. It also helps if you identify the coolest room in the house so you know where to go to keep cool.

2. Keep rooms shaded

Keep rooms cool by using shades or reflective material outside the windows. If this isn't possible, use light-coloured curtains and keep them closed (metallic blinds and dark curtains can make the room hotter).

3. Get a fan

Buy a fan for your home to keep it cool or for when you leave the house a small portable fan.

4. Mad dogs and Englishmen

Stay out of the sun around midday. Particularly between 11am and 3pm (the hottest part of the day) if you're vulnerable to the effects of heat.

5. Bath regularly

If you're on holiday by the beach regular trips to the sea can help. When at home cool baths, showers, and splash yourself with cool water.

6. Take a cold drink with you where ever you go

Bring a screw top bottle of cold drinks, such as water or fruit juice and sipping them throughout the day will keep you hydrated throughout the day. Remember caffeine and alcohol can dehydrate you. Too much alcohol can also worsen tremors and give you

a hangover the next day, so it is advisable to drink no more than two units and to alternate with soft drinks.

7. Dress cool

Light clothing made out of materials such as cotton will help. Also make sure they are loose and easy to put on. Bring a hat and sunglasses if you go outdoors.

8. Tune in!

Remember to listen to alerts on the radio, TV and social media about the weather and keeping cool.

Sources:

Parkinson's UK: Heatwave, Keeping cool when you have Parkinson's, www.parkinsons.org.uk/news/heatwave-keeping-cool-when-you-have-parkinsons

NHS Choices, Heatwave: How to cope in hotweather, www.nhs.uk/live-well/healthy-body/heatwave-how-to-cope-in-hot-weather/



NTF secures large donation for campaign in Scotland



Scotland was brought to the Scottish parliament by Scottish MP Rhoda Grant on 16th May 2018.

The first UK clinical trials of the treatment took place at St Mary's Hospital last year, using a MRI machine funded by Imperial Health Charity. On June 20th and after the success of the trials, which was used to treat 13 patients, positive news emerged that unilateral MRI guided focused ultrasound to treat essential tremor was approved by NICE (National Institute for Health & Care excellence).

The National Tremor Foundation are delighted to have secured this donation and proud to be at the forefront in campaigning for research & funding into this condition. A successful campaign in Scotland will give hope to many that their lives will be made a little easier with the availability of this equipment.

The National Tremor Foundation have secured a donation of £40,000 towards a fundraising campaign at the University of Dundee to obtain a MR Guided focused ultrasound machine for the treatment of essential tremor.

If the campaign is successful the machine will be the first of its kind in Scotland and will bring the number of MR Guided focused ultrasound machines in the UK to 2, with the first

already in place at St Marys hospital in London.

“A successful campaign in Scotland will give hope.”

As a result of some tireless work from NTF member Mary Ramsay, from Inverness, the motion to bring a MR Guided focused ultrasound to



National Tremor Foundation

The NTF depends on donations, sponsorship and contributions in order to carry out its work.

If you would like to make a donation go to **www.tremor.org.uk/donate**



Imperial Health Charity launch

The National Tremor Foundation were delighted to be invited to the Imperial Health Charity launch of a £1.5 million fundraising campaign to help develop a new treatment for patients with essential tremor.

The event launched on Thursday June 21st was attended by various members of the medical & charitable sectors including Parkinsons UK, EPDA & Insightec. The NTF were represented by chairman Kevin Harfoot, support group co-ordinator Jackie Farrell & Dr Peter Bain, consultant neurologist & founder trustee of the NTF. Dr Bain played a pivotal role in carrying out the trials and the National Tremor Foundation made a small grant available to help pay the costs of one of the researchers.

The Tremor Lifeline Appeal aims to enhance the Acute Imaging Centre at St Mary's Hospital, enabling world-leading neurologists to offer the treatment to many more patients.

Essential tremor is a brain disorder characterised by uncontrollable shaking. It affects over one million people in the UK, with around 250,000 severely disabled by the condition.

Current treatments such as drug therapies, surgery and a technique



(L-R) Dr Peter Bain neurologist & Trustee NTF, Ian Lush Chief Executive Imperial Health Charity, Kevin Harfoot NTF Chairman, Jackie Farrell NTF support group coordinator and Professor Gedroyc Consultant Radiologist

known as deep brain stimulation are often ineffective, and some carry significant risks and side effects.

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.

The first UK clinical trial of the treatment took place at St Mary's Hospital last year, using a £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.

The treatment has now been recommended by NICE – the National Institute for Health and Care Excellence – meaning the team at St Mary's can continue their essential work.

In order to support them, the appeal will seek to raise £1.5 million to pay for an additional MRI machine as well

as structural improvements and a new patient waiting area at the Acute Imaging Centre at St Mary's.

An event, hosted by comedian and broadcaster Mel Giedroyc, was held at St Mary's on Thursday 21 June to launch the appeal.

Guests included former essential tremor patients, senior members of the Trust executive team and representatives from Insightec, which manufactured the MRI machine.

Professor Wladyslaw Gedroyc, a consultant radiologist at St Mary's, said the treatment was "as close as you can get to a medical miracle".

Launching the appeal this week, he added: "We are very grateful to Imperial Health Charity for their initial grant which allowed us to buy the focused ultrasound brain hardware and also for their continued support in our ambition to set up a dedicated focused ultrasound centre to allow us to continue and expand our work in this field."

Prof Gedroyc and the team at St Mary's are also exploring how the procedure could be used to treat other brain disorders, such as Parkinson's disease. In the future it may also be used to treat tumours, epilepsy and dementia.

Lord Fellowes visits St Mary's Hospital to learn more about MRI Guided Focused Ultrasound treatment

NTF Honorary president, Lord Julian Fellowes visited St Mary's hospital in Paddington on Thursday 5th July to see for himself the work done to date in the treatment for essential tremor and to learn more about the Tremor Lifeline Appeal.

Lord Fellowes was met by Professor Wladyslaw Gedroyc, consultant radiologist at St Mary's who explained the new procedure involving MRI guided focused ultrasound. The procedure 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. Current treatments such as drug therapies, surgery and a technique known as deep brain stimulation are often ineffective, and some carry significant risks and side effects.

The tremor lifeline appeal will seek to raise £1.5 million to pay for an additional MRI machine as well as structural improvements and a new patient waiting area at the Acute Imaging Centre at St Mary's.

Having got past one hurdle with the treatment, which has been recently approved by NICE (The National Institute for Health & Care



Lord Julian Fellowes visited St Mary's hospital.

excellence), the next step is to sell it to NHS England as a treatment that is sufficiently needed in the community to be funded by the NHS. This next step in the process is something in which the NTF itself will be hoping to get involved.

After his visit, Lord Fellowes said: "Essential Tremor is a serious disability that has been largely ignored for too long. It may, from the outside, seem trivial or even comic that a person cannot hold a cup or a glass or pour from a jug or write a postcard or tie their shoe laces or drink soup without the risk

of leaving half of it down their front. But it is far from comic for the sufferer. It is distressing and degrading, a condition that makes hermits of its victims, that destroys skills and ruins social lives, and frequently results in chronic depression. The idea that there is now a real and effective treatment that works - as opposed to pills that often don't - is immensely heartening. Once this is available to the general public, it will release many, many men and women from a humiliating prison where they have been held for far too long. I speak with knowledge, for I am a sufferer. "

Jackie invited as speaker at Disabilities and Neurological Study Day

By Jackie Farrell, NTF Support Group Coordinator

NTF Support Group Coordinator Jackie Farrell describes her day as a guest speaker at the Physical Disabilities and Neurological Study Day in Southampton on Monday 16th July 2018.

“It was a remarkable day not only for raising awareness of essential tremor and orthostatic tremor but also NTF too.”

I was pleased to have been invited to share my personal experiences with essential tremor and explain in more depth about one of the most common, but lesser known neurological movement disorders. It was also an opportunity to demonstrate how my hands, head and leg tremors affect my daily life including trying to cope with simple tasks such as eating and drinking.

The Study Day organised through Hampshire Neurological Alliance and Hampshire County Council was held at King's Community Centre, Hedge End, Southampton.

Invitations had been extended to Occupational therapists, social workers and staff working in health, social care or the voluntary sector which resulted in a full capacity audience of 80 people.



Alyson Farr, and Jackie Farrell at the Neurological Study Day

Although some of those present had heard of essential tremor or knew someone with it, there were a few that had no knowledge of it. One lady with familial essential tremor had taken the day off work to attend the presentation and a mother mentioned her 19yr old son had recently been diagnosed. Both were interested in the familial essential tremor study being carried out by Professor Hawkes.

The Q&A session was interesting and included “had essential tremor ever been misdiagnosed as Parkinson’s”. Easy to answer as I personally knew of one such person and had heard of others being misdiagnosed.

It was also a good opportunity to introduce Alyson Farr chair of

NTF Orthostatic Tremor group who explained about this even lesser known tremor disorder.

A remarkable day not only for raising awareness of essential tremor and orthostatic tremor but also National Tremor Foundation too, with the exception of three or four people, no one else knew of the charity. The NTF information table attracted much interest with people taking plenty of literature that will surely help spread the word. Pleased to say NTF have now been added to a few online health services in Hampshire & surrounding areas.

We would like to thank the organizers for the invitation and making us feel so welcome.

To find out when the next London & South East event is go to www.tremor.org.uk/events

Raising awareness in Hampshire

By Alyson Farr, Chair of the Orthostatic Tremor Group

Alyson Farr, Chair of the Orthostatic Tremor Group shares her experience of raising awareness at the Neurological Study Day in Southampton.

On Monday 16th July 2018. I was invited by Jackie Farrell, the essential tremor coordinator, who introduced me to the organisers, to share part of her allocated time to explain about orthostatic tremor and raise the awareness of this neurological condition.

The presentation was through the Hampshire Neurological Alliance, linked with PaCT (Partnership in Care Training).

It was organised by Hampshire County Council to organise

a 'Physical Disabilities and Neurological Study Day. Empowering, Enabling and Supporting

Independence. The venue was the King's Community Centre at Hedge End, Southampton. The invitation had been extended to occupational therapists, social workers and staff working in health, social care or the voluntary sector

Jackie Farrell was the lead speaker and did a fantastic job in describing her life with essential tremor some of those present had heard of essential tremor or knew someone with essential tremor as it has been known to be misdiagnosed as Parkinson's.

Alyson Farr, Chair of the Orthostatic Tremor Group

Would you believe that no-one attending the Study Day, and I am talking about over 80 people present, who have a close involvement with people having neurological disorders had never heard of orthostatic tremor.

Well they have now, there was a good response of interest and found those present very friendly. I was able to make other contacts with therapists and support group members within the Southern Region. Whilst talking to 'CONNECT TO SUPPORT' Hampshire, they offered to add the NTF Organisation to their website. Other regions also have contact branches offering help, care and support. I will be following these up in due course.

To find out when the next Orthostatic Tremor event is go to www.tremor.org.uk/events

Shaking it up in Salisbury

Sheelagh Wurr, Chair of the Salisbury Tremor Group

Sheelagh Wurr, Chair of the Salisbury Tremor Group, the 'Salisbury Shakers' shares her experience of their latest meeting.

There were only six people at today's meeting (14th July) of the Salisbury Shakers. This was due to many factors such as visits to Australia, tooth extraction, people on holiday etc. However, those who came along enjoyed a pleasant morning in St Thomas's.

We talked about Professor Hawkes' research into essential tremor which suggests that those



The Salisbury Tremor Support Group

who have it might live longer and also have an enhanced sense of smell. Steve 'Mushy Peas' Minott led us in some relaxation exercises and we then all walked to the Red Lion where we found ourselves in the middle of a wedding reception surrounded by bridesmaids and the bride herself! Since nobody offered

us any wedding cake, we had some lunch there on the table reserved for our group.

They will have a break in August and they meet again on September 15th. Put the date in your diary now and perhaps more members will be able to join us. For more information go to www.tremor.org.uk/events

Essential tremor and children

**By Kitty Reilly,
NTF Children's Liaison Officer**

Essential Tremors in children can leave parents with many unknown questions such as; can it be cured, will it progress, how will it impact my child, what will their future be like etc. I know this as I am a mother of a child who has an Essential Tremor and despite being the Children's Liaison Officer and Trustee at the National Tremor Foundation (NTF) I still have these questions and thoughts and live with them daily as I am sure does my son.

I became involved with the NTF to start raising awareness of children who have Essential Tremor, primarily to let them know they are not alone, as my son believed he was, and to support parents in what can often be challenging times especially to get others to recognise the impact Essential Tremor can have on their child's day to day life, including and not limited to school.

I am often asked what parents can do to help their children with their day to day life and there are a couple of things that my son has found useful which include Velcro on school uniform to help fasten and unfasten things quicker and removes the need for fiddly buttons and zips, weighted cutlery that helps when eating, gadgets to open cans of drink independently, pens and pencils with a larger grip, Velcro school shoes, electric toothbrush, core strengthening exercises, house keys with an extended grip hold, electric tin opener, extra time from

school to complete tasks etc. I find talking to my son about how he is feeling really helps me understand his difficulties, challenges and helps us both to work together to resolve the issues about how he sometimes feels.

What is needed to understand the impact of children with Essential Tremor is more research. This is something that is lacking globally and would be extremely beneficial to help children and their families understand the condition further. Currently, few know that Essential Tremor in children is one of the most common neurological conditions yet the awareness of the impact and research around the prognosis and treatment is limited this is something together we can change.

If you need any further support or are considering carrying out research in to Essential Tremor in children, please do get in touch at kitty@tremor.org.uk.



Support groups

The National Tremor Foundation 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.

Meetings can vary in frequency from regular monthly groups or on a casual basis perhaps three or four times a year. We realize not everyone can commit planning too far in advance. For example a few members in Southampton meet occasionally in

a local garden centre café. As well as coffee & chat they also get to enjoy the plants! Would this idea or similar be something you could consider in your area?

Groups give people the opportunity to learn about their conditions, chat to people with similar problems, compare notes and pass on helpful hints and tips in a welcoming environment. They are not only about supporting one another, but also about having fun and making new friends.



**Jackie Farrell,
NTF Support Group Coordinator**

If you would like further details on essential tremor support groups in your area or are interested in starting up a group, please contact NTF support group co-ordinator Jackie Farrell on 07843 777288 or email jackie@tremor.org.uk

Essential Tremor

Cambridge

Jamie Goodland
essentialtremorcambridge@gmail.com

Havering and Essex

Tom Schubert
01375 373993

Leeds and Sheffield

Merane Todd
lands@tremor.org.uk

Warwickshire

Nuneaton
Larz Jackson
nuneaton@tremor.org.uk

Northwest

Liverpool
Tom and Joan Reader
0151 475 3252

June Jones
01942 246050

Norfolk

Toby Howes
01508 498431

Oxfordshire

Oxford
Katherine Phillips
07851 774182
oxford@tremor.org.uk

Scotland

Mary Ramsay
07967 428036

London and South East

Jackie Farrell
07843 777288
jackie@tremor.org.uk

Wiltshire

Salisbury
Sheelagh Wurr
01985 216056

Primary Orthostatic Tremor

Alyson Farr
Alyson@tremor.org.uk

Advice for children

Kitty Reilly
kitty@tremor.org.uk

Online support groups

We now run a number of online support groups.

NTF Facebook Support Group & Orthostatic Tremor Support Group

www.facebook.com/nationaltremor-foundation



Did you know that the NTF represents over one million people? You are not alone.

**Share your personal story about tremor.
Email enquiries@tremor.org.uk**