

The Big Lottery Funding for support groups

GyroGear wins €1.8m EU funding

Summer support group growth

Support groups  
& more!

Amanda is running the  
Yorkshire Marathon

-AUTUMN EDITION-



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## Summer support group growth!

**The number of NTF support groups continues to grow, making the NTF bigger than ever.**

The summer saw over 12 successful support group meet-ups, making it the busiest season yet. This included the newly formed Nuneaton Support Group organised by Larz and the Cambridge Support Group led by Jamie, who many may have met at the NTF Annual Conference.

This is great news for the NTF and people with tremor as it shows the dedication and enthusiasm of NTF support group leaders who's willingness to volunteer to run these meetings are appreciated by everyone involved with the NTF.

Events already lined up for this autumn Include the very first Cambridge meeting on Saturday 3rd November.

**For more about NTF events go to [www.tremor.org.uk/events](http://www.tremor.org.uk/events)**



**Botley Food Fayre saw live music and food.**



**The first ever Nuneaton Support Group Meet-Up.**



**The NTF stand at the Annual Community Safety Day.**



**The Salisbury Shaker's have lunch at a local pub.**

# NTF awarded The Big Lottery Fund support group funding

**We are pleased to announce that the NTF has been awarded £4000 by The Big Lottery Fund to go towards support group development.**

The Big Lottery Fund gives grants to organisations in the UK, such as the NTF, to help improve their communities.

## **What's the importance and impact of NTF support groups?**

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.

## **How will it make a difference to the people who run support groups?**

NTF funding is very limited and currently support groups are entirely run by our dedicated volunteers.

The funding will give them the ability to expand on their work and help support those that suffer from tremor and the community.

## **How will it improve lives?**

The development of support groups for essential tremor & orthostatic tremor will directly improve the quality of lives, as many people feel alone when dealing with tremor and do not know who to turn to.

The support groups allow people to build a network of friends who they can turn to. In addition, support

groups play an active role in raising awareness of tremor.

## **How will it improve the whole community?**

The development of support groups will have an impact on a range of personal and social issues faced by communities as a whole. Tremor does not only affect people who suffer from the disorder but also their families and friends. Support groups play a vital part in educating members of the public from educational professionals to health care practitioners.

We look forward to hearing more about The Big Lottery Fund and the development of our support groups.



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](http://www.tremor.org.uk/donate)



# Mary's fight for tremor

**Mary Ramsay runs the Scottish Tremor Society – and as she's quick to tell you, 'that's Scottish with three Ts, two for Scottish and one for tremor.'**

Mary has had essential tremor since birth, and is currently treated with a deep brain stimulation unit. 'It's electrodes in the brain, basically like a pacemaker in the brain.' And if that sounds uncomfortable it's not just the treatment, but the distances involved, which can be exhausting. 'There's nothing for people with tremors in the north and east – it's all centralised in Glasgow, and they will not accept anyone from the north and east because they have a long waiting list – so I have to travel from Inverness to Newcastle, which is a long journey. I could do Inverness-Dundee return in a day, but the trip to Newcastle involves an overnight stay.'

Mary has campaigned for disability rights and equality for 40 years, most recently on the need for a focus ultrasound device in north-east Scotland. Focus ultrasound, perhaps unsurprisingly, does what it says on the tin – it focuses ultrasound on specific parts of the brain related to tremors, and can be of great benefit to those with tremor conditions, such as essential tremor, Parkinson's, and multiple sclerosis (MS). And, it's non-invasive. 'Not everyone wants electrodes attached to their brain,' Mary says, 'and this would give them hope for alternative treatment.'

Recently, Mary brought her fight to the Scottish Parliament. 'It wasn't until becoming involved with Inclusion Scotland that I had the confidence, thanks to Mr. John Beaton, to go for a parliamentary motion.' On May 16th, a motion on focus ultrasound was brought to the Scottish Parliament by Mary's MSP, Rhoda Grant. 'Rhoda was very driven when I drew her attention to the fact that there is nothing for people with tremors in the north and east. She got cross-party support, and she and her assistant Olivia did a lot of research, including speaking to Dr. Tom Gilbertson at Ninewells. Because of their work, I felt every piece had been gathered and was ready to be presented.'

Mary attended the debate at the Scottish Parliament, and quickly made a name for herself. 'I had a long, interesting chat beforehand with Edward Mountain MSP. He said I'd make him nervous, staring at the back of his head from the gallery, and I said "that's okay, then." The debate started – Rhoda said her bit, other MSPs contributed too, then it was Edward Mountain's turn. He got a bit tongue-tied, and looked up at me in the gallery. "See Mary, I told you you'd make me nervous!" At this the Presiding Officer said "I wish Mary could teach me to make you all nervous!"'

'Beyond her instant notoriety, Mary is encouraged by the debate's outcome. 'Shona Robison, the Health Minister, didn't come out and say no, like I thought she might, but has put the ball in Dundee University's court



**Mary, Scottish Tremor Society Coordinator**

to apply for research grants. Dr. Tom Gilbertson has been back in touch with Rhoda Grant to pursue this, so it is moving forward. I feel very positive that this wasn't a "no".'

Mary is determined to keep fighting for those with essential tremor and other conditions. 'This has spurred me on to help other people, because I went to hell and back as a child, growing up not knowing what this was. I didn't get a definite diagnosis until I was 48. I was told when I was 20 not to have children, but now I have three children and ten grandchildren. Not all medical professionals are right. If focus ultrasound helps someone avoid what I went through, I will fight to my last breath to get it. This isn't the end of my fight for focus ultrasound, it's the beginning.'

'My advice to people who are wanting to fight is go to your local MSP. Speak to them, be confident, and don't give up at the first hurdle. Fight, and keep fighting.'



# GyroGear wins €1.8M European funding

by Deborah Evanson

**An Imperial startup has received €1.8M from the EU's Horizon 2020 programme to develop a device that helps stabilise the hands of people with tremors.**

GyroGear, which was founded by Imperial alumnus Dr Faii Ong, is developing wearable technology that can improve quality of life for people who suffer from hand tremors – such as those with Parkinson's disease and Essential Tremor.

Elderly person's hand holding a glass. Their first product, the GyroGlove, uses gyroscopes to counteract hand tremors. This means that everyday tasks – such as eating, drinking and writing – can be performed more easily.

A gyroscope is a spinning wheel or disk which is used to maintain orientation or stability. Like spinning tops that try to stay upright, gyroscopes similarly seek to remain in the same position. They are used in cutting-edge aerospace technology, such as guidance systems for planes and satellites, and gyroscopic effects are also responsible for the stability of a moving bicycle.

GyroGear has received €1.8M through the Horizon 2020 SME Instrument, which offers support for ground-breaking innovative ideas for products, services or processes with the potential to create entirely new markets or revolutionise existing ones. GyroGear

was one of only 2 applicants from the UK to win this grant.

The team is currently working with volunteers to further optimise their prototypes and ready the design for manufacture. The funding from Horizon 2020, which is the largest ever European funding programme for research and innovation, will help them bring the GyroGlove, to market.

In search of a solution

Dr Faii Ong came up with the idea for the GyroGlove while studying Medicine at Imperial. He was caring for a 103-year-old woman who was becoming increasingly frail because she was struggling to feed herself due to hand tremors.

Faii said: "I passed by her bed during lunch and saw that she had spent half an hour trying to finish a bowl of soup, most of which had gone down her front.

"I skipped an imminent tutorial to tidy her up. I then asked the busy nurses why nothing was done, and why was she still being served soup. I was told that the lady had severe dementia, had already stopped responding to medication to stop the shaking, and there was nothing more medically that could be done. I was genuinely taken aback, and resolved to find a solution."

Reviewing over 40 different technologies and concepts, Faii recalled gyroscopes from childhood toys and their current applications in aviation and electronics. Faii looked into whether the same technology could be used to stabilise the hands.

Faii received advice from Professor Jeffrey Karp at the Harvard-MIT Health Sciences and Technology Division and Professor Alison McGregor, Professor of Musculoskeletal Biodynamics at Imperial, to help take his concept to full scale medical device development.

Multidisciplinary environment  
The team developed their first prototypes through Imperial College

Advanced Hackspace, which provides access to specialist manufacturing equipment, training, and a network of like-minded members, to help anyone at the College turn their ideas into tangible breakthrough prototypes and solutions.

They were also supported through Imperial's Enterprise Lab, which works to support enterprising activity across the College by providing access to state of the art facilities, training, mentoring and a range of programmes to help Imperial innovators develop new business ideas, hone their pitching skills, and raise their entrepreneurial aspirations.

Faii added: "Imperial has a unique multidisciplinary environment. As a medic, I had access to quality engineers and facilities. I am appreciative and supportive of the grassroots efforts to develop unique solutions at the intersection of multiple disciplines. GyroGear has indeed benefitted from the effort, generosity and constant support rendered by ICAH and the Enterprise Lab. There is still significant, untapped potential within the Imperial community, and I still urge every member of the college to take a step to see what can be achieved"

"Given the rigour and repute of the H2020 programme, this latest round of funding is a marked vote of confidence in GyroGear's progress to date and market potential. To have reached this stage with minimal expenses and just 2 years of development time is exceptional for a medical device company.

"We have seen and validated the effect of the GyroGlove with users. This grant will allow us to hyperfocus far more, and bring the glove even more effectively to market. So much time, guidance, support has been afforded to us by multiple individuals from every walk of life. We must not let any of them down."

**Source: <http://www.imperial.ac.uk/news/187612/hand-stabilising-glove-wins-18m-european-funding/>**

# Orthostatic Tremor Awareness Month

**The National Tremor Foundation is proud to have celebrated Orthostatic Tremor Awareness Month this September.**

Orthostatic Tremor Awareness Month is about working together with the common goal to build awareness, compassion and research of orthostatic tremor.

Orthostatic Tremor Awareness Month was started by Dr Sue Boyd, a former Australian Ambassador and delegate to the United Nations.

Orthostatic tremor is characterised by high frequency tremors of the legs when in a standing position and an immediate sense of instability. It is a little known, and often ill diagnosed neurological movement disorder.

This was the NTF's first year raising awareness during the month, and hopes to make next year's Orthostatic Tremor Month even bigger.

**We would like to thank the Orthostatic Tremor website ([orthostatictremor.org](http://orthostatictremor.org)) for this information.**

## Amanda is running the Yorkshire Marathon

**Amanda is running the Yorkshire Marathon on Sunday 14th October for the NTF and to raise awareness of tremor. Amanda shares her story of living with tremor.**

"My dad, Geoff, was diagnosed with tremors at the age of 17 and it took him many years to be able to speak about it, even to family. He was perceived to be an alcoholic, especially as he worked in the nightclub trade and people assumed the tremors were due to withdrawal. As a child my brother and I didn't really notice the hand tremors but as we got older we became more aware but didn't really talk about them, just worked with them and around them. His difficulties lie with eating, drinking, writing and general holding of things. We often cut up food, hold tight to glasses and assure him that it's ok to have tremors. Easy for us to

say when we do not have them.

"My dad has researched cures such as medication, surgery and more recently cannabis oil and non invasive surgery but the only cure he found was alcohol! Not the best cure to continue daily life.....

"During his research he came across the National Tremor Foundation and was so reassured that he was not alone with his tremors. There is a surprisingly large amount of people affected, on varying scales. This knowledge gave my dad more confidence in being able to speak about and explain his tremors to friends, family and others much more openly and has led him to be further involved in the group on a local level.

"I chose to run the Yorkshire Marathon for all the "movers and shakers" to



**Amanda who is running the Yorkshire Marathon**  
raise money and awareness for this group."

The run will take place around York on Sunday 14th October. Support her at Virgin Money Giving.

**Donate to Amanda at**  
[www.tremor.org.uk/amanda](http://www.tremor.org.uk/amanda)

# 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.

For further information contact Jackie on 07843 777288 or email [jackie@tremor.org.uk](mailto:jackie@tremor.org.uk)

## Essential Tremor

### Cambridge

Jamie Goodland  
[essentialtremorcambridge@gmail.com](mailto:essentialtremorcambridge@gmail.com)

### Havering and Essex

Tom Schubert  
01375 373993

### Leeds and Sheffield

Merane Todd  
[lands@tremor.org.uk](mailto:lands@tremor.org.uk)

### Warwickshire

Nuneaton  
Larz Jackson  
[nuneaton@tremor.org.uk](mailto:nuneaton@tremor.org.uk)

### Northwest

Liverpool  
Tom and Joan Reader  
0151 475 3252

### Norfolk

Toby Howes  
01508 498431

### Oxfordshire

Oxford  
Katherine Phillips  
07851 774182  
[oxford@tremor.org.uk](mailto:oxford@tremor.org.uk)

### Scotland

Mary Ramsay  
07967 428036



Jackie, Support Group Coordinator

### London and South East

Jackie Farrell  
07843 777288  
[jackie@tremor.org.uk](mailto:jackie@tremor.org.uk)

### Wiltshire

Salisbury  
Sheelagh Wurr  
01985 216056  
[salisburyshakers@btinternet.com](mailto:salisburyshakers@btinternet.com)

## Primary Orthostatic Tremor

Alyson Farr  
[Alyson@tremor.org.uk](mailto:Alyson@tremor.org.uk)

## Advice for children

Kitty Reilly  
[kitty@tremor.org.uk](mailto:kitty@tremor.org.uk)

## Online support groups

### NTF Facebook Support Group & Orthostatic Tremor Support Group

[www.facebook.com/nationaltremor-foundation](http://www.facebook.com/nationaltremor-foundation)

# Autumn events listings

### NTF information stand at Health & Wellbeing Event, Surrey

19 October 2018  
Holy Trinity Church, Maldon Rd,  
Wallington SM6 8BL  
Jackie  
[jackie@tremor.org.uk](mailto:jackie@tremor.org.uk)

### Cambridge Essential Tremor Support Group - First Meeting

3 November 2018  
Caffe Nero 17 King's Parade, City Centre, Cambridge CB2 1SP  
Jamie  
[essentialtremorcambridge@gmail.com](mailto:essentialtremorcambridge@gmail.com)  
01223 813556

### Salisbury Shakers November

3 November 2018  
St Thomas & St Edmund's Church, St Thomas's Square, Salisbury SP1 1BA  
Sheelagh Wurr  
[salisburyshakers@btinternet.com](mailto:salisburyshakers@btinternet.com)

### North West Tremor Support Group Meet Up

7 November 2018  
Liverpool, Lord Nelson Street,  
Liverpool L3 5QB  
Tom and Joan Reader  
0151 4753252

### Leeds Tremor Support Group Meet Up

17 November  
Marriott Hotel, 4 Trevelyan Square, Boar Ln, Leeds LS1 6ET  
Merane Todd  
[lands@tremor.org.uk](mailto:lands@tremor.org.uk)

### Shaking and dining

Thursday 29th November 2018  
6pm to 8pm  
Attleborough Arms, Highfield Road,  
Nuneaton CV114PL  
Larz  
[nuneaton@tremor.org.uk](mailto:nuneaton@tremor.org.uk)

To keep up-to-date with our events please go to  
[www.tremor.org.uk/events](http://www.tremor.org.uk/events)





**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](mailto:enquiries@tremor.org.uk)**



