

Young people with essential tremor

Alan running the London Marathon

New NTF Friend Scheme

Support group
news & more!

Do people with
essential tremor
live longer?

-SPRING EDITION-

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Become a Friend of the NTF

The National Tremor Foundation has recently launched the new Friends of the NTF scheme.

By becoming a Friend of the National Tremor Foundation, not only will you be supporting the foundation

and people with tremor but you will receive:

- An NTF card
- A wrist band
- A pin badge
- A pen
- A key ring

To become a Friend of the NTF you need to make a minimum donation of £10.

To join the Friends of the NTF scheme go to www.tremor.org.uk/friends

Do people with essential tremor live longer?

Background to this proposal.

The idea that essential tremor might be associated with long life was proposed way back in 1922 by Minor but it has never been resolved completely. We may now have the means to address this using 'telomeres' extracted from your salivary cells.

The telomere is a section of DNA present at the end of chromosomes in all animals. In general, the longer the telomere the longer the life span. There is evidence from animal experiments that some strains with involuntary movement have increased life span. Thus, we would like to determine whether people with familial Essential Tremor (FET) have longer telomeres than expected.

Also, our earlier work suggested that some people with Familial Essential Tremor have a superior sense of smell implying that they might be biologically 'fitter'.

Plan. Ethical approval is being sought from the Queen Mary Ethics of Research Committee. Once obtained, we would invite 12 volunteers with typical FET, measure their telomere length and compare them with their

12 healthy partners or non-blood related family members e.g. in-laws. Telomere length is measured by extracting DNA from cells normally present in saliva. We will also measure your ability to identify 40 different odours from a scratch and sniff pad (University of Pennsylvania Smell Identification Test)

What would happen if I am interested in taking part? We plan to interview people with Familial Essential Tremor and their partners at the AGM of the National Tremor Foundation meeting on June 16th. You must have Familial Essential Tremor to take part. It would be most helpful if you could bring along your medical records, especially those concerned with tremor diagnosis. We will give you a detailed explanation of what is involved and you could ask as many questions as you like now, by email or on the day. You would be asked to sign an information and consent form. If you agree to participate there are virtually no risks we can think of.

We require two samples:
1. 2ml (half a teaspoon) of saliva in a special test tube

2. Completion of the smell identification test

Analysis would be totally confidential and we will only analyse your telomere length, no other DNA examination will be performed

If you would like to take part or require more information, please email Prof Chris Hawkes: c.hawkes@qmul.ac.uk

Hope you can help!

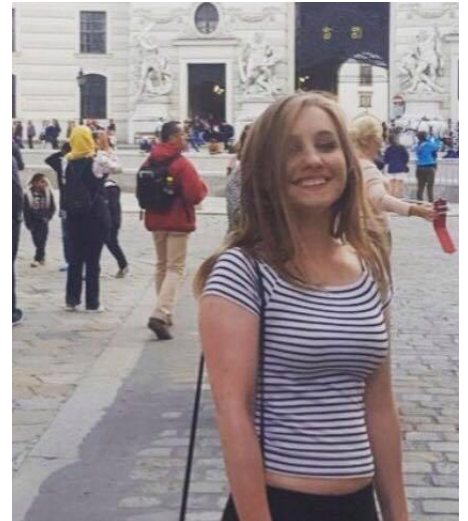
Research team: Professor Chris Hawkes, Professor Tom Vulliamy, Professor Leslie Findley, Professor Gavin Giovannoni. We work at the Neuroscience/ Molecular Biology and Neuroimmunology Units, Blizard Institute, Queen Mary University of London and (LJF) at Neurology Department, Queens Hospital, Romford

Young people with essential tremor: Chloe's story

My name is Chloe Hodge, I'm 21 and live in Cheshire. I was diagnosed with essential tremor when I was 13 but I can't remember not having it. For younger people with tremor there is often a lot of confusion because we have only ever seen older people being portrayed as the ones who shake in film and TV shows etc. This can lead to distressing and embarrassing moments when growing up. When other children were thinking about the fun they would have that day, I was wondering if I could get through the day without anyone noticing me shake. As you get older new issues begin to arise such as people thinking you have alcohol/drug problems- I even had a cashier

ask me if I was scared of her once!

Although these comments can be upsetting and at the very least, irritating- you just need to remind yourself that these people are simply uneducated about the condition and definitely try not to read too much into it. We are very lucky to be growing up in the age that we do. Right now, acceptance and equality is at the forefront of people's minds and as they continue to grow and learn about different conditions/disabilities, we will hear less and less of these comments. I hope you continue to embrace your tremor and remember it doesn't control you- you control it!



Chloe Hodge

If anyone would like to read my blog about living with Essential Tremor as a 21 year old the link is:
<https://mytremorsandme.wordpress.com>

Joan's U3A letter

Support group member Joan recently wrote to her local U3A group. Read her letter:

Do you know anything about ET ? No, I don't mean that little fellow from outer space but a neurological disorder called Essential Tremor where any part of your body can have an uncontrollable shake.

I have had ET for over twenty years and it is when I go to use my hands that the tremor is evident - one of the reasons that I don't join you for a cup

of tea after the meetings ! I recently attended a talk on ET at the Holiday Inn in Southampton, an audience of perhaps 50 people who all agreed that until the meeting they had never met another sufferer. Also, for me at least, it was the first time I had heard of the National Tremor Foundation.

The purpose of this letter is to ask whether anyone in our U3A Group has ET, or knows anyone who has, and would be interested in meeting, informally, now and again

to chat about our experiences. As far as I am aware the nearest group to our area is in Salisbury,

There is no cure for this disorder although tests are taking place in UK for a non-invasive laser treatment to the brain (guided focused ultrasound).

Joan

Joan is happy for other NTF members to use her letter as a basis to write to their local communitygroup.

Alan and the London Marathon

Alan shares his story about living with tremor and his plans to run the London Marathon for the NTF.

I decided it would be a good idea to submit my name to run the London Marathon in 2018 via their lottery system. I wasn't successful, and to be honest I exhaled a huge sigh of relief.

That was until I found out that the NTF had selected me to be their one and only entrant, running on behalf of the charity.

I've had a tremor since I was a child and I got diagnosed with essential tremor when I was about 17. I've taken propranolol since then, which really does help, however I've always struggled with the embarrassment of having shaky hands.

My tremor is often so mild that it goes unnoticed; however since I was a teenager it's been a huge issue for me, mainly because of embarrassment, fear, and the fact that I always try to hide my condition from others. The tremor has in a way been debilitating for me, and throughout my life has often dictated what I could, and couldn't do - what I could eat, what I could drink, if I could go out,

and what I could work at, the list is endless...

Then earlier this year I happened to be looking at the Portsmouth visitor Information page and I noticed that Jackie from the NTF had organised a local coffee meeting in Southsea for anyone who had essential tremor. First I thought coffee? I can't hold a cup and saucer, so how can we meet up for coffee? I'd never heard of the NTF before and I'd never met anyone else who had essential tremor, however I went along and it was really lovely to meet others there with the same condition, and to finally realise that I should no longer be embarrassed.

Later when I heard that the NTF had a charity place in the London Marathon, I jumped at the chance. Not only would the marathon be good for me personally and get me fit again, but it would be an amazing opportunity for me to do something positive about my tremor, and to raise awareness about the condition.

I have always run a little bit, and even completed the Great South Run in 2016, however this will be my first marathon, and it's the London Marathon of all things. My training started as soon as my place was confirmed and I now run about



4 times per week and I'm slowly increasing the distance and my speed until I'm ready for the 26 long miles ahead of me in April.

This will be the first that that my tremor hasn't been restrictive, in fact, in many ways it's enabling me to run the marathon and for once have a very positive influence in my life.

The London Marathon is taking place on Sunday 22nd of April 2018. Please have a look at my fundraising page and donate what you can, with all donations going directly to the NTF, and if you live in London or nearby then please come along and cheer me on.

Help Alan raise funds at
<https://uk.virginmoneygiving.com/AlanCorrigan>

Essential Tremor Open Day success

The National Tremor Foundation March Open Day held on the 17th March was the biggest yet.

Despite snowy conditions, 50 people attended the event. During the event people were able to learn more about essential tremor and the NTF. There were talks about NTF support groups, and developments from GyroGear and INSIGHTEC.

GyroGear, talked about their new glove which helps stabilise hand tremors; and INSIGHTEC talked about the new neurological disorder



surgery, called focused ultrasound treatment.

held on Saturday June 16th, at Holiday Inn, Brentwood, Essex.

Annual Conference

Following this success we look forward to the NTF Annual Conference to be

Raising awareness in Cambridge

The new Cambridge support group meeting held on the 24th March at Cambridge Central Library. was an amazing success.

There was an information table and they spoke to a diverse range of people, including a lot of young people, who asked questions about tremor and shared experiences.

Members of the public were able to sign up and join the new Cambridge Support Group.

After this success we look forward to the next Cambridge Support Group event.

Find out more about our support groups. [got to www.tremor.org.uk/support-groups](http://www.tremor.org.uk/support-groups)



Support group member Jaimie at Cambridge Central Library

Support groups

We run a number of support groups to support all types of tremor.

If you would like further details on essential tremor support groups in your area or are interested in starting up a support group in your area 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

Hull

Nicki Kelly
01482 498432

Leeds and Sheffield

Merane Todd
lands@tremor.org.uk

Northwest

Liverpool
Tom and Joan Reader
0151 475 3252

June Jones
01942 246050

Warwickshire

Nuneaton
Details TBA

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

Jenny Beckingham
01263 837248
ajb.kilwhang248@gmail.com

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

Health Unlocked

www.healthunlocked.com/national-tremor-foundation



Don't forget the NTF Annual Conference 2018!

Saturday 16th June, Holiday Inn, Brentwood, Essex.

For further details go to www.tremor.org.uk/events

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

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

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

