



National Tremor Foundation

Issue 007

Support groups
& more!

SUMMER SPECIAL

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New Sheffield tremor support group launch

October 19th 2019, 12:45pm-4:00pm

Ponds Forge International Sports Centre, Sheaf Street, S1 2BP

For more details contact Merane on lands@tremor.org.uk

Summer 2019



Tony Foulds at the Annual Conference



A BIG THANK YOU you to Merane Todd who raised £365 by taking part in 10 sporting challenges



Jackie Farrell gives a talk on the Queen Elizabeth



Salisbury Shakers Meet-Up

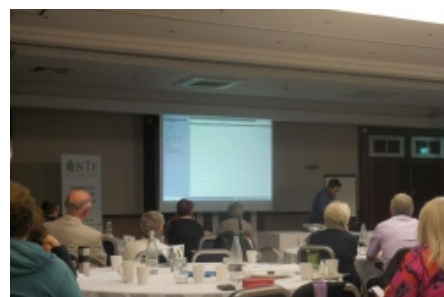
Annual Conference biggest yet!

The NTF Annual Conference at the Hilton Hotel, Sheffield on Saturday 6 July was the biggest yet

Over 60 people attended the event where people were able to learn more about essential tremor, orthostatic tremor and the NTF. There were talks about NTF support groups, and presentations.

Faii Ong from GyroGear, talked about development in their new glove which helps stabilise hand tremors; Dr. Peter Bain gave an update on MR-guided focused ultrasound treatment; and Prof Chris Hawkes gave an update & results on 2018 Telomere study.

This success follows on from the Sutton Essential Tremor Awareness Day held earlier this year. We look forward



The Annual Conference was a huge success

to hearing more about NTF events.

More information and images can be found at www.tremor.org.uk

Writer raises £10,000 for the NTF

Writer and ex-RAF Officer, Bob Kermeen, whose wife Jan, suffers from essential tremor has raised £10,000 for the NTF since January 2013.

Over the last six years, Bob has given over 200 talks, where he gets paid to talk on a number of modern history issues by organisation, including The Rotary Club, 41 Club, and the Women's Institute.

Bob was born and schooled in the Isle of Man. After graduating from Nottingham University, Bob was commissioned

into the RAF in 1966. During 29 years' active service, he gained an MSc in Operational Research. Specialising in software design, he became a Chartered Engineer. For his expertise in war gaming he was subsequently awarded a Fellowship of the British Computer Society. He retired as a Wing Commander in 1995, but retained his rank as a retired officer to become the senior RAF recruiting officer in the North West of England for 10 years.

He now spends his time writing



Witer Bob Kermeen with his wife Jan,

and giving talks to raise funds for the NTF. The NTF would like to thank him for raising awareness of tremor and funds for the Foundation.

Salisbury Shakers celebrate summer

The Salisbury Shakers will be celebrating their second birthday in October. Our numbers have fluctuated over the two years, for various reasons. Sadly, one couple – a lady with ET and her husband who brought her – both died within days of each other; another lady is too immobile to travel the long distance from her home. At present, we have fourteen members altogether, of which eleven have Essential Tremor, one has Dystonic Tremor and two are supportive spouses who come along with their 'other halves'. Members come from far and wide, including as far away as Cornwall.

Our meetings, which are held every four to six weeks, tend to be quite informal. At one, we had a speaker from Gyrogear who gave us a very interesting talk and demonstration of the Gyroglove.

At each meeting during the first year, Steve, one of our members, led us in guided relaxation and mediation exercises, which were very much enjoyed



The Salisbury Shakers celebrate summer

by all of us. Unfortunately, Steve's health problems mean that he has been unable to drive for some time and has not been able to attend.

Most of our get-togethers take the form of chatting over coffee, followed by chatting over lunch! People can exchange tips and bring any gadgets they have found helpful, to share with the rest of us.

One of the highlights of the year was our tour of Salisbury Playhouse where the theatre archivist showed us the dressing rooms, the costumes, the scenery workshop and let us into many backstage secrets.

Another highlight was the publication of our booklet, 'The Answer is Mushy Peas – a light-hearted guide to living with Essential Tremor.' This publication was the brainchild of our group and contains many hints and tips provided by the Salisbury Shakers.

Our group welcomes people from all over the Southwest of England. We are based in Salisbury which is a fairly easy place to reach by train, bus and coach.

Please contact us for more details if you are interested in coming along, at salisbury-shakers@btinternet.com

ET talk onboard Queen Elizabeth!

Support Group Coordinator, Jackie Farrell, shares her experience of hosting an essential tremor awareness meeting on Cunard's Queen Elizabeth cruise ship.

While on board a recent cruise, permission was given for me to host an Essential Tremor awareness discussion. The talk was well received by 15 fellow guests from Australia, New Zealand, UK and Ireland. Not all had ET, but those who did were surprised to see the disorder mentioned in the daily programme! Interestingly, it was mainly males with essential tremor who attended, at previous meetings it has been mainly females.

The talk being on the last day of cruise was not an ideal slot as attendees expressed having met once it would have been good to have opportunity to meet



Support Group Coordinator, Jackie Farrell hosting an essential tremor awareness meeting again during the trip.

However those with ET were appreciative to have been able to meet another with the disorder. Speaking out about Essential Tremor is so worthwhile.

A huge thank you to Cunard's Queen Elizabeth

Entertainment Team for finding a vacant slot for the ET discussion.

Loved my first ever cruise and wouldn't hesitate to arrange another talk if cruising again, but would try for a day earlier in the cruise.

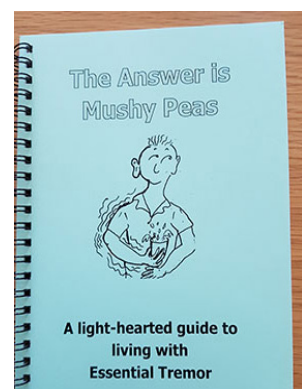
Sheelagh's new book on tremor

We would like to congratulate Sheelagh for producing her new book.

Her book: "The answer is mushy peas", is a light-hearted guide to living with essential tremor.

She self-published the book and it includes an introduction by Lord Julian Fellowes, Honorary President of the NTF.

To order a copy contact Sheelagh on sh.wurr@btinternet.com



Larz's story

Shaking and Dining organiser Larz Jackson, shares his experience of living with essential tremor

In January 2018 I had my official diagnosis that I have essential tremor. Since 2016 I knew that something was not right and it took me a long time to finally go to the doctors, however early signs I had since my early teen years, which looking back I may have had essential tremor since I was like 13 or 14.

When I was diagnosed with essential tremor it was not a surprise for me as I am someone who goes "prepared" to the doctors (I am not an easy patient :D). So, when the neurologist said it was essential tremor I said "Okay, thanks, see you later."

One or two days after the diagnosis I made contact with Jackie from the NTF who is support group coordinator at the NTF and said I would like to start a support group as at the time there was no support group in the area where I live. I have been on the website of the NTF a few times before my official diagnosis and found many useful information. I think the biggest surprise was that there are about 1 million people in the UK with essential tremor, with about 60 million people living in the UK that means about 1 out

of 60 people(!!) have essential tremor.

It was for me very important after my diagnosis to do something for the essential tremor community locally as I know from past experience how important it is to do something, when you are different to other people. :)

I for myself was very open about this disorder, I told my family, friends and work colleagues about it. I do understand that this is very challenging for many people. Many things go through your mind. You think "How will my family, friends and work colleagues react?" "Will there be people who do not want to have anything to do with me?" etc.! There are so many things going through your mind, however I have been through this before. It was somehow different, but somehow it was the same.

A few years prior to have my essential tremor diagnosis I had my coming out as being gay. At that time the same questions were going through my mind as the time with essential tremor. With going through that and people never had a problem that I am gay, I knew myself "Okay, I never faced a problem with coming out as gay, my family and friends still love me, so why should this disorder change it?"

I was right, nothing changed.



Larz's first meet-up

And I believe that is the most important message. If you family, friends, work colleagues really care about you, they will accept you no matter what :)

In March 2018 I went to Oxford Awareness Day, where I met many people close to my age and even much younger (I'm 35 myself) and was really surprised about it as I thought at the time of my diagnosis I have something that is some disorder that is just usual for people of a more mature age.

It was so amazing to meet other people who had the same disorder as myself and both seemed really nice. On the day both wished to meet up again soon again and they came up with the idea of starting my own support event Shaking and Dining, where we go out for a for a meal.

The next Shaking Dining is on Saturday 21 September at Attleborough Arms, Highfield Road, Nuneaton. If you would like to come contact me on nuneatontremor@gmail.com

Interview with Tony Foulds

Tony Foulds who came to fame from his work maintaining a USAF memorial tells us about living with tremor

What is your name?

Anthony James Foulds

How old are you?

83

What type of tremor do you suffer from?

Essential Tremor

Can you tell us about yourself?

I was diagnosed in 1981 by my doctor who at first thought it was what they call metal's disease, because I used to work grinding.

Then of course they then found out it was essential tremor. I don't take anything for it because the side effects were worse than the actual tremor.

What were the side effects from it?

I would get dizzy, tiredness, irritable. I used to grouse at people.

How would you explain to people about your essential tremor before you were well known?

People on the bus used to always think that I was either a wino or a druggie and I used to get that regularly.

Did people sometimes mistake it for Parkinson's?

Funnily enough people use to think it was Parkinson's.

And you are not on medication or physio?

No not at all.

How has the National Tremor Foundation helped you?

It has helped me in a lot of ways, as it has helped me realise that a lot of people have got the same condition, but it affects them in different ways. Mine is worst when I have to get a urine sample. Everything I wear has to be Velcro, if I do have to wear a shirt my son has to fasten my buttons for me.

How do you get on with cooking for example?

I don't, it's all microwaved.

If you go out what do you order – do you ask them for something special?

I ask them to cut it up for me.

Do you avoid things like soup?

Yes. I love soup but can't eat it.

Do you have any other family members with essential tremor?



Tony Foulds

Yes, a lot of my family are dead god bless them. But my younger brother did my mother did and my older sister did. It's just my brother and myself, he's got it not as bad as me, but he does have trouble with it. My brother finds that drinking whisky calms it, now I don't drink so can't use that sort of thing

Do you have any coping tips you'd like to share?

Persevere. I always use a spoon, never use a fork.

What advice would you give someone with essential tremor?

Cope as best as you can, there is not much else you can do. As far as I know there is no cure for it, but you have got to be strong-willed. Forget what people say as you will get nasty comments, but this is the way of the world

Tony plans to attend the new Sheffield Support Group launch 19 October 2019.

Orthostatic Tremor Weekend, Wales



Saturday 28th to Sunday 29th September 2019

Stradey Park Hotel, Llanelli, Carmarthenshire, Wales. SA15 4HA

For more details contact Alyson on alyson@tremor.org.uk

Events for 2019

September

Southampton Shakers

13 September 2019 13:00 - 15:00
Haskins Garden Centre West End, Mansbridge Rd, West End, Southampton SO18 3HW
For further details contact Jackie on jackie@tremor.org.uk

Shaking and Dining

21 September 2019 17:00 - 19:30
Attleborough Arms, Highfield Road, Nuneaton, CV11 4PL
For further details contact Larz on nuneatontremor@gmail.com

Leeds Tremor Support Group Meet Up

21 September 2019 13:00 - 16:00
Leeds Marriott Hotel, 4 Trevelyan Square Boar Lane, Leeds, LS1 6ET
For further details contact lands@tremor.org.uk

Salisbury Shakers meet up

27 September 2019 10:30 - 13:00
Salisbury Playhouse, Malthouse Ln, Salisbury SP2 7RA
For further details contact salisburyshakers@btinternet.com

Orthostatic Tremor Awareness Weekend

28 September 2019 - 29 Sep 2019
Stradey Park Hotel, Llanelli, Carmarthenshire, Wales. SA15 4HA
For further details contact Alyson on alyson@tremor.org.uk

October

Worthing Mental Health Week

Essential tremor awareness discussion with Jackie Farrell
7 October 13.30–14.30
Offington Park Methodist Church, 271 S Farm Rd, Worthing BN14 7TN
For further details contact Jackie on jackie@tremor.org.uk

Sheffield Tremor Support Group Launch

19 October 2019 12:45 - 16:00
Ponds Forge International Sports Centre, Sheffield, S1 2BP
For further details contact Merane lands@tremor.org.uk

November

Shakers Social Get Together

24 November
The Civil Service Club, 13-15, Great Scotland Yard, London, SW1A 2HJ
More details to follow for further details contact 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.

For more information contact Jackie on 07843 777288 or email jackie@tremor.org.uk



Essential Tremor

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Primary Orthostatic Tremor

Alyson Farr
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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



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

www.tremor.org.uk
01708 386399
enquiries@tremor.org.uk

Charity No: 1042013

 NationalTremorFoundation
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