



National Tremor Foundation

Issue 005



Support groups
& more!

AWARENESS MONTH SPECIAL

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Annual Conference, Sheffield, 6 July 2019

Saturday 6th July 2019

Hilton Hotel, Victoria Quays, Furnival Road, Sheffield S4 7YA

For further details contact
Geoff on geoff@tremor.org.uk

National Essential Tremor Awareness Month 2019



Getting busy at the Sutton Awareness Day



Leeds Awareness Day



Essential Tremor Awareness Day Canterbury



Loch Ness Boat Trip

Success for Shakers in Sutton

The NTF celebrated National Essential Tremor Awareness Month this March at Holiday Inn Sutton on Saturday 9 March 2019.

Over 70 people attended the awareness event, funded by Sutton Neighbourhood Grant, including Councillor Steve Cook, Mayor of Sutton; Lady Mayoress Pauline Cook; Cllr Lily Bande; Cllr Jane Pascoe; Cllr Catherine Gray; Cllr Nali Patel; Cllr Tim Crowley; with exhibitors including award-winning tech-start-up GyroGear and drawing with Jo.

Sutton Neighbourhood Grant aims to promote community and voluntary activity in the local area, foster sustainable projects and support activities that the whole community can participate in.

Councillor Steve Cook, Mayor of Sutton, said: "Six months ago I did not know the condition essential tremor existed - I was wandering round a Queen Elizabeth Foundation event, where I met Jackie, who introduced me to understanding



Celebrating Essential Tremor Awareness Day

about the condition. Now I know a great deal more, and how it is different to Parkinson's. Today's event helped educate and engage members of the community. There was a lot for us all to learn and I really enjoyed the event. I look forward hearing more about the Sutton Essential Tremor Support Group and to the next awareness day."

Councillor Lily Bande, said: "The Essential Tremor Awareness Day at Sutton Holiday Inn was a great success as it had a huge impact on our communities. It enabled young people with the condition to meet up

and share their experiences, parents of children with the condition, the elderly as well as other members of our communities who were not aware of the condition to be in the know and be in a better position to seek medical advice and support. I now have a better understanding of the condition, and as a teacher as well as a ward councillor, I feel more of these awareness events are needed for our communities. The talk was quite informative, well executed and engaging! A big thank you to Jackie for the talk and organising the whole event



Jackie with local councillors at the Sutton awareness day

and Sutton Council for the funding!”

Councillor Catherine Gray said: “Essential tremor is a widely unknown condition, and Saturday’s event at the Holiday Inn in Sutton really helped to raise awareness and educate the attendees. Both myself and the other Councillors who attended will now be able to confidently discuss essential tremor with our residents, and can do our bit to get the word out. As I am related to someone diagnosed with Essential

Tremor, I thought I knew a lot about the subject already, but the event on Saturday provided me with even more knowledge and insight in to the condition, and the confidence to signpost anyone that I come across to the NTF if required. The work that the local NTF coordinator Jackie is invaluable to the local community, and the NTF and their objectives, and I look forward to supporting her in the future.”

Event organiser, Jackie Farrell, said: “It was great to see

so many people attend from the local community, including some new faces. I’m thankful for Mayor, Mayoress, Councillors, and GyroGear who supported the event, and a huge thanks to Sutton Neighbourhood Grant”.

Jackie also runs the Sutton Shakers tremor support group. If you would like more information or are interested in attending future Sutton meet-ups contact Jackie on jackie@tremor.org.uk

Canterbury celebrates tremor awareness month

The Essential Tremor Awareness Day on Saturday 23 March at AgeUK, Castle Row was an amazing success.

Over 25-people attended the event, many who had the disorder had never met others with tremor before and some were not even aware of NTF.

During the event Jackie, NTF Support Group Coordinator, was present to talk about the neurological disorder and how it differs from Parkinson's disease.



Jackie with Katie Plumb, Dr Mark Plumb's sister

The event held fell as part of March National Essential Tremor Awareness month,

and this success follows on from the Essential Tremor Awareness Day in Sutton.

Loch Ness Boat Trip

The Scottish Tremor Society Loch Ness Boat Cruise on Saturday 11 May was huge success.

19 people attended the trip and gave people with both essential tremor and orthostatic tremor the opportunity to meet-up and share experiences. With some people having never met others with tremor before and one was as young as 19 years of age.

The cruise started at Dochgarroch Lock, which is at



19 year old Hannah who has essential tremor since childhood and joined us on the Loch Ness cruise with her parents

the start of the Caledonian Canal, where people saw some beautiful scenery, and views of Loch Ness Castle.

Organiser Mary Ramsey, said: 'The cruise was a terrific

success. We had a great time followed by lovely meal at Beaufort hotel, Inverness and staff were very helpful.'

We look forward to hearing more from the Scottish Tremor Society.

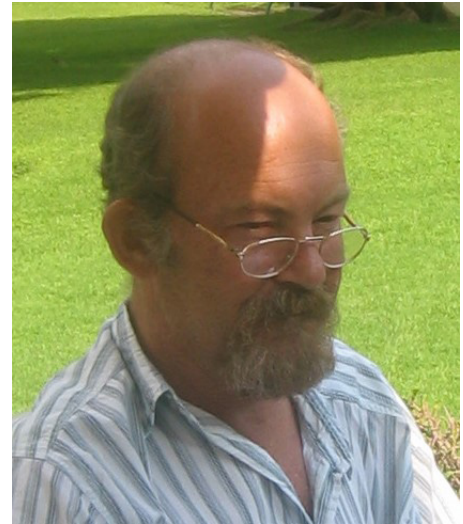
Katie Plumb's Story

Katie is sister of the late author and geneticist Dr Mark Plumb. Mark had essential tremor, and co-wrote with Dr Peter Bain the book Essential Tremor: The Facts. Katie was at the Canterbury Awareness Day.

It was a real pleasure to be able to attend and participate in Jackie Farrell's talk on Essential Tremor in Canterbury on 23rd March. She is a wonderful speaker and does a tremendous amount to raise awareness of our condition, Essential Tremor. She asked me to speak briefly about my brother Mark and his book, "Essential Tremor the facts" (co-written with Peter Bain 2007 Oxford).

What I focused on was how Mark had written the book to inform the wider public but also for his own family who suffer from ET in varying degrees. Our grandmother was Russian and although her hands shook noticeably she carried herself with incredible grace and dignity

so we never mentioned it. Of her five children, three inherited ET. My mother was most affected with very shaky hands, one aunt's head shook and the other also had shaky hands. From these aunts and uncles fourteen of my cousins have inherited ET in varying degrees. One cousin has a shaky voice and has only just realised it was ET. My mother had three children, Mark was the one who was affected the most and was unable to become a surgeon so went on to become a biochemist. My sister also has the condition as do I slightly. One of my two sons has ET and my sister's two daughters have it. Mark's daughter did not inherit it. Mark never took any medication for ET and in the last two years of his life, when he was suffering from lung cancer, he wrote the book on ET. This was his legacy to



Geneticist Dr Mark Plumb

his family and to those who suffer from the condition. His expertise as a biochemist enabled him to carry out the research and produce this book which is accessible and informative. In the last years of his life when he knew he was terminally ill, he was very happy to be able to address an NTF conference. Fortunately, his book on ET was published before he died.

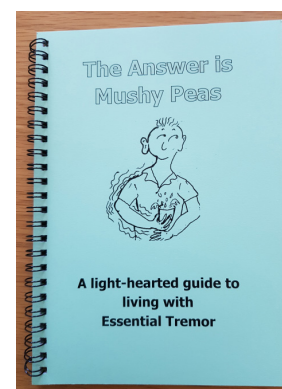
Sheelagh's new book on tremor

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



Leeds raises tremor awareness

Leeds Essential Tremor Awareness Day held in Leeds on Saturday 23 March was a huge success.

32 people attended the awareness event, which is part of National Essential Tremor Awareness month, where there were information tables, raffle and talks from: Leeds Neurological Senior Registrar about research projects being run at Leeds NHS; MindWell Leeds on reducing stress, anxiety and coping mechanisms.

Specialist Registrar Neurologist Stefan Williams from Leeds Teaching Hospitals NHS Trust, spoke in depth about essential tremor and presented a very interesting talk about his current research "Computer Vision for Neurological Signs".

He said: "It was a real privilege to take part in this event. It gave me a richer understanding of the experiences and perspectives of people living with tremor. From my (clinical's)



A fantastic turn out at the Leeds awareness day

organiser said: "A massive thank you to everyone for all your support and help with organising, setting up and making sure the event went well."

Fantastic prizes were all generously donated for the raffle - with so many that extra time was needed just giving them out! At the end they had raised £456.50.

Merane Todd, Leeds Support Group Coordinator and event

The Leeds Tremor Support Group meet every other month, with the next meeting date to be confirmed. For more information about the group and meeting dates please email lands@tremor.org.uk

Shaking it up in Salisbury

The Salisbury Shakers met on Saturday 13 April in St Thomas's church, Salisbury to chat and share experiences. Sheelagh, Salisbury Shakers Group Coordinator shares her story of the day.

Ten members of the Salisbury Shakers met up, starting in St Thomas's church for coffee (and cake, in most cases!)

As usual, we then moved into the meeting room which is booked for us and chatted. Unfortunately, Steve was not well enough to join us so there were no exercises or meditation this time. We had lunch in the Red Lion and, as usual, Sheelagh forgot to take a group photo! However, we managed a few pictures showing some members of the group.

We discussed our next meeting which takes place on June 15th at Salisbury Playhouse. We will meet as soon after 10am as we can manage and have a cup of coffee. At 10.30 we will meet the theatre archivist who will give us a short talk about the theatre and take us backstage to see the dressing rooms, the props, allow us



Raising awareness in Salisbury to go on the stage from the wings and all sorts of other interesting bits and pieces. There will be a display of post-

ers, programmes and artefacts relating to past productions. It sounds as though it will be an interesting morning.

Genesis Charity Golf Day

Genesis Choice will be holding their charity golf day at The Burstead Golf Club, Billericay on Wednesday 3 July 2019.

If you are coming along - just drop Terry Martin on terry-martin@genesischoice.co.uk (Genesis Choice) a line with Team name/name of the players and their handicaps. Payment can be a cheque/credit

card or preferably BACS. They would ideally like the money before the day as collection on the day gets very messy and it shows commitment to coming along!!

So n polish your balls, brush up your swing and contact Terry ASAP to avoid missing out on what is always a great day!

Events for 2019

May

Sutton Shakers Tremor Group meet up

Friday 31 May 2019, 11pm - 1pm
Holiday Inn Hotel, Gibson Road,
Sutton SM1 2RF
For further details Jackie on
jackie@tremor.org.uk

June

North West Support Group meet up

Wednesday 5 June 2019, 1pm–2pm
Liverpool, Lord Nelson Street,
Liverpool L3 5QB
(Every first Wednesday of the month)
For further details contact Joan on
0151 475 3252

Salisbury Shakers meet up

Saturday 15 June 2019, 10am - 2pm
Salisbury Playhouse, Malthouse Ln, Salisbury
SP2 7RA
For further details contact
salisburyshakers@btinternet.com

July

Genesis Charity Golf Day

Wednesday 3 July 2019, 11.30am–8.30pm
The Burstead Golf Club, Tye Common Road,
Billericay CM12 9SS
For further details contact Terry on
terrymartin@genesischoice.co.uk

North West Support Group meet up

Wednesday 3 July 2019, 1pm–2pm
Liverpool, Lord Nelson Street, Liverpool
L3 5QB
(Every first Wednesday of the month)
For further details contact Joan on
0151 475 3252

Annual General Meeting

Saturday 6 July 2019
Hilton Hotel,
Victoria Quayside, Sheffield.
For further details contact Geoff on
01708 386399.

Southampton Shakers

Friday 12 July 2019, 1.30pm - 3pm
Haskins Garden Centre West End, Mansbridge Rd,
West End, Southampton SO18 3HW
For further details contact Jackie on
jackie@tremor.org.uk

Cambridge meet up

Saturday 13 July 2019, 10.30am-12.30pm
Friends' Meeting House, Jesus Lane, Cambridge,
For further details contact Jamie on
essentialetremorcambridge@gmail.com

Shaking and dining

Saturday 13 July 2019, 5pm–7pm
Attleborough Arms, Highfield Road,
Nuneaton, CV11 4PL
For further details contact Larz on
nuneatontremor@gmail.com

September

Orthostatic Tremor Awareness Month
Details TBC

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 Jackie on 07843 777288 or email jackie@tremor.org.uk



Essential Tremor

Cambridge

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Jackie, Support Group Coordinator

Oxfordshire

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07843 777288
jackie@tremor.org.uk

Wiltshire

Salisbury
Sheelagh Wurr
01985 216056
salisburyshakers@btinternet.com

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



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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