

Merry Christmas

Support groups
& more!

CHRISTMAS SPECIAL

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QR Codes

We have decided to include QR codes in this edition. We have found QR Codes useful for people with tremor when trying to locate a web address.

To use using Android search for the QR app and download, then activate the app and point your camera at the QR code.

For iPhone users just activate the camera and point the camera at the QR code.

Try using a QR code



Thank you Merane!

Well done to Merane, Leeds and Sheffield Support Group Organiser, for taking part in 10 different sport challenges to raise funds and awareness of tremor.

You may remember first reading about Merane, who has found that running has helped her with her essential tremor. Her first of the 10 challenges was Abbey Dash 10K on 4 November and these challenges built up to Endure 24, a mammoth 24-hour run on 29 June. Her events included:

1. Abbey Dash 10k - 4 November

2. Otley Chevin Chase 7 mile trail run- 26 December
3. Brass Monkey half marathon 13.1 miles - 13 January
4. Bradford epilepsy 10k 17 March
5. Skipton Triathlon - 14 April
6. Ackworth half marathon - 22 April
7. Leeds Half marathon 13.1 miles - 12 May
8. Liverpool rock & roll marathon 26.2 miles - 25-26 May
9. Great North Open Water Swim 2 miles - 7 June
- 10 Endure 24, 24 hour run - 29 June

Donate to her Virgin Money



Merane took part in 10 sporting challenges to raise money for the NTF

Giving page

<https://uk.virginmoneygiving.com/MeraneTodd>

Shakers Social November

The Shakers Social in November was an informal afternoon to share stories, fun, laughter and meet others with tremors.

At the event there was a craft corner and a quiz which was received well by members.

For full review and other reviews of London and South East go to www.tremor.org.uk/london-and-south-east-support-group



2019 Round-up



Prof. Wladyslaw Gedroyc talking to Baroness Golding about MRgFUS at the Parliamentary drop in



Actor Jim Carter with Liz Twist MP and essential tremor patient Ann Collins at the Parliamentary drop in



Shadow Health Secretary of State for Health & Social Care, Jonathan Ashworth MP, signs the pledge to support the campaign for MRgFUS being available on the NHS



The Parliamentary Drop In for MRgFUS for essential tremor was an amazing success





Getting busy at the Sutton ET Awareness Day



Sheffield Support Group launch



Tony Foulds at the Annual Conference



Loch Ness Boat Trip



My Life with essential tremor

Actor Ryan Williams shares his experience of living with essential tremor

My name is Ryan Williams and I am an actor with Essential Tremor.

Contrary to my profession, I was fairly shy growing up, but at around 16 or 17 years old something changed. I had started to become hyper-sensitive to how other people would see me and treat me, because my hands had begun to shake uncontrollably.

One of the first time I can recall, I was giving a cashier some change at the local supermarket when they asked me:

“Are you alright?”

“Yeah, I’m fine. Thanks,” I replied.

“Would you like some help?” the cashier asked.

“With what?” I questioned.

“Your hands. Are you a little hungover from the weekend?”



Ryan Williams with Support Groups Coordinator Jackie Farrell

the cashier chuckled. I hadn’t had a drop of alcohol. I didn’t even drink coffee then. Maybe I was tired. Maybe I hadn’t eaten enough. I scoured my brain for an answer yet, the more I did, the worse I felt and from then on, I would get anxious standing in line everywhere. Worrying that everyone was thinking I was some local drunkard who couldn’t even keep his hands steady to pay for his shopping. A paranoia that would haunt me on a daily

basis. I didn’t want to be seen that way.

I used to think a lot of how my father and how his hands would shake when he tried to perform seemingly simple tasks. Yet he always would brush off any comments about it and just accept that he just had ‘shaky hands’. I decided to talk with my mum about it and from that conversation alone, I think she knew how much it was getting to me. She arranged an appointment



with our local doctor as soon as she could.

After some basic tests, like lifting a sheet of paper and holding both my arms out straight, he would go on to conclude that I had a Benign Essential Tremor and:

- a) It's nothing to worry about.
- b) It can sometimes be inherited from a parent.
- c) It may even get worse as you get older.
- d) There was no cure.

A cold wave washed over me. I was terrified. I had aspirations to perform for a living. How was I going to be able to do that when I couldn't even hold a script steading in an audition? He offered me a prescription drug called Propranolol – a beta-blocker that he told may reduce the shaking but is only effective in 20-30% of cases - and that was it. I couldn't believe it. No leaflets. No websites. No further reading.

How could there be no cure? After 6 months on Propranolol, the feeling that this condition was only getting worse had started to take its toll so much that it inevitably evolved into depression. I would have panic attacks before going into auditions. I would dread if a girl asked to hold my hand or dance. I didn't even want to go to the gym for the fear that people would laugh at me shaking as I did one push-up. I started not wanting to partici-

pate in anything at all.

Then came the second prescription: Anti-depressants along with a diagnosis that I was a unipolar depressive by the age of 19 ironically leaves you feeling a little low. I needed an alternative solution. I desired a deeper understanding and perspective that I never had before in order for me to feel I could be part of the world again rather than feeling exempt from it. I would not let this condition beat me.

"I have a tremor." has become my mantra. Seems obvious, right? But by simply starting to admit to myself and others what it was before they could make any conclusions of their own seemed to ease my paranoia and, concurrently, my condition. I suddenly felt more relaxed in social situations. I felt like I was finally able to focus on more important aspects of my life for once. I enjoyed interactive with humanity again. Some responses even started to baffle me. People would tell me they 'never even noticed it' or that 'they have a friend who is like that. It's fine.'

In fact, it was one of those same friends who recommended I try things like meditation and yoga as a way to be more present with the condition and truly gain an even deeper sense of empathy towards it. Relaxation; mindfulness and awareness. The more I prac-

tised these fundamental principles, the happier I became.

I finally had some foundation and confidence to talk about it with others. Talking and writing about what ails you is the ultimate expression of awareness and it is what I and so many others are here to do: to initiate the conversation. In fact, you reading this is proof of that. It's true that having this condition can be an extremely isolating experience but I assure you that you are not on your own. There is help out there. So tell your family; your friends; your teachers; your boss.

Shake things up a little. You might just get the answers you're looking for.





Worthing Shakers Support Group Launch

Saturday 18th January 2020

Goring Methodist Hall, Bury Drive, BN12 4XB

1pm –4:30

1:30 - Launch by Worthing Mayor Cllr Hazel Thorpe

Meet others with neurological tremor, such as essential tremor or orthostatic tremor, and share experiences and tips

Free entry

Pre-booking is not necessary. However it is advisable to reserve a place along with a contact number should there be any updates.

For further information, programme or reserve place please contact:

Jackie Farrell - organiser jackie@tremor.org.uk 07843 777288



www.tremor.org.uk

Honorary President: Lord Julian Fellowes

Registered Charity 1042013

Sheffield Shakers Drop-in

**By Ann Collins
Sheffield Support
Group Organiser**

Sorry for the delay been a hectic week ending with a cold. Good to see those of you who managed to attend the very first Drop-in event. We had a good attendance with two new members and others travelling to support us.

Lots of talking, laughs and discussions about how we cope with our day to day living. Our

new ladies had never met anyone with the same tremor other than family members and were unsure about what to expect. They were very soon at ease and confidently joining in.

We had our ever faithful Phill Alcock join us and now he has new people wanting to do Nordic Assisted Walking. Thank you, Phill for your continued support.

I must give a big thank you to Michelle and her team for

the lovely mince pies, coffee, tea and a very special cookie for one of our ladies.

Our next meeting will be in February 2020. Date and venue to be confirmed. Don't forget the Leeds meeting on January 18th at Leeds Hilton, 1.00 –4.00pm

Just remains for me to wish you all a very Happy Christmas and Happy New Year. As Strictly Come Dancing would say Keep on Shaking.

Leeds Festive Walk

**By Merane Todd, Leeds and
Sheffield Support
Groups Organiser**

Leeds Festive walk, well we definitely had festive weather. Luckily the hail stopped as we gathered to go outside the cafe.

Everyone who attended the walk decided to try using the Nordic Walking poles. And after a quick demonstration on how to use them from Phill Alcock from British Nordic Walking, we were ready to practice using the whilst walking in the beautiful grounds of the Kirkstall Abbey.

With Phil giving continued advice and adjustments as

we walked, even I the most uncoordinated managed to walk with the poles, as long as I didnt think about what I was doing too much.

We all walked at our own pace so suitable for everyone. After we enjoyed warming up with a warm drink in the cafe where some others joined us for the social side. It was lovely to chat with everyone and see

everyone so relaxed. Everyone said using the poles whilst walking gave them more stability, Phill kindly let everyone take the poles home so we can practice with them.

The next walk has been planned for 11th January, meeting at 11am at Kirkstall Abbey Cafe, next door to the museum.



Leeds Support Group November

By Merane Todd, Leeds and Sheffield Support Groups Organiser

Another lovely support group meet up, after a catch up about the positive visit with the MP's in London to discuss MRgFUS along, with an update on the fantastic launch of the Sheffield Shakers.

Thanks to Geoff Sleight for obtaining some Sunflower Lanyards. These are designed to act as a discreet sign to staff and work colleagues that the wearer has a hidden disability and requires additional assistance.

It has been successfully introduced to several major UK airports, supermarkets, railway stations and sports venues. People shared their positive experience of using them in the shops, airports and trains. We then moved on to planning for the next year, with lots of ideas about ways we can individually and as a group raise awareness and reach out to others along with fundraising for the groups.

We have planned our first festive walk on the 14th December, meeting at Kirkstall Abbey Cafe at 10:30. This will



A fantastic turn out for the Leeds November meet-up

hopefully be the first of many walks with people from the group. For anyone wishing to attend we will also have some Nordic Walking poles for you to try if you wish. Anyone wishing to attend are asked to confirm attendance by emailing lands@tremor.org.uk

People from the Leeds and Sheffield group have recently been very busy raising funds for the groups with donations from the sales of hand made cards, crafts and Body Shop products along with NTF products. All together a total of £270.30 was donated. A big thank you to Chris Knowles, Jo Ward, and Jo Squires for their very generous donations.

So that's it, I can't believe this was the last meet up of the

year. It's lovely to see how much the group has grown and evolved over the last year. Taking a step back to watch and listen to everyone mingling and chatting. There was lots of comments on how friendly and supportive the group is. To quote one person "thank you for holding this group I look forward to attending, it's so nice to be able to speak to others who understand, I feel so relaxed when I am here, it's like a little family".

I just want to say a big thank you to everyone who attends, this group is only successful because of you.

For further details about the Sheffield Support Group contact .Merane on lands@tremor.org.uk



Salisbury Shakers

By Sheelagh Wurr
**Salisbury Support
Group Organiser**

The Salisbury Shakers celebrated 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 Gyrolove.

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 by all of us. Unfortunately, Steve's health problems mean that he has been unable to



The Salisbury Shakers celebrated their second birthday

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.

Our Christmas meeting took the form of a visit to the pantomime Robin Hood, in Salisbury Playhouse, at the end of November. This was great fun!

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.

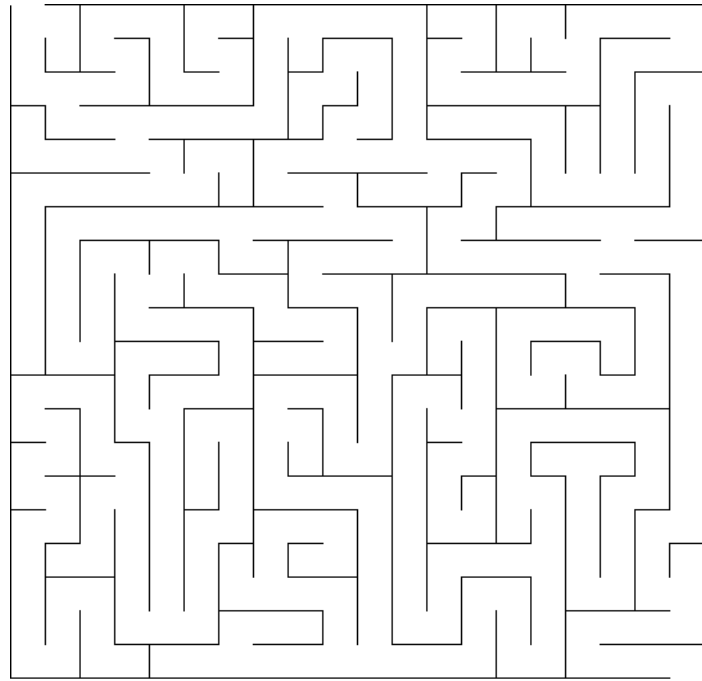
Our group welcomes people from all over the Southwest of England. We are based in Salisbury which is a fairly easy place to reach by train, bus and coach. Our next meeting takes place on January 11th.

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



Christmas Quizzes

Instructions: Trace the path through the maze. Help get the star to the top of the Christmas Tree.



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APPLICATIONS CLOSE SUNDAY 5TH JANUARY 2020



Events for 2020

January 2020

North West Tremor Support Group Meet-Up

8 January 1pm - 3pm

Liner Hotel, Liverpool, Lord Nelson Street,
Liverpool L3 5QB

For further details contact Tom and Joan Reader
0151 4753252

Leeds Walk

11 January

Kirkstall Abbey Cafe, Abbey Rd, Leeds LS5 3EH

For further details contact
lands@tremor.org.uk

Salisbury Shakers

11 January

For further details contact Sheelagh on
salisburyshakers@btinternet.com

Manchester meet-up

12 January 1pm - 4:30pm

Crowne Plaza, Oxford Road, Manchester

For further details contact Jackie on
jackie@tremor.org.uk

Worthing Shakers Tremor group launch

18 January 1pm - 4:30pm

Goring Methodist Hall, Bury Drive, BN12 4XB

For further details contact Jackie on
jackie@tremor.org.uk

Central Scotland Shakers

18 January 2pm - 5pm

St Paul & St John the evangelist Episcopal Church,
Springwells Avenue, Airdrie, North Lanarkshire, ML6
6EA

For further details contact Scott Pender on
centralscotlandshakers@gmail.com

Leeds Tremor Support Group Meet Up

18 January 1pm - 4pm

Marriott Hotel, 4 Trevelyan Square Boar Lane,
Leeds, LS1 6ET

For further details contact
lands@tremor.org.uk



Central Scotland Shakers launch of new group

Saturday 18 January 2020 2pm to 5pm

St Paul & St John the evangelist Episcopal Church,

Springwells Avenue, Airdrie, North Lanarkshire, ML6 6EA

For more details contact: Scott Pender on centralscotlandshakers@gmail.com

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

Essential Tremor

Cambridge

Jamie Goodland
essentialtremorcambridge@gmail.com

Haverling and Essex

Tom Schubert
01375 373993

Norfolk

Toby Howes
01508 498431

Northwest Liverpool

Tom and Joan Reader
0151 475 3252

Oxfordshire

Oxford

Katherine Phillips
07851 774182
oxford@tremor.org.uk

London and South East

Jackie Farrell
07843 777288
jackie@tremor.org.uk

Warwickshire

Nuneaton
Larz Jackson
nuneaton@tremor.org.uk

West Sussex

Worthing

New group launching January 18 2020
Jackie Farrell
07843 777288
jackie@tremor.org.uk

Wiltshire

Salisbury
Sheelagh Wurr
salisburyshakers@btinternet.com

Yorkshire and Humber-side

Leeds

Merane Todd
lands@tremor.org.uk

Sheffield

Ann Collins
lands@tremor.org.uk

Scotland

Central Scotland

Airdrie

New group launching 18 January 2020
Scott Pender
centralscotlandshakers@gmail.com

Scotland

Mary Ramsay
07967 428036
mary@ramsay.scot

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

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 @NatTremor

