

CHESTERFIELD & NORTH DERBYSHIRE TINNITUS SUPPORT GROUP



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Newsletter

Edited by Audrey Carlin

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WE INVITE YOU TO CHESTERFIELD & ND TINNITUS SUPPORT GROUP'S

30TH ANNIVERSARY CONFERENCE

Please come along and join us as we celebrate our **30TH ANNIVERSARY** on **SATURDAY 16TH APRIL 2016 AT THE WINDING WHEEL IN CHESTERFIELD**

The Conference is from 10.30 am – 3.30 pm. Registration at 10.00 am where you will be able to have a cup of tea and a biscuit before we start. We are providing a hot buffet lunch of **Pie and Peas** along with a drink. For anyone with hearing problems, we have speech-to-text reporters who will type out word for word what is being said so you will be able to see this on a screen.

The Conference is free. However, it is essential to book a place and to let us know if you have any special dietary requirements. The day will be interesting and eventful. Toby Perkins MP, will welcome everyone to the Conference. During the morning there will be an interview style session with three members of our group, to compare how things have changed for people with tinnitus over the last 30 years. Jodie Rogers, Senior Audiologist, Chesterfield Royal Hospital will also give a presentation and David Carr from the BTA will talk about support groups.

The afternoon session will be given over to James MacKenzie from

StressBusters, returning by popular demand, who will be exploring aspects of Mindfulness and Relaxation and discussing brain science and attentional control. The session will begin and end with questions and



answers and will be quite conversational and interactive throughout. (Photo James Mackenzie at our 2013 conference)

For those of you who may wish to do so, he has asked if, before the session, you would invest a little time to consider the following:-

"Most people with tinnitus find that there are some circumstances when they become less aware (or completely unaware) of the sounds they experience. In what sort of situations does this happen for you? Could you write these occasions down (not just remember them) and, if you are happy to do so, please share them in the afternoon session of the conference." James MacKenzie continues *"For those who may be wondering, yes there is a brain science reason for every aspect of this 'question' including the way in which it is phrased."*

We realise that not everyone will wish to do this as it may draw your attention to your tinnitus. However, he would like the opportunity to try this out on three or

four people and we have already asked four people who are willing to take part but if you wish to take part also, please make a note of your experience.

To bring the Conference to a close, after you have relaxed throughout the relaxation and mindfulness techniques, you will be aroused gently by the dulcet tones of "Peak Performance". "Peak Performance" are a group of singers, one of whom you may recognise as Debi Alvey, Senior Audiologist at Chesterfield Royal Hospital. Their songs will be from shows including 'My Fair Lady', 'Les Miserables' and 'Hello Dolly'.

A Flyer and Booking Form is enclosed for the event and please remember to book your place early.

MAY DAY CELEBRATIONS MONDAY 2ND MAY 2016

As in previous years, we have a stall at the May Day celebrations. We will be situated in New Square opposite the Peacock cafe. Joy

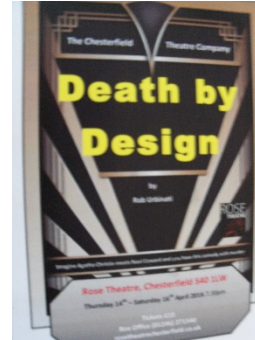


has been busy collecting items for a big Tombola but if you have anything suitable we would very much appreciate

it. There will be many charity and voluntary organisations who have stalls, along with speakers, music/singers and the usual march that takes place from outside the Town Hall to the market place. Come along, visit our stall, and enjoy the day. (Photo of Joy and Muriel 2015)

DEATH BY DESIGN by Chesterfield Theatre Company – 14th – 16th April

Despite its title, this is a very funny play. It has always been said that laughter is the best medicine! Chesterfield Theatre Company are putting on a play that will certainly boost your happy hormones and make you feel good. Think Noel



Coward plus Agatha Christie with a touch of madness and mayhem and you have the scenario for ***Death by Design*** by Rob

Urbinati. The setting for the play is an English Country Manor in 1932. Edward Bennett, a playwright, and his wife Sorel head to their home in Cookham after disastrous reviews of the opening night of their play in London. Various guests arrive unexpectedly, a conservative politician, his partner, a fiery socialist and a bohemian modern dancer. When one of the guests is murdered, all the characters have a long-held secret and a motive for murder. It is left to the outspoken maid – Bridget to solve the mystery. Joanne and her husband, Simon, are in the play. ***Death by Design*** will run from **Thursday 14th April – Saturday 16th April** from 7.30pm at Rose Theatre, Chesterfield Studios, Rosehill, Chesterfield, S40 1LW. Please ring the Box Office for tickets on

01246 271540. (Flyer enclosed)

SPONSORED "30-MILE HOBO WALK AND RACE" FOR TINNITUS

On the 14th May Joanne is taking part in a 30-mile sponsored walk to raise funds for our group whilst Simon is doing it as a 30-mile run. This will take place in

Nottinghamshire, starting at Sherwood Forest.

Please help to boost our funds so we can continue to help and support people who have tinnitus. A Sponsor Form is enclosed.

DONATION THANK YOU

To Muriel who dressed another doll in a knitted outfit and to Tracey of "Chameleon", Chatsworth Road, Chesterfield, who kindly sold the doll in her shop for £20.00.

REPORT FROM OUR FOUR EVENTS DURING JANUARY AND FEBRUARY

The **Table Top Sale**, hosted by Shay, was very successful. Shay was joined by Joy and Muriel and some of his friends who went along to help.



The **Butty and Brew** was a great success. We filled Blu Bistro on the ground floor and



were served with delicious breakfast butties. David Stockdale, Chief Executive of the BTA came along and gave an informative talk. Jodie Rogers, Senior Audiologist, Chesterfield Royal Hospital also called in and was available to answer

questions. We enrolled a new member on the day who later called in to say he had also received excellent service at



the Royal Hospital; all this resulting from his initial contact

[Sandra and Jennifer enjoying a Butty & Brew] with our group a few days earlier, coming along to his first meeting at Blu Bistro, and learning about ourselves, the BTA and the Audiology department.

Summarising David's talk; he spoke about three areas:

1. *Commission and lobbying for Research*
2. *Supporting Clinicians*
3. *Supporting Individuals*

1. Research

The BTA support ten different research projects. The research is multi-faceted; research into finding a cure (hopefully drugs which can target the tinnitus for an effective cure).

- It is believed that **hearing aids** support patients with tinnitus – the BTA are looking at providing evidence for this.
- **Psychological research** – there is a lot of information about Mindfulness. The BTA have a research project with the University College of London to determine the usefulness of Mindfulness to support tinnitus patients.

If the research does not have an impact on tinnitus patients they will look at other research projects.

- **Paediatric Tinnitus** – looking at the impact of tinnitus on children. Presently there is no way of measuring tinnitus in children so they hope to design a questionnaire to support children.
- 2. **Supporting Clinicians** – they run Advisor Training courses. Some Clinicians may feel isolated because they are the only person dealing with tinnitus patients. The BTA is there to share information and offer support.
- 3. **Individual Support** – there is a helpline staffed between 9 and 5 Monday – Friday and they deal with over 6,000 calls per year. All the staff are involved with answering the helpline. There are 12 staff at the BTA – 3 are full-time, the rest are part-time. They provide a listening ear and have over 30 leaflets to provide advice and information.

The BTA recognises that tinnitus is like a finger print – everyone's tinnitus and how they react to it is different. There is still a lack of understanding about tinnitus; not everything is known.

Tinnitus Information Days

The BTA provide support and advice at Tinnitus Information Days, the next one of which is in Tunbridge Wells. They produce the **Quiet magazine** and a range of new products.

They are currently running new projects including **Plug'em** – an initiative to help reduce the stigma of wearing hearing protection. They also support groups. One of their staff, David Carr, helps to set up groups around the country and the number of groups have doubled to around 70 over the last 3 years.

Training for Groups - The BTA are also researching groups – again to provide evidence based proof as to why groups are important and offer value.

The meeting was then open to questions. There was inevitably a question about the understanding of GPs. Jodie said that every year for Tinnitus Awareness Week she informs all GPs what is happening and reminds



them about the referral routes. David said there is often a negative

[Sheila and her husband enjoying a Butty & Brew] reinforcement for GPs. Patients only go back to tell them when things haven't worked, not when things have, so GPs themselves believe nothing can be done.

[My tinnitus started 32 years' ago and I went along to my GP who was very helpful. He said he didn't know much about tinnitus, but he did about the brain (how forward thinking he was!) and what he said to me inspired and helped me to move forward in a positive way, despite the fact that there was no support group that I could turn to nor did I know anyone who had tinnitus.]

I did my own research as I looked for ways in which I could help myself to manage the tinnitus. I would ask my GP questions and he supported me as I went through the hospital system to see an ENT specialist who, along with other negative remarks, said “you will have to learn to live with it!” However, like everyone else, I tried to find a cure, but then decided the only way forward was to develop coping strategies. Finally I came to a point where I felt happy and in control again – at this point I returned to my GP to thank him for being there for me and to tell him how his positive remarks at the early stage of my diagnosis, had been instrumental in my working my way through to acceptance of my tinnitus. [His name was Dr Jeremy Brewer who was a GP at Blue Dykes Surgery in Clay Cross for many years until his retirement quite a number of years ago.]

David Stockdale then posed a question to us – “If there was money available for research, what would you like to see?” The group stated – a more robust diagnostic pathway – very often the patients are left with unanswered questions. What do Clinicians need to do to ensure the questions are answered? My suggestion was that if money was available, I would like to see more “specialist” counsellors in hospitals – not just general counsellors. [In 1995 I undertook the BTA’s Lay Counselling Course which was designed by two Psychologists, one of whom had tinnitus, so it was specifically designed to be appropriate for people who experienced tinnitus.]

OUR NEW BEE LOGO



As you will see from this newsletter, we have a new Bee logo. This has been designed specifically for our group by North East Derbyshire District Council who designed the flyer for our 30th Anniversary Conference. The “old” bee will be phased out as we use up our stationery.

RESEARCH BY NBRUH

Their latest newsletter highlights some of the research they are involved in to help people with tinnitus. We are taking this opportunity of sending you this information

TEA FOR TINNITUS – ARKWRIGHT

This was a drop-in event held on the 9th



February where people came along and had a cup of tea and a cake whilst having the opportunity to ask questions and chat to others. About 15 people called in during the two hours, some of whom had one-to-one sessions to ask questions and to seek support. It was a successful event.

TEA FOR TINNITUS – CLAY CROSS

This was a much bigger event, even more than we had imagined. The tables had been set up for us in the relaxed surroundings of the Social Centre and we placed on our white

tablecloths and set out the vintage crockery with a Hellebore in the centre



of each table. With a colourful selection of cakes and with teapots brimming with freshly brewed tea, it looked so inviting. Over 50 people attended and listened to presentations by Joanne, our Co-ordinator, as she told them about our group and the support we could offer them. Muriel told her personal story of her tinnitus journey and Jodie talked about how they help and advise people in the management of tinnitus.



After the presentations Jodie and I had one-to-one sessions with the people who wanted more help and advice. Everyone enjoyed their tea and cakes in a relaxed atmosphere and it was evident that people were having a good time chatting to each other, smiling and laughing. Rykneld Homes came along to support us bringing with them their lovely chocolate fountain (as seen in the photo – John enjoying a piece of delicious chocolate-covered fruit)

Very positive comments were made by people that, they had not only learned more about their tinnitus and ways in

which to manage it, but also enjoyed a really good afternoon meeting other people. 90 per cent of the people who joined us at Clay Cross were new to our group so the “Tea for Tinnitus” had achieved its aims in raising awareness about tinnitus and the help and support that is available to them.

JOY'S STORY

Did you read Joy's story in the March edition of “Woman and Home”? If you haven't got a copy, there is still time to get one as they should be available

throughout March (look out for the magazine with Julie Walters on the front). There was a



lot of information on the radio and television about Tinnitus Awareness Week which was excellent too.

AFTERNOON TEA AT HOLLINGWOOD HUB – 19/2/16

At this meeting Toby Perkins MP joined



us to find out more about our group. As he also has hearing problems he was interested to find out, not only about our support group, but also about the services of Audiology and the links between ourselves and Audiology. Presentations were given by Joanne

and Jodie (Audiology), after which Toby gave an insightful talk about his work, both in parliament and at a local level. This was followed by questions and answers. Toby said that if we wanted him to take up any issue, he would be happy to do so on our behalf. I am sure we will at some time take up his offer. He has agreed to do the “welcome” speech at our conference.

TINNITUS OUTREACH EVENT, DRONFIELD 2ND MARCH



The day was a success and we met a number of people who needed help and support. Shay did hearing tests and Audiology and the BTA were also busy dealing with enquiries as were the other stall holders. A very worthwhile event which reassured many people.

ANNUAL SUBSCRIPTION

Please find enclosed the Annual Renewal Form for subscriptions to the group. If you wish to remain a member, please complete and return along with your subscription. We hope you will wish to do so.

MONITORING QUESTIONNAIRE

Would you please take a few moments to complete the enclosed questionnaire as we want to continue providing you (our members) with what you enjoy and we are open to ideas.

BRAIN POWER

I am always interested in anything to do with the brain and have been following the series on television about The Brain. I think my interest started when my GP said to me 32 years ago when I presented him with my symptoms of tinnitus – “the brain is a wonderful piece of machinery. A noise that is there constantly, your brain will learn to *accept it* as another bodily function and so ignore it.” He was a wise man and his words resonated with me, giving me some control over myself. That’s what I needed – positive words! When I saw an article in Joanne’s magazine “Psychology” about “Brain Power” it reinforced those words of wisdom.

“Brain Power”

“Most of us operate on autopilot, letting our brain lead us; we assume our brain is teaching us. The super brain, on the other hand, is what you create consciously, so you have more insight, intuition, creativity and choice. This awareness can help us with many aspects of life, such as controlling anxiety, improving our memory and dealing with personal crises. The brain can only do what it thinks it can do. When you say, ‘my memory isn’t what it used to be’, you are training your brain to meet your diminished expectations. But what if you do the opposite and teach your brain to be unlimited? Cultivating the super brain rests on five fundamental practices: *increasing self-awareness, self-reflection; meditation, conscious choice-making and by realising that your perceptions of the world are shaped by yourself and your brain.* It also helps to change your environment,

reduce stressful conditions, find work that reinforces your strengths, do something every day that you haven't done before, and get enough sleep and exercise."

"An example of how the super brain works can be seen in how we control anxiety. Our feelings of anxiety are based on anticipating future pain." *(In our case it's about anticipating the noise).* We anticipate pain *(and the sound of tinnitus)* because we remember past situations where we couldn't handle it. These thoughts 'stick' – they keep repeating, which makes the fear response stick in the brain. Then the fear becomes convincing and stirs the memory leading to low self-esteem." *(In the case of tinnitus it leads to a vicious cycle of anxiety, perceiving tinnitus as getting worse.....)* With the super brain, you question every fear you have and learn new responses. The writer of this article, Deepak Chopra, encourages people to ask: why am I afraid of this? Is this true? What is this belief doing to me? Who would I be if I didn't have this belief? What is the opposite of this experience?"

[Extracts from Brain Power by Deepak Chopra, the author and mind-body healing pioneer]. (Psychologies, February 2013)

(At our Workshops we encourage people to look at their unrealistic beliefs which result in negative emotions and to encourage them to look at more positive thoughts, resulting in happier emotions. We realise that our own beliefs can be very strong but some of our beliefs are unrealistic and it is necessary to look at better ways of

dealing with anxieties. We also encourage people to become emotionally stronger and to listen to what their body is telling them. We focus on having a more optimistic outlook on life which will lead to more self-confidence and happiness).

HAPPINESS CORNER

"Everything you need to be happy today or in the future lies within you right now."

"Happiness begins from within. Others cannot give us happiness, and nor can they take it away".

HAPPINESS PROJECT

Leading up to the Conference, we asked children at Calow Primary School to draw pictures of what makes them happy. Many depicted family, friends and animals. All age groups participated. We will print the winning pictures in the Conference-edition newsletter.

Happy Memories!



Look at your old photos from years back and make yourself a lovely collage of happy memories. This is me as a 3-year old doing an

Irish jig with a family friend!

Happy Times!

Best Wishes, Audrey