CHESTERFIELD & NORTH DERBYSHIRE TINNITUS SUPPORT GROUP

34 Glumangate, Chesterfield, S40 1TX

Glumangate, Chesterfield, S40 1TX Tel: 01246 380415

Email: mail@tinnitussupport.org.uk

Website: www.tinnitussupport.org.uk

Novelettor Edited by Audrey Corlin Edward 2018

Newsletter Edited by Audrey Carlin February/March 2018

MEETING NUMBER 1 "COFFEE AND CHAT" at THE CAFÉ – MONKEY PARK CHESTER STREET, CHESTERFIELD ON TUESDAY 27TH FEBRUARY FROM 10.30AM – 12.30PM

This is a new idea. We have been given the facilities of the Café for the "Coffee and Chat" which will be an informal event where you can come along, ask questions about your tinnitus if you wish and chat to your friends. However, we have also opened it up to the public who experience tinnitus and may feel isolated. Please come along and join us for this informal gettogether. The café is comfortable and quite spacious.

MEETING NUMBER 2 OUR NEXT SOUP & SOCIAL WILL BE HELD AT "THE BADGER" ON WEDNESDAY, 14TH MARCH 11AM TO 1PM

At this meeting Joanne and I will talk to you about our Tinnitus Wellbeing Workshops, giving you an insight into what we do. We have decided to rename the workshops - "Wellbeing" as this better reflects the format of the workshops. Our aim as a group is to help, support and encourage you to manage your tinnitus in order to achieve a state of wellbeing and happiness. Our talk will be interactive and we hope you will find it interesting and helpful. We will also ask two of our members who have attended our

workshops to tell you about their experience.

Feedback from last year's workshops

"Making the initial phone call is the best thing I've done. I've really enjoyed it (the workshops) and found it helpful"

Very good content, handouts and photos

I always feel happy when I come to the workshops

Outreach Event

We are also active going out into the community and will be doing an Outreach Event at Clowne Community Centre on Friday 9th March 2018 from 11am to 2pm. If you know anyone who would benefit from coming along, please give them the above details.

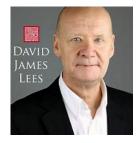
FUTURE DATE FOR YOUR DIARY:

This year we are holding a Conference at the Winding Wheel in Chesterfield on Wednesday 27th June 2018 (during Tea for Tinnitus Month). We have some good speakers lined up and again the theme will be "Wellbeing".

MINDFULNESS - DAVID JAMES LEES

Listening to what you said in your feedback, one of our speakers is David James Lees, who came along to our 2015 conference. He will be talking

about Mindfulness as well as doing a



practical session.

David is an experienced and insured meditation teacher and a traditional Chinese medicine practitioner,

counsellor and hypnotherapist. David

Be mindful of your Self-Talk. It's a conversation with the Universe.

David James Lees

Mindfulness
means
learning to live
in the here and
now, rather
than in the past
or future.
Research
suggests that

says

mindfulness meditation may improve mood, decrease stress, and boost immune functions. David specialises in helping individuals with emotional imbalances such as stress, anxiety, phobias, fear and depression.

Being happy and successful



with
you
being in
a good
place.

starts

PSYCHOLOGICAL WELLBEING - TIM BUCKLE

Also speaking is one of Professor Steve Peter's elite team – Tim Buckle, who is a Psychological Skills Mentor.

Professor Steve Peters is a Consultant Psychiatrist working in Elite Sport and has worked with Sheffield University as a Senior Clinical Lecturer since 1994. He is the author of the "Chimp Paradox". You may have seen Prof Peters on The One Show just before Christmas.

Trained by Professor Peters, Tim will about maintaining talk our psychological wellbeing, stress management and developing emotional skills in an interesting and entertaining way. Having experience of the work of Prof Peters and his elite team, you will find it thought-provoking and it will get you thinking about how you currently manage your emotional wellbeing. Tim's talk is aimed at helping you to become a happy, confident healthier person.

Tim is young and vibrant and is looking forward to coming to our conference and has already been to see us to talk about it. He has also asked if he can come along to one of our meetings to meet people. He told us that he has a friend who has hearing loss and tinnitus but having been fitted with hearing aids he was amazed at the difference it made to him

HEALTH & WELLBEING - JAMIE BROADLEY

Jamie Broadley is the Staff Wellbeing Lead at Derbyshire Community Health Services NHS Foundation Trust. Jamie's talk will be based on our health and wellbeing. He will send details of his talk nearer the time. Jamie sent us a quote of the week: "You have power over your mind, not outside events. Realise this and you will find strength" (Marcus Aurelius).

REPORT FROM OUR JANUARY MEETING



Talk by Emily
Ducker,
Volunteer
Engagement British
Tinnitus
Association.
Photo of Emily

joining in with our support of "Tinnitus Week".

RESEARCH AND CAMPAIGN

The BTA's mission statement is "a world where no one suffers with tinnitus".

Starting early last year the BTA looked at priorities to focus on the most important thing in finding a cure.

- Prevent
- Manage
- Cure

They are trying to drive progress towards a cure.

During 'Tinnitus Week' this year, the BTA are focussing on Tinnitus in Children; making people aware that children can have tinnitus and reaching out to parents. Most people associate tinnitus with age and hearing loss. 80% of people with hearing loss will have tinnitus. 20% do not have hearing loss.

In 2015/16 the BTA revealed that 53% of the BTA's income was spent on research. They have funded PhD students as well as the Nottingham

Biomedical Research Centre. Now they have a Research Officer who is solely funded by the Royal British Legion, as well as funds from donations.

The "Cure" Mind Map

Emily talked about the "Cure" mind map which was illustrated in Issue 4 (2017) "Quiet" Magazine. They got together some people within the BTA to see if there were any gaps in their knowledge. taken This was along to their conference in September to see if the professionals could make some They do have some suggestions. feedback on it and students from Sheffield University will use it to put on the internet.

Website

Currently there are tinnitus guidelines for Clinicians in Denmark, Germany, Netherlands, Denmark and the US. The guidelines for the UK are currently being written to help Clinicians to know what course of action to take. Cognitive Behavioural Therapy (CBT) is the most widely prescribed treatment.

Hearing Aids

As the majority of you will know who wear hearing aids, this is the first-line treatment at hospitals in helping people to manage their tinnitus.

There is no proof that herbal substances help as there is no clinical research to evidence this. This includes such things as Gingko Biloba and vitamin B12 etc.

Mindfulness

The most recent research was by Laurence McKenna, who is a Clinical Psychologist at the Royal National Throat Nose & Ear Hospital in London. Also involved Elizabeth M. Marks,

Christopher A. Hallsworth and Roland Schaette.

In an article "Mindfulness-Based Cognitive Therapy as a Treatment for Chronic Tinnitus: A Randomized Controlled Trial" it states:

Abstract

Background: Tinnitus is experienced by up to 15% of the population and can lead to significant disability and distress. There is rarely a medical or surgical target and psychological therapies are recommended. We investigated whether mindfulness-based cognitive therapy (MBCT) could offer an effective new therapy for tinnitus.

It then stated the Method and Results used and finally the –

Conclusion:

MBCT is effective in reducing tinnitus severity in chronic tinnitus patients compared to intensive retraining therapy. It also reduces psychological distress and disability. Future studies should explore the generalisability of this approach and how outcome relates to different aspects of the intervention. (2017)

Shared Decision Making

When people go to their GP or Audiologist it is much better if the patient has some control over the decision making. They have drawn up a "tinnitus care option decision guide" for Clinicians to give to patients beforehand so they give back control over their treatment and how they can access different treatments. This came out in September.

Sound

Emily spoke about tinnitus sound apps where there are up to 240 apps for tinnitus management. There is not one that 'absolutely' works for everyone. The person would have to choose which they prefer. There are areas that need more research. In America. research was conducted but only with 21 people; although the results are good they are not robust enough. This is where tones are simulated to the person's tinnitus noise and their frequency. Most people recorded there was a reduction in their tinnitus. However, this costs thousands of pounds.

Rhythm Electrical Stimulation

Emily also referred to rhythm electrical stimulation which was tested on those people who have somatic tinnitus.

[Somatic tinnitus is a condition where the sensory system in the body can cause or influence tinnitus in some way eg reducing the perception of tinnitus by moving the jaw]. (BTA website) More research is needed into this.

Neurofeedback

Neurofeedback is a type of biofeedback that measures brain waves to produce a signal that can be used as feedback to teach self-regulation of brain function. (BTA website)

CAMPAIGNS - TINNITUS WEEK

Formerly called tinnitus awareness week. Emily referred to the various types of social media which they use including Thunderclap, Facebook, Twitter as well as Celebrities.

They use social media to spread the word about tinnitus and last year they exceeded their target by over half.

They have coverage on TV and newspapers etc and this increased by 200% over the previous year.

They hope to get more out of Thunderclap as it reaches people throughout the world. They have already reached 1.4 million people and this will increase during Tinnitus Week 2018.

Share your Sound Campaign

The BTA created images of what tinnitus would sound like to make it visual and encouraged people to share on social media as well as take packs to GP's.

Tea for Tinnitus

This year **Tea for Tinnitus** is during the month of June.

Last year the BTA raised £10,457.73 for Tea for Tinnitus month. The band, Spiral Carpets, raised a lot of money for them too in memory of their band member.

Campaign – Plug'Em

The BTA's hearing protection campaign "Plug'em" want to get the hearing protection message out to as many people as possible attending music events and in November last year they attended Shiline on Weekender music festival. They gave out 325 ear plugs to people at the festival asking them to This was very complete a survey. successful and they had good response to the branded earplugs which they are stocking in their shop. www.tinnitus.org.uk/shop

Over 30 of our members attended this meeting and after Emily's talk everyone tucked in to Soup, Sandwiches and Chips.

MORE RESEARCH INFORMATION The BTA's Quiet Magazine

We have just received our latest copy of Quiet in which there is quite a lot of information about Research.

In their "Research Update" section

- Dr Martine Hamann and Nicolas Sylvius report on their BTA funded study evaluating the presence of genetic markers for hearing loss and tinnitus.
- Professor Deborah Hall talks about the COMiT initiative. The aim of COMiT is to improve the quality of future clinical research by identifying a minimum standard for assessing how a tinnitus treatment has worked and proposing standards for how they should be measured.
- Kathryn Fackrell talks about a new initiative to direct research into Hyperacusis
- Also Paul Chinnock reviews the current state of research into Cochlear Implants and Tinnitus.

There is also "The Big BTA Survey"

How you can join the BTA

If you don't already subscribe to the BTA's magazine "Quiet" if you want to keep up to date with Research as well as "Real Lives" where people share their personal journeys then you can receive the magazine by contacting the BTA on 0800 018 0527.

NOTTINGHAM BIOMEDICAL RESEARCH CENTRE - Clinical Trials

We receive quarterly Newsletters from the Nottingham Biomedical Research Centre and enclose the latest edition which we have just received.

You will find information about research they are involved in and details about how you can go on their mailing list if you wish to be involved in future research trials.

WELLBEING

I found the following definition of Wellbeing on the internet and thought this was an excellent way of describing it.

How is wellbeing defined?

"There is no consensus around a single definition of wellbeing, but there is general agreement that at minimum, wellbeing includes the presence of positive emotions and moods (eg contentment, happiness), the absence of negative emotions (eg depression, anxiety). Satisfaction with life, fulfilment and positive functioning. In simple terms, wellbeing can be described as judging life positively and feeling good."

The above fulfils the aims of our group in helping, supporting and encouraging people to manage their tinnitus.

The first-line treatment within the NHS is to fit hearing aids which in the majority of cases are successful in helping people who have hearing loss and tinnitus. This fulfils the practical measures. The senior audiologists also provide support to people whose tinnitus is affecting their life but obviously their time is limited

particularly as the number of people needing help is increasing.

However, in the absence of a cure for tinnitus to date, our group aims to fill the gap and enhance the service already given by the hospital, by providing emotional support to those who need help in managing their tinnitus.

It was with this in mind that we have carefully chosen our speakers for the conference as we feel that this area is important in the overall management, not only of tinnitus, but also in supporting many who suffer from stress and anxiety.

WELLNESS

I think the ultimate aim of possibly everyone on the planet is to seek "wellness" which is why I then looked up the definition of "Wellness" and found much more information of interest, including Global Wellness Day.

However, The World Health Organisation (WHO) states the following:

"Wellness is a state of complete physical, mental, and social wellbeing, and not merely the absence of disease or infirmity."



GLOBAL WELLNESS DAY

Global Wellness Day this year will be celebrated on the 9th June 2018 (which is during "Tea for

Tinnitus Week".)

Coincidentally this also fits in with our Conference theme.

I found quite a lot of information about Wellness; the following are extracts from the Global Wellness site.

"Wellness is an active process of becoming aware of and making choices towards a healthy and fulfilling life. It is more than being free from illness, it is a dynamic process of change and growth. A good or satisfactory condition of existence."

"Wellness the conscious is development of the whole self. Embarking on a wellness journey is a searching process of for appropriate "tools" to make you a healthier and happier human being, plus discovering your own effective methods to use these "tools" for continued growth and development. As there is a great variety on all aspects of life, there are also countless ways to cultivate yourself on an ever-changing path of wellness."

OUR "WELLBEING" WORKSHOPS

In our "Wellbeing" workshops we aim to give you the tools to manage your tinnitus and different ways of looking at life. This in turn gives you the opportunity to discover your own effective methods of, not only managing tinnitus, but also other aspects of your life. The workshops

aim to take you on a journey into discovering your own resilience and cultivating a happier, healthier and positive life.

A Little Kindness

Someone listens, someone shares,
Someone hears and someone cares,
Someone says a kindly word
And joy and hope are gently stirred

Someone is in need of you,
Needs a cheerful line or two,
Be the one to light their day
Sending happiness their way.

Someone needs a friendly smile,
Just to make their day worthwhile,
Show a little kindness too,
And kindness will return to you.
(By Iris Hesselden, courtesy of "Grace",
published by the Editor and Owner of Grace
Magazine)



TINNITUS
WEEK
At our
January



Soup & Social meeting we asked our members to show their support for Tinnitus Week and here are some of the

photographs.



During Tinnitus Week we took our service into the "Wellbeing" section of Chesterfield

Library which was a great success.

Around forty people accessed our support, many of





whom not only picked up information but also wanted to have a oneto-one talk about their tinnitus. We were

joined by Jodie Rogers, one of the Senior Audiologists at Chesterfield Royal Hospital and we were all incredibly busy for more than three hours.

THE BENEFITS OF SHARING YOUR STORY

For thousands of years, humans have shared stories through speaking, pictures and writing.

Many people find comfort and a sense of connection when they share their story. Sharing personal accounts can also help us cope with traumatic life events. Events that have a big impact

on us need to be processed and integrated into our new reality.

Research in the field of linguistics and psychology shows that sharing life events can benefit us physically and emotionally.

Emotions such as anxiety, fear, stress and sadness can get jumbled in our heads in a way that feels disorganised and overwhelming. Keeping a journal or talking to a supportive listener are good ways to release negative thoughts and feelings. [If you haven't already got one of our "Tinnitus" Journals" please do ask for one.]

Celebrating successes (as in the case of successful management of tinnitus and living life to the full) is inspirational to others. [We welcome your stories that can be shared with others]

By sharing your inspirational stories, you are helping others to know "there is a light at the end of the tunnel". Not only for tinnitus but for other stressful situations in life.

Our aim is to help people to be happy and smile; your stories could help this too.