Cambs Tinnitus Support Group

No. 164 NEWSLETTER November 2022

SELF-HELP SESSION

For our November meeting we are hosting our usual annual self - help session, where everyone has the opportunity to share thoughts about their tinnitus with others in a relaxed and comfortable atmosphere. As usual we are under the expert guidance of Rachel Knappett, Head of Adult Auditory Rehabilitation at Addenbrookes, who will lead us through the session. No Bring & Share Brunch again this year unfortunately, but there will minced pies and mulled wine!

Saturday 19 November

10.00 for 10.30 am

Meadows Community Centre

1 St Catherine's Road, Cambridge, CB4 3XJ, off the junction between King's Hedges and Arbury Rds

(NB: Temporary carpark in use; follow Signposts)

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EDITOR'S CHAT

With the sad passing of Queen Elizabeth II, our scheduled September meeting was naturally cancelled. The format of the meeting was to be a first for us, involving a recording of Dr James Jackson's talk as he was unable to be with us in person. And as Rachel had already heard his talk, she was going fill any gaps and take questions from the audience. Anyway it did not happen, however the good news is that James has agreed to give his talk (in person!) on his research for the Tinnibot app to us at our next June's meeting. Interestingly, the Leeds Trinity University Psychology researcher and audiologists from Hearing Power, an Australian-based company, have been recognised for their Tinnibot smartphone app, in the third annual prestigious Hearing Technology Innovator Awards. So James's talk should be well worth the wait!

Perhaps the enforced long gap between our meetings will encourage more of you to come along to our popular self-help session. It's an ideal opportunity to ask questions of a real tinnitus expert, and you also absorb information from other member's queries which may be of help to you personally. Although we won't be having our Bring & Share Brunch, there will be mince pies and mulled wine to enjoy, plus our usual raffle.

As most of you are aware, a brand new Meadows Community Centre is nearing completion next to our usual building, and if all goes to plan we will be using the new building for our scheduled meeting in February. By coincidence, it could well be that our November meeting will be one of the last ones to be held in the old building, and we may be one of the first groups to use the new building in the New Year! This is the reason we won't be having our Bring & Share event; hopefully next year!

You will see below that the BTA have found David Stockdale's successor as CEO. We wish Deanne Thomas all the best in her new role, she has a hard act to follow!

Here's hoping we see lots of you on the 19th November; it's been a long wait since June!

British Tinnitus Association appoints Deanne Thomas as CEO

The British Tinnitus Association (BTA) is delighted to announce that, after a rigorous and thoughtful process, Deanne Thomas has been appointed as its new chief executive from 21 November, taking over from David Stockdale who left in June 2022 after 12 years in the role.

For the last 16 years, Deanne has led the Sailors' Children's Society, a national charity that provides support to children whose parent has made a living at sea or from the inland canals or rivers.

Deanne said "I am delighted to have this opportunity to lead such a fantastic team into its new chapter and to build on the support that the BTA provides to those living with tinnitus across the UK."

"Having led a family support charity for many years, I see how health conditions like this impact people, their family and life. The remarkable plans for a Tinnitus Biobank are something I'm particularly passionate about. This will advance our understanding of what causes tinnitus and I'm excited to talk to you more about this in my new role."

Lynne Gillon, Chair of the BTA, said: "Deanne brings experience, energy and ambition to the BTA, as well as a commitment to drive forward our vision of creating a world where no one suffers with tinnitus. She has valuable leadership experience in the voluntary sector and a genuine passion for delivering quality support to the tinnitus community whilst also pushing for increased investment in tinnitus research."



JIM'S PIECE

I hope you are enjoying reading another of Alan's wonderful newsletters. They always contain interesting articles spiced with nuggets of humour. With my own little contribution, I always try to give a positive spin on things when the news around us can often feel so depressing. After all, without hope what do we have? I am fortunate enough to have been climbing again in the magnificent Dolomite mountains in northern Italy. I often walk alone as I enjoy the silence and love to take in the scenery and sights of nature undistracted. In my case the 'silence' is accompanied by other sounds, although not too loud and I try to ignore them. Those things I have no control over I try to accept and endeavour to make sure they don't spoil my life. Those things I can do something about, I do try to influence.

I hope to see you a lot of you at our November meeting, which I believe will be our last gathering in the current Meadows Community Centre.



Best Wishes Your Chairman, Jim

Tinnitus Lenire® Therapy™ trial results

(Edited from the Tinnitus Clinic article)

Recent results of the second randomised controlled trial (RCT) examining the efficacy of the Lenire tinnitus therapy system, have now been published in the respected journal "Nature - Scientific Reports" (July 2022). The trial showed that optimizing treatment plans can result in greater reduction in tinnitus symptoms, and this can be sustained for 12 months after treatment.

Lenire is a non-invasive home-use medical device that has CE-mark certification for the treatment of tinnitus under the supervision of an appropriately qualified healthcare professional.

The Tinnitus Clinic has partnered with Neuromod Devices Ltd to bring you this amazing, new, clinically proven tinnitus treatment device. Lenire is a new bimodal neuromodulation device for tinnitus shown to reduce the symptoms and improve the experience of those living with tinnitus. The recent clinical trial showed that 80.1% of participants who used Lenire as directed achieved an improvement of their Tinnitus Handicap Inventory (THI) score that was sustained for 12 months after treatment.

Lenire is intended for prescription use only. If Lenire is deemed suitable and thus prescribed by the Tinnitus Clinic audiologist, the audio and tongue stimulation will

be configured and calibrated to the person's individual characteristics during the fitting appointment. Once they are comfortable using the device, having been shown how to use

80.1% of compliant TENT-A1 participants reported improvement in their THI score that continued for 12 months after treatment ended

the various device components during the fitting, the individual can then proceed to use Lenire from the comfort of home.

TENT-A1: Average Reduction in Tinnitus Handicap Inventory (THI) Score



A typical treatment plan advises daily home use of the device for a minimum of 10 weeks. Lenire is recommended to be used for 30 to 60 minutes per day. It's important that each session is completed in a place that is quiet and comfortable; the more relaxed the person is during the treatment, the better.



This includes feeling physically comfortable in a seated position during the session. Where possible, the individual should try to keep a routine for

the treatment sessions, where the treatment is delivered in or around the same time (or times) each day. The audiologist may follow this up at regular intervals over a period of months or years. A follow-up appointment is advised within 6 to 12 weeks of the fitting with

a second follow-up taking place 6 to 12 weeks after the first follow-up. This allows the individual's progress to be assessed as they progress through their treatment plan. At the end of your prescribed treatment plan, the Tinnitus Clinic audiologist will advise about continued use of Lenire. If there are any issues during the treatment plan, it is important to



communicate with The Clinic as a visit may be required so that the stimulation settings are adjusted for comfort.

PS: In an interview for Tinnitus Talk with Dr Dirk de Ritter from the University of Otago, NZ, he was asked if bimodal neuromodulation devices (such as the Lenire above and Dr Susan Shore's Michigan Tinnitus Device - see p5/6 February 2022 newsletter) targets only the tinnitus distress, or is it actually an effective treatment. He thinks, despite the inventors claims, they only treat the distress. Although the sound will decrease a little the problem is that bimodal neuromodulation is no better than any other treatment that treats the distress, and the moment you stop the stimulation, the loudness is back.

CHUCKLES

- Two blokes are working in a city park. One digs a hole and the other one comes behind to fill it in. All day long the two men work furiously, one digging and the other one filling. A passer-by watches this activity and eventually comes over to ask them what are they doing. The hole digger explains, 'I guess it must look funny, ' he says. "But the guy who plants the trees is off sick today.'
- A father is attending his young son's piano recital at a music competition. He turns to whisper to one of the judges, 'What do you think of his execution?' The judge replies, 'I'm all in favour of it.'
- A group of chess enthusiasts are standing in a hotel lobby discussing tournament victories. After an hour, the manager come along and asks them to go to their rooms. 'But why?' they ask, as they move off. 'Because I cannot stand chessnuts boasting in an open foyer.'

Constant tinnitus is linked to altered brain activity (Edited from an article in The Journal of Clinical Investigation) *Auditory brainstem responses (ABR) may be a possible diagnostic tool in identifying constant tinnitus*

Researchers from Karolinska Institute in Sweden have found that brainstem audiometry can be used to measure changes in the brain in people with constant tinnitus. This means that auditory brainstem responses (ABR) may be a possible objective diagnostic tool in identifying people with constant tinnitus.



In the study, ABR measurements were carried out on 405 persons, 228 with tinnitus and 177 without tinnitus. The study found that in people with constant tinnitus there

was a clear difference in the measurements when compared to people without tinnitus or people who rated their tinnitus as occasional.

Risk of developing constant tinnitus

The researchers also followed over 20,000 people with no or varying degrees of tinnitus in order to track how the symptoms develop over time. Here, the researchers found that people with occasional tinnitus are at increased risk of developing constant tinnitus, especially if it recurs often. The study also found that for those who already experience constant tinnitus, the chances are that the problem will persist.

The study was conducted in collaboration with the Karolinska University Hospital, Stockholm University in Sweden, the University of Bergen in Norway and a private company.

WICKED WIT

- Television is an invention that permits you to be entertained in your living room by people you wouldn't have in your living room.

 David Frost
- Television: the bland leading the bland. Anon
- Television: a medium. So called because it is neither rare or well done. *Ernie Kovacs*
- Television: chewing gum for the eyes.

Frank Lloyd Wright

 America is a large friendly dog in a small room. Every time it works it wags his tail, it knocks over a chair.
 Arnold Joseph Toynbee

- Most rock journalism is people who can't write interviewing people who can't talk for people who can't read.

 Frank Zappa
- A man travels the world in search of what he needs and returns home to find it. George Moore
- There is very little between men and women in space.

 Helen Sharman
- The sheer complexity of writing a play always had dazzled me. In an effort to understand it, I became a critic.

 Kenneth Tynan
- Hatreds are the cinders of affection. Walter Raleigh

New Tinnitus Smartphone Treatment Boasts "Encouraging Results" All you need is a smartphone and some headphones

with thanks to Martin Middleton)
weeks, the results showed that the polythera-

(Edited from IFLScience journal

"Encouraging results" have come out of a new trial that used a smartphone-based "digital polytherapeutic" approach to treat tinnitus. The findings were reported in the journal Frontiers in Neurology earlier this month. (Digital therapeutics are customized, tech-based tools that use specialized software to help treat, manage or prevent a broad spectrum of physical, mental and behavioural health conditions. They can be characterized as any approved software-based tool that treats a health issue).

The therapy uses an app that can be downloaded onto any iPhone or Android smartphone. Each treatment plan is personalized to the individual's experience of tinnitus, but it generally involves the person listening to a variety of sounds through Bluetooth headphones and providing the app with feedback.

In a statement, Associate Professor in Audiology Grant Searchfield, study author and director of the University of Auckland's Hearing and Tinnitus Clinic, said "What this therapy does is essentially rewire the brain in a way that de-emphasizes the sound of the tinnitus to a background noise that has no meaning or relevance to the listener."

Scientists at the University of Auckland in New Zealand gathered 61 people with tinnitus and divided them into two groups: 31 people used the new digital polytherapeutic approach, while the remaining 30 used a popular white noise app.

After 12 weeks, the results showed that the polytherapeutic group experienced clinically significant improvements, while the control group did not.

"Sixty-five percent of participants reported an improvement. For some people, it was life-changing – where tinnitus was taking over their lives and attention," said Audiology research fellow Dr Phil Sanders. "This is more significant than some of our earlier work and is likely to have a direct impact on future treatment on tinnitus," Searchfield added.



As the researchers note in their paper, the severity of tinnitus is "a complex interaction between detection of the signal, presence of external sound, and influences of attention, memory, and emotion. Psychosocial

factors including personality and environment affect the expression and degree of tinnitus severity."

Given its complexity, chronic tinnitus can be really difficult to treat, and can also take a huge toll on a person's well-being.

As ever, the researchers are looking to carry out larger trials and get regulatory approval. Optimistically, however, they believe their app could become clinically available in around six months.

Thoughts on David Baguley

Very sorry to hear about the passing of David Baguley. I will always remember my first encounter with him having been told I had tinnitus. Just talking it through and understanding what it was, explained in such a clear and knowledgeable way, was the best relief I could have been given, and of course he told me to join the local CTSG and here I am still! *Jim Infield*

Can't believe the news about David, saddened and stunned to tell the truth, so many people passing away ... not good. I always thought he was younger and fitter and more positive than me. Such a kind man. Does not seem fair, as is often in life. The only thing I remember David saying on arrival in his consultation room was "I think John that you'd easily spot some one in the waiting room that was in distress." I guess meaning I have empathy for fellow humans; I shall miss his warmth of character. *Jon Overton*

When I first met David Baguley in the Audiology Clinic at Addenbrooke's, I was in a bad way. I had developed tinnitus and hyperacusis unexpectedly and suddenly, following a post lumbar puncture cerebral spinal fluid (CSF) leak. As my symptoms became more pronounced and debilitating, I felt angry and resentful, particularly towards the hospital where I'd had the procedure. All the medical professionals denied that my symptoms were caused by the lumbar puncture, but I knew they were. Eventually, the one and only person who actually listened to me and acknowledged me was David Baguley. He really listened, he empathised, he understood, he acknowledged that my tinnitus was real. Only after meeting him face to face, and having received his kindness, his gentleness, his wisdom and his empathy, did I start my recovery and acceptance. I will always be grateful for that. Thank you Julie Robinson I was very sad to learn of the sudden death of David Baguley who I vividly recall meeting at Addenbrookes at one of my first Audiology appointments when I moved to Cambridge over 12 years ago from London. He was very helpful, attentive and kind to me and I felt comforted by his confident, knowledgeable and pro-active approach. I still have the tinnitus masker he gave to me and have always remembered his advice about microsuction and warning 'never let a nurse syringe your good ear'. From what I read about him he made a major difference to the quality of audiology care for patients and will be sorely missed by his colleagues and all those

Use of painkillers increases the risk of tinnitus

(from Journal of General Internal Medicine)

Suzi Gardiner

Women who use certain painkillers are at an increased risk of persistent tinnitus, a study* finds.

An American study has found that frequent use of nonsteroidal anti-inflammatory drugs (NSAIDs) and frequent use of acetaminophen (also known as Paracetamol) is associated with a higher risk of incident persistent tinnitus among women. The risks tended to be greater with increasing frequency of use.

helped by his passion and drive. Deepest condolences to his family.

Use of aspirin

The study also found that the risk of developing persistent tinnitus was not elevated among frequent low-dose aspirin users. But among younger women, frequent moderate-dose aspirin use was associated with higher risk of persistent tinnitus.

About the study

The study included 69,455 women aged 31-48 years who did not experience tinnitus at the beginning of the study. 10,452 cases of incident persistent tinnitus were reported during the study. Participants completed questionnaires at the beginning of the study and every 2 years regarding a wide range of demographic, health, diet and lifestyle factors, including detailed information on medication use. The study did not include men.

* 'Longitudinal Study of Analgesic Use and Risk of Incident Persistent Tinnitus'



The Hidden Noise – Tinnitus & Art

By Nina Thomas
Her work for this exhibition explores the themes of loss and memory. In particular, she has been thinking about her own experience of tinnitus following a sudden hearing loss and looks on tinnitus as a bodily response to loss. Nina thinks tinnitus is always a trace of our past selves and our environment. This work for this exhibition is an attempt to reframe tinnitus this way – representing a loss that is both part of her and separate; she has learnt to live with it, without feeling haunted by it.

DEFINTIONS

Alimony: a mistake by two people paid for by one. **Anarachnophobia**: the fear of spiders wearing waterproof coats. **Budget**: an orderly system for living beyond your means. **Boycott**: somewhere to keep male babies .

Living Well with Tinnitus - A self-help guide using cognitive behavioural therapy

(Edited from various sources)

A new book by Professor Brian C.J. Moore, Emeritus Professor of Auditory Perception in the University of Cambridge, and Dr Hashir Aazh, Audiologist, Specialist in Tinnitus, Hyperacusis and Misophonia Rehabilitation.

Why a Book About Tinnitus?

Aazh and Moore are two of the most respected names in the field of tinnitus management, experimental psychology, and hearing disorders. The authors designed this book to be used by those who are experiencing distressing tinnitus. It is mainly for patients – a self-help tool, but it is equally helpful for clinicians. "Most of the materials presented here are original and have not been covered in most audiology or psychology university courses in the past, so the book can also be useful for clinicians," said Aazh.

"Evidence-based specialized therapy and support for tinnitus patients is not widely available in the UK National Health Service," said Moore, and few audiology departments have any programme for dealing with or treating tinnitus. This book is a way of reaching those people and giving them a chance to self-treat this condition."

"Our usual instinctive ways of dealing with things may not work in coping with tinnitus", said Aazh. "This book aims to teach people a systematic and evidence - based Cognitive Behavioural Therapy (CBT) approach to dealing with tinnitus."

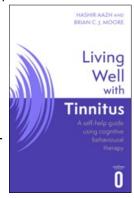
What's interesting about this book is that there is an underlying theme of poetry, classic literature, and culture throughout, something you don't expect when you pick up a book about a medical condition. What have these literary undertones got to do with tinnitus? CBT relies on the individual's ability to learn different ways of thinking. Research studies have shown the use of metaphors can promote the learning process during CBT. The book refers to old philosophers such as Aristotle and Dante Alighieri, and Moore explains that this illustrates that the basic concepts of CBT have been around for a long time.

"The references to real-life stories, such as the boxing match between Muhammad Ali and George Foreman, give people concrete examples of how the way you think about things influences how you behave and how much you are bothered by things," said Moore. "We used these real-life analogies to help people understand the ideas behind CBT and make the theories relatable."

"Although not widely available, certain NHS hospitals offer some forms of tinnitus-focused CBT, however for the people who find themselves unable to access or afford CBT for tinnitus, Aazh and Moore have created an easy-to-read, evidence-based CBT programme in this 10-step self-management guide," says Dr Rory Allot, Clinical Psychologist, Greater Manchester NHS Trust:

"The book does not just open up a discussion about

an under-discussed medical condition. It does much more than that. It delves into the reality of living with tinnitus. And most importantly, it provides a 10-step self-management guide to living well with this condition that so many find distressing. The self-help guides use clinically proven techniques to treat long-standing and disabling conditions, both psychological



and physical. With real life examples to guide the reader and proven cognitive behavioural techniques, this will help people to overcome the distress associated with tinnitus and live a meaningful life."

JOKE?

President Coolidge once invited some friends from his home town to dine at the White House, worried about their table manners, the guests decided to copy everything that Coolidge did. This strategy succeeded until coffee was served. The president poured his coffee into his saucer. The guests did the same. Coolidge then added sugar and cream. His guests followed suit. Then Coolidge bent over and put his saucer on the floor for his cat........

Please remember

This is your newsletter and all comments, letters, contributions or editorial copy relevant to tinnitus or CTSG, or anything you think maybe of interest to our members would be very welcome. Please send to:- Alan Yeo, c/o Newsletter Editor, 4 Claygate Road, Cherry Hinton, Cambridge CB1 9JZ (Tel. 01223 243570 alan.yeo622@outlook.com)

CONNECTIONS

CTSG website: www.cambstsg.com Facebook: Cambs Tinnitus Support Group

CTSG is an independent voluntary organisation with a good supporting relationship with the Audiology Department at Addenbrookes Hospital. It is also a BTA-registered tinnitus support group. We receive no financial support other than from membership subs, donations and sales. This pays for the hire of the meeting room, printing and postage of newsletters, replacement equipment and associated activities.

Our next meeting is on Saturday 18 February at the brand-new Meadows Centre, where our speaker is Nic Wray, BTA Communications Manager. Her topic will be the coming rebranding of the voluntary tinnitus organisation.