Cambs Tinnitus Support Group

No. 174 NEWSLETTER February 2025

MEETING

Saturday 15 February 2025

at

10.00 for 10.30 am

"Discussing some of our latest research topics"

Speaker: **Dr Eldré Beukes**
Lecturer in Audiology
Anglia Ruskin University

Dr Eldré Beukes is a lecturer and researcher at Anglia Ruskin University, Cambridge. Her research focus has been in developing, managing, and evaluating evidence-based internet-based interventions for tinnitus. She received the Shapiro prize from the British Tinnitus Association (now Tinnitus UK) for her research three years in succession between 2017 -2019 and the Hallpike Research Prize in 2019 for her work. She is the author of Cognitive Behavioural Therapy for Tinnitus and has published numerous tinnitus-related articles. She works as an audiologist, seeing a range of patient through Audiological Specialist Care (ASC)..

New Meadows Community Centre

299 Arbury Road, Cambridge, CB4 2JL

The car park is located off Arbury Road between the new Community Centre and the apartment building
(Parking is free for members attending a group meeting, but please be aware that available spaces can be limited)
NB: Other free parking is available in St Albans Road. Turn Right out of car park, St Albans Rd is next Right
The Centre is along the path across the green space

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Refreshment & Raffle

EDITOR'S CHAT

As mentioned in the previous newsletter, Alex Brookes – Thompson has been parachuted into the Tinnitus UK CEO role to raise awareness, raise funding, research support, treatments and deliver better support to people with tinnitus, the professionals and and research. Our group was one of the earliest to experience his 'focus group' format of meeting, and as reported on pages 2 & 3, the November meeting was unlike any meeting we have had before. Which made it really pleasing to see how those present rose to the challenge, and gave of their very best to the task.

In Alex's subsequent e-mail to us, he said he was very pleased to have the support of such a well-established and successful group. 'They certainly got stuck in and I've been digesting the notes this afternoon on the train. We have some very useful feedback and input to work from.'

Talking to members afterwards, they think that Alex is definitely the person to see Tinnitus UK through this rough patch, and we would be happy to have him return in the future to give an update. Personally, I was very impressed with his manner and willingness to listen to our members opinions.

Tinnitus Week is Monday 3 –9 February, and on Tuesday Tinnitus UK will launch their report on the state of tinnitus care. The report by Sonja Jones, from their Scientific Advisory Board, will highlight there is already a lot of excellence in care in tinnitus support and they want to use this as an opportunity to share best practice and discuss excellence in tinnitus care. Representatives of the British Academy of Audiology, British Society of Audiology, the British Society of Hearing Aid Audiologists and ENT UK will also be present.

Following the release of the above report on 4 February, Alex is hosting two public strategy consultation meetings, one in London and another in Sheffield - he really will be a busy man that week!

Our chairman, Martin, will be attending the initial event at the home of the Royal College of Surgeons, at Lincoln's Inn fields in London, and you will no doubt hear all about his trip in the April newsletter.

February 2021 was the last time Dr Eldré Beukes spoke to us, unfortunately only a Zoom meeting because of Covid, but she still pulled in 30 members and guests for her excellent presentation, and filled nearly 2 pages of the ensuing newsletter. We are very lucky to get another opportunity to hear her; don't miss out!

MARTIN'S MISSIVE - If a Picture paints a 1000 words


PHOTO 1


PHOTO 2

How come I need four? Pictures that is. In the last few missives I've tried to illustrate how having tinnitus can be misunderstood by friends and family. Now I'd like to show how other people may see it affecting our mood (s). The first picture below was taken at The Victoria & Albert Museum. We can't tell why the lady has her head in her hands or if she's just on the phone. Or why she is slumped over her small suitcase. We will never know her story or what journey she's on. This is a story about a single photograph with changing moods.

The first comment from my photographic club's critique group was that there's too much empty space in the foreground. And that if empty space was important, it should be on the right side in front of the lady, as though she had been looking in despair at something or someone just out of shot. Having cropped the picture to remove the foreground we were left with the problem of how to add space to the right. (Photo1)


PHOTO 3

One idea was to crop the left side so that it would appear, with the lady off centre to the left of the frame, that there's more space to the right. Then our ideas started getting a bit weird. Just because you can do something it doesn't mean you should do. "How about changing the perspective of the picture?" (Photo 2)

Undeniably this is a bit weird and although not quite abstract, not the world as we know it. Enough to want to put your head in your hands? The next step was to illustrate how the subject of the picture may see things differently to the observer. (Photo3)

Now we're in a dark place. Not where we expected to be when we started playing about with this image. (Photo 4)


PHOTO 4

How does this story end? Well for those of us with tinnitus we should work backwards though the pictures. Firstly by getting a bit of focus on what's happening around us. Then putting some perspective on what's happening in our heads. And finally lifting our heads up and looking for the other people in the room.

With Best wishes

Martin Middleton
CTSG Chair

November meeting report -Your voice, Our future

Meeting report by Alan Yeo

In my last Editor's Chat I mentioned that our speaker Alex Brookes -Thompson, the new Tinnitus UK CEO, wanted to meet people to gather their ideas, opinions and thoughts to help his new strategy, and this was the reason behind his visit to us in November. Alex explained that to make a success of this process, he wanted us to engage in respectful discussion, offering open and honest answers to the questions that would be asked. We divided ourselves into four, more or less equal groups, with one person from each group being 'nominated' as spokesperson. The outlined format was three 20 minute sessions, with ~10 minutes allowed for discussion and ~10 minutes for feedback, with Alex gathering 'answer' sheets from each group for further analysis by himself and his team later. He also made rough notes of key points on a flip chart as the session proceeded.

Alex Brookes –Thompson
Tinnitus UK CEO

Session 1 - You

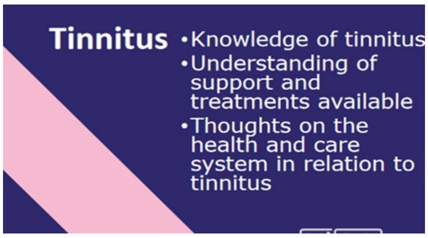
You
- What is your connection to tinnitus?
- What is the impact of tinnitus
- Why are you here today?

- Connections varied across all the groups. One group varied from those who have had tinnitus many years to someone who recently was having problems after having the covid vaccination. In another group one member thought they experienced it for a long time, possibly from childhood; just thought it was normal until tested for hearing loss and prescribed hearing aids. Another suddenly acquired his 'noise' in his 20s, over a weekend, for no apparent reason.

- Not surprisingly the impact of tinnitus was very much a personal affair. Some have learned to partially block it out by concentrating on something else or listening to music, nearly everyone agreed it bothers them at night or when they are on their own. An additional factor was whether the tinnitus was accompanied by a loss of hearing, leading to mishearing odd words or parts of words due to the internal background noise. One lady's husband was very supportive and was keen to learn more.

- As part of the CTSG programme, meeting with Alex Brooks-Johnson, to hear first hand about his role and aspirations for Tinnitus UK to improve the help for those experiencing/having problems with tinnitus.
All the participants agreed we were there to meet others with the condition and to share experiences. This applies particularly to newcomers, who really benefit from this interaction.
We also learn a lot from the speakers at our meetings, particular about the latest research being done.
One lady had travelled all the way from Woodbridge because there was no suitable local tinnitus group.

Session 2: -Tinnitus



Tinnitus
- Knowledge of tinnitus
- Understanding of support and treatments available
- Thoughts on the health and care system in relation to tinnitus

- Most members were reasonably knowledgeable about tinnitus and those new to the condition were keen to learn from the others.
Members were pleased with the meeting reports in the newsletter, particularly of any new research, and they also helped keep non-attendees informed of developments.

- Most GPs initial diagnosis, no cure. GP's not as well informed as patients expectations, frequently omitting to say "it will get better through the process of habituation". Referral to ENT for MRI scan increases anxiety. One member of the group was prescribed a nasal spray (upon group discussion, to remove a possible problem with the eustachian tube) but not told to return to GP if no improvement. General feeling that referral to ENT before an Audiologist is like putting the cart before the horse. Not told by GP that anything advertised as a cure will probably be a waste of money and possibly harmful. Use of ear plugs at concerts and ear defenders in the workplace seldom mentioned.
If NHS Audiology prescribe hearing aids it is likely they will select something suitable to give some relief. Similarly with other devices, sound generators for use at nighttime. Audiology also likely to advise other suitable therapies like CBT and Mindfulness etc.
Purchase of hearing aids in the high street may not pick up on suitable tinnitus options. Ear plugs and defenders, for use in noisy environments, are seldom (one assertion) rated specifically beneficial for people with tinnitus. Ear plugs specifically for musicians or concert goers are available but it a bit hit and miss if they are most appropriate. The maxim "anything is better than nothing" and word of mouth recommendations seems prevalent.

- Although it is said that 1 in 7 people in the UK experience tinnitus, that doesn't appear to translate to a fair distribution of resources compared with other less populus illnesses and disabilities. Most likely because it is not life-threatening/limiting. The issue of suicide is seldom discussed openly and I suspect this is because of a lack of training in many caring environments.

Session 3 –Tinnitus UK

Tinnitus UK
- The vision and purpose
- Strengths & Weaknesses
- Do you feel part of a community?
- Who are we here for?
- What could we do differently/better

- Lobbying to get recognition, funding and implementation of proven remedies.
Raise the profile of Tinnitus UK as a world-leading player. The commissioning of research into cause (s) and remedies seemed to be of paramount importance.
Raise the profile of tinnitus and encourage a better understanding of the problem both in the general public and medical profession.

Tinnitus UK

- The vision and purpose
- Strengths & Weaknesses
- Do you feel part of a community?
- Who are we here for?
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- Among those aware of the organisation (and the BTA prior to recent rebranding) it is probably the first, and possibly the only, place of call addressing the specific issues surrounding tinnitus. For those not aware of the organisation, the internet is awash with websites offering relief and cures, at a price. The rebrand was an attempt to improve the hit rate of web searches. The relative size of the administration, compared to other charitable organisations, maybe a factor. Whilst there is a lot of information on Tinnitus UK's website, including many useful downloadable help sheets, publications like *Quiet* need to reach a larger audience who may prefer a printed copy.

Many thought the website was good and fairly compassionate, but some present had never looked at it at all. Meeting in person was deemed more valuable.

Most did not feel part of a wider tinnitus community. The local group was by far the nearest to a community. Martin thought we could divide the 'community' into several groups: those with no diagnosis and support, those referred by GPs to ENT and/or Audiology but don't seek further help, those who seek additional help via support groups (affiliated to Tinnitus UK or not) and those who have Tinnitus UK-affiliated support groups and have possibly taken out membership of the charity. Then there are professionals, including GPs, medical experts, researchers etc.

- The target audience should be all of the above. Resource allocation will be the governing factor, and it is very likely that the top two groups above, who are probably in need of the most help, will receive the least. We thought Tinnitus UK were there for those people with tinnitus, whether chronic or manageable. They need to reach a wider audience including the medical profession.
- Pam's group agreed that there should be more market research to understand the problems and needs of those with tinnitus; introduce campaigns and lobby government so that the general public are more aware of tinnitus and the impact it can have on individuals. Encourage helpful measures e.g. reduce the noise levels in cinemas, restaurants and at public events; where possible provide quiet areas in public places and promote the use of ear defenders where appropriate for excessively loud noises.

Addendum:

Sometime before the actual meeting there had been much discussion within the committee, as we were concerned regarding the 'focus group' format, our members having never taken part in such an undertaking before. We needn't have worried, as everyone present rose to the occasion and tackled the task at hand with enthusiasm.

I would also like to thank Pat Bowker and Martin, our chairman, for providing me with a cross section of the members responses that made up this report.

Working towards better **H**ealthcare **I**nterventions for **T**innitus**:** a **B**rain stimulation stud**Y**

Tinnitus – the awareness of sound without any outside source - affects around 15% of people and can seriously impact quality of life.

Current treatment options may help manage the impact of tinnitus on daily life, but do not address tinnitus directly. To do that we may need to change the brain activity that causes tinnitus.

Transcranial Direct Current Stimulation (tDCS) is a promising approach. This low-dose electrical stimulation technique is safe and easy to administer. Several small studies have tested tDCS for tinnitus, showing some benefits.

To assess whether these benefits will generalize to other patients, need to conduct a 'so-called' trial – a large rigorously controlled experiment based on prior agreed procedures. Clinical trials are expensive and time-consuming to run, and thus require meticulous "pilot" work to establish the most effective treatment regimes and the most sensitive measures of treatment outcome.

Current treatment options may help manage the impact of tinnitus on daily life, but do not address tinnitus directly. To do that we may need to change the brain activity that causes tinnitus.

The WHITBY study will involve 10 in-person visits to the University of Nottingham, over the course of two weeks. Every visit will involve a 20-minute session of tDCS. The first and last visits will also include various questionnaires, a hearing test and an EEG (a recording of brain activity)

(My thanks to John Williams for this item copied from a RNID article. He has been asked to volunteer for this research at Nottingham Uni, but bearing in mind it will involve him either commuting up there or staying in hotels or some of each, he has not yet made up his mind whether to or not to participate)

Cochlear nerve damage associated with tinnitus (Edited from a study originally published in **Scientific Reports**)

At a Glance

- People with chronic tinnitus were more likely to have signs of damage to their cochlear nerve than people without the condition.
- Therapies to regenerate this nerve, which helps route information from the ear to the brain, may hold promise for treating tinnitus in the future.

More than 10% of adults worldwide will experience tinnitus during their lifetime, and the causes of tinnitus are not well understood. Most people with tinnitus have some degree of hearing loss. One theory of tinnitus suggests that, when hearing is damaged, the brain becomes hyperactive, leading to the perception of phantom sounds. But many people with tinnitus appear to have normal hearing on an audiogram test.

To look more closely at the association between tinnitus and nerve activity, a research team led by Dr. Stéphane Maison from Mass Eye and Ear recruited almost 300 people who had normal hearing results on an audiogram test.

The participants were sorted into one of three groups based on their self-reports of tinnitus. These included 201 people with no tinnitus (beyond the occasional phantom sound that resolved quickly); 64 people with intermittent tinnitus (defined as being continuous but lasting for less than 6 months at a time); and 29 people who had been experiencing chronic tinnitus for more than 6 months.

The researchers performed a range of testing on the participants. This testing covered numerous aspects of sound processing, from the sensory hair cell responses in their inner ears to the auditory reflexes of their brainstems.

The team found that people with chronic tinnitus were much more likely to have reduced responses to sound in their cochlear nerve compared with people in the other two groups. This nerve, which is also called the auditory nerve, carries sound information from the sensory hair cells to the brain. People with chronic tinnitus also had a weaker reflex in response to sound in the muscles of the middle ear.

Those with chronic tinnitus, however, were more likely to have increased activity in related nerves in the brainstem. This combination of findings supports the idea that reduced functioning in the cochlear nerve may lead to increased activity in the brain to cause phantom sounds.

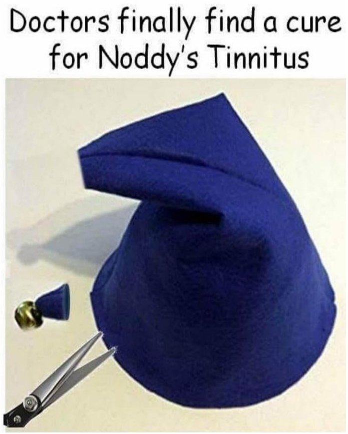
"Our work reconciles the idea that tinnitus may be triggered by a loss of auditory nerve, including in people with normal hearing," Maison says.

As not all people who experience cochlear nerve damage develop tinnitus, more research is needed to understand other contributors to the condition. Maison and his team plan to explore approaches to boost regeneration of the auditory nerve as a potential treatment for tinnitus.

Chuckles

- A sniper takes a potshot at a general visiting the front line. We know exactly where he is sir, says one of the soldiers. 'He's been up there for weeks.' 'Then why don't you see him off?' asks the general. The soldier replies, 'Because if we got rid of him, they might replace him with someone who could actually shoot straight.'

  Every night a couple are kept awake by the barking of the next door neighbours dog. Finally the man has had enough and jumps out of bed. 'Right!' he says. 'I'm going to teach them a lesson.' So saying that he runs downstairs and comes back five minutes later. 'What did you do?' ask the wife. 'I've put their dog in our garden,' replies the man. 'Now let's see how they like it.'
- An old man is driving on the motorway when his mobile rings. It's his wife calling. She says she's heard a news report about a car driving the wrong way up the motorway. 'I know, 'says the old man. 'but it's not just one, it's hundreds of them.'


Doctors finally find a cure for Noddy's Tinnitus

Tinnitus researchers at the Bionics Institute published findings of an important study in the Journal of Neural Engineering in August 2024 that has a twofold impact.

Firstly, it provides definitive evidence that the tinnitus diagnostic tool developed by our researchers can detect changes in tinnitus severity or presence in the same person, which means the technique can be used to determine the effectiveness of potential treatments.

Secondly, it provides a better understanding of the neural mechanisms underlying the suppression of tinnitus with cochlear implant use. Lead tinnitus researcher, Dr Mehrnaz Shoushtarian says that use of cochlear implants is known to improve the perception of tinnitus (hearing sounds that are not present externally), although it can have the opposite effect in some cases.

In this study, researchers investigated whether changes in brain networks with a cochlear implant turned on and off were associated with tinnitus perception, as rated subjectively by 14 participants.

Dr Shoushtarian said: "The findings showed that we can objectively measure changes in tinnitus perception in an individual, which will be critical for monitoring treatment effectiveness in our upcoming clinical trials of emerging treatments in collaboration with clinician researchers."

Bionics Institute Chief Technology Officer, Professor James Fallon said: "These findings could also pave the way for effective use of cochlear implants, or other less invasive techniques, as a treatment for tinnitus."

Martin Kemp and wife Shirlie endure a health condition that affects millions of Brits

(Edited from Surrey Live)

Martin Kemp and his wife Shirlie Kemp have candidly spoken about the toll their passion for loud music in their youth has taken on their health. Appearing on a January episode of That Gaby Roslin Podcast, the couple discussed their battle with tinnitus, a condition that affects over 7 million Brits. The couple reminisced about their days in the music scene of the 1980s, suggesting their condition likely stemmed from that lifestyle.

Shirlie said: it was not surprising, both being in bands in the '80s and clubbing in the '80s and I used to go and see punk bands all the time, the same as Martin did, and always up the front by the speakers."
When asked about her condition, Shirlie recounted: "When I first had it, it actually drove me mad and I didn't think I could live with it."
She revealed that the tinnitus developed after giving birth to her son Roman Kemp, describing the incessant sound as comparable to living next to a "generator", but has since become something she has learned to live with.
Martin, who played bass for Spandau Ballet, explained how his musical practices might have led to the condition, stating "I only have it in my left ear and that's from where I used to play my guitar. My left ear used to be pointed at our amplifiers"
He went on to describe the mindset at the time: "If you've got number 11 on it, turn it up to number 11 and the louder you were, the more 'rock and roll' it was.
To combat the symptoms, Shirlie meditates with the help of headphones on, although her partner Martin humorously remarked that her "generator" fuels his "high-pitched whistle".

What do tinnitus patients want?

(Edited from LinkedIn message from Dr James Jackson)

I have an upcoming paper going into this in some depth, from predictions of help-seeking behaviour (who seeks help, who does not, and why), through to patient satisfaction with healthcare professionals, tinnitus patients and more. Both Specsavers and Hearing Health & Technology Matters have recently - and kindly - invited me to speak on such matters. The latter as part of their fascinating InFocus: Rethinking Tinnitus Symposium (https://tinyurl.com/rec589vu), gave me a good 30mins on the topic. Feedback was very pleasing, and they have published the whole recording on their YouTube channel (https://tinyurl.com/3p7kxspm).
It is, in my view, a very important topic, and further training (by me??) is needed.

Wicked Wit of Insults

- I occasionally play works by contemporary composers and for two reasons, first to discourage the composer from writing any more, and secondly, to remind myself how much I appreciate Beethoven. *Jascha Heifetz*
- Why do we have all these third-rate foreign conductors around - when we have so many second-rate ones of our own? *Sir Thomas Beecham*
- Musical people always want one to be perfectly dumb at the very moment when one is longing to be absolutely deaf. *Oscar Wilde*
- I love his work but I couldn't warm to him even if I was cremated next to him. *Keith Richards on Chuck Berry*
- Golf is a lot of walking, broken up by disappointment and bad arithmetic. *Mark Twain*

Imaginary words

- Sherpes (a skin condition common to Tibetan mountain climbers) • Lidocanine (anaesthetic for dogs)
- Meloncholy (Fruit of the Gloom) • Fedorca (a whale watcher's hat) • Holipstic (an organic cosmetic)
- Sacrivice (giving up a bad habit) • Jestation (period of time in which a comedian develops his act)
- Laborastory (a place for testing works of fiction) • Grandinose (Cyrano de Bergerac) • Halitoesis (smelly feet)

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** TINNITUS UK REGISTERED 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 Tinnitus UK-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. Reports and comments expressed in this newsletter do not necessarily reflect the views of CTSG.

Saturday 26 April is the date of our next meeting, when our speaker is Dr Derek Hoare, Associate Professor in Hearing Sciences at Nottingham Hearing Biomedical Research Unit. He will be updating us on the latest tinnitus clinical trials.