

Cambs Tinnitus Support Group

No. 173

NEWSLETTER

September 2024

MEETING

APOLOGIES FOR THE UNUSUAL FRONT PAGE, BUT CURRENTLY WE ARE WITHOUT A SPEAKER FOR THIS MEETING. AS EXPLAINED ON PAGE 2, NIC WRAY IS LEAVING TINNITUS UK TO PURSUE A PhD IN TINNITUS, AND ROGE REENWOOD, INTERIM CEO, WHO WAS STANDING IN, HAS NOW CANCELLED. WE WILL INFORM YOU WHEN ANOTHER SPEAKER IS FOUND.

Saturday 21 September 2024

at

10.00 for 10.30 am

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 block
(Parking is free for members attending a group meeting)

NB: Other free parking is available in St Albans Road. Turn R out of car park, St Albans Rd is next R.
The Centre is along the path across the green space

CONTENTS

2. Editors Chat ~ Martin's missive
3. Meeting Report: Odd Causes and Types of Tinnitus - Professor Manohar Bance
4. Loss of auditory nerve fibres uncovered in individuals with tinnitus ~ Can you help? ~ You asked. We did!
5. Sound of silence - Story and Science by Claire Wilson Pt 2 ~ Imaginary words ~ Chatbot-based CBT app brings tinnitus improvement to 64% of test group subjects
6. The noise-cancelling headphones that can change the sound of the world ~ Chuckles

Refreshments and Raffle

EDITOR'S CHAT

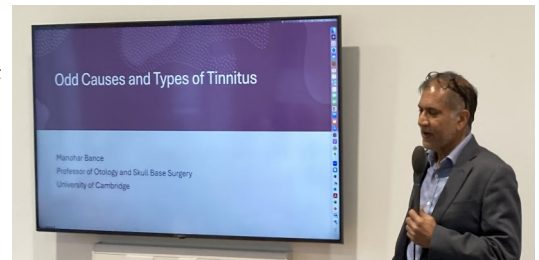
As explained in the e-mail chat, Robin Greenwood, Interim CEO, should have replaced our speaker Nic Wray, but has since cancelled as the new CEO is apparently starting early. After 14 years with the charity (formerly BTA) Communications Manager Nic Wray will shortly be leaving the organisation; however she won't be leaving the tinnitus and hyperacusis field, as she will be working towards a PhD at NIHR (National Institute for Health and Care Research), at the NBRC (National Biomedical Research Centre), University of Nottingham. "Working for the charity has been a fantastic experience, and I will be sad to leave Tinnitus UK, but I am beyond excited to take all this knowledge and experience I have gained to work on a project which will bring real benefit to people living with tinnitus and hyperacusis." Nic has already hinted to me she hopes to be able to come and talk to us in the future.

You will be pleased to know that our meeting programme for next year is coming along nicely, and we have lined up some interesting speakers. The completed programme will be sent out before the end of the year. Don't forget November will bring our popular Bring & Share Brunch along with our self-help session where everybody has the chance to ask their questions about tinnitus.

On page 4 is a reminder that Anglia Ruskin University (ARU) have an ongoing research study looking for ways to promote relaxation, known to improve tinnitus distress, which cannot be a bad thing. If you have any questions, if you live near Cambridge, occasionally visit, or know someone that might be interested, please do not hesitate to contact the team at: ac1777@student.aru.ac.uk. The link to register is on page 4.

Also on page 4 the piece about the Tinnitus UK professional leaflets is good news as they have always been a very useful source on all matters to do with tinnitus. Remember we have copies of these that are available at our meetings, and which are replaced when the updated version become available.

Professor's Bance's talk was one of the most difficult I've had to report on. By his own admission, he speaks very quietly, and much of the audio recording was not clear. In hindsight I should have given him the recorder to carry, and this would significantly have improved the end result. However, by referring to his slides and accessing one of his papers on this topic, I hope I have managed to give those who weren't there, particularly, a reasonable flavour of his absorbing talk.



Professor Bance explaining what objective tinnitus is all about!

MARTIN'S MISSIVE

We're sitting on a hotel balcony in Bled, on the wrong side without a view of the lake, and wondering about our next adventure. Time to kill and then panic, I need to write the equivalent of "Jim's Piece" for the next newsletter. Nobody writes postcards anymore. "The weather here is beautiful; wish you were too". Then it occurred to me, perhaps I should continue with the photographic theme I submitted for the April newsletter. How to explain in picture form the way tinnitus affects us. Tinnitus UK's website featured the picture on the right as an illustration of Tinnitus. A picture like this may help explain the funny noises we hear to others with tinnitus and audiologists, but it is meaningless to those without the condition, even those with hearing loss. It's like trying to explain the white snow interference on an old black and white television to a digital-age teenager. Could I do any better?



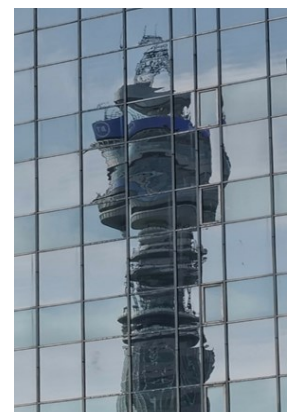
The picture below left, of the refinery at Salford Quays, got a third place in my local club's photographic competition.

The judge liked it's Daliesque reference but couldn't figure out how it had been manipulated in post processing.

It hasn't, apart from some slight cropping to remove buildings not in the reflection. My idea was to illustrate how tinnitus can fragment and distort sounds, conversation in particular. I asked my wife if this helped her understand my tinnitus. "Well it's colourful and quite pretty but not very helpful if you don't know what a refinery looks like." Challenge accepted.

The photograph on the right is something you might recognise. Another distorted reflection, not pretty and not much fun with the colour drained out of it.

Does this look and sound familiar?



With Best wishes

Martin Middleton
CTSG Chair

Unusual forms of objective tinnitus, i.e. sounds that other people can hear.

Edited by Alan Yeo

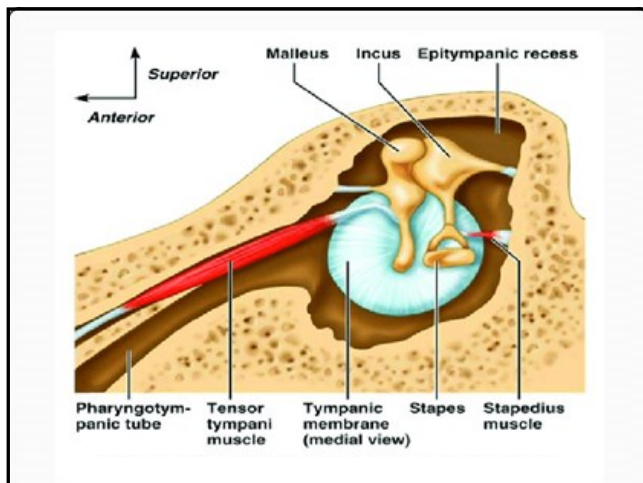
Objective tinnitus (OT), sounds produced by the ear and/or its surrounding structures, is audible to both the patient and examiner and can be both physically impairing and mentally distressing for patients. Objective mechanical tinnitus is due to abnormal muscular contraction of the middle ear, as can occur in palatal myoclonus (PM): Palatal sounds are sounds produced with a constriction at the hard palate of the roof of the mouth, myoclonus are sudden, brief involuntary twitching or jerking of a muscle or group of muscles. [NICE description]

Professor Bance began by describing some of the things what people with OT complain of:

- Conductive hearing loss
- Oscillopsia (the apparent motion of objects that are known to be stationary); others may perceive that objects are moving in time with their pulse (pulsatile oscillopsia).
- Dizziness with certain sounds (fire alarms, sirens, high-pitched voices etc.) which is known as the *Tullio* phenomenon.
- Dizziness with straining - on the toilet, heavy lifting, laughing.
- Weird types of noises: "I hear my eyes moving" "I hear my heartbeat in my head all the time." "When I walk, I am hearing every heel strike like it's going through my head."

Middle Ear Muscles (MEM) - see diagram

Two of the principal inner ear muscles that were mentioned in the opening paragraph are the tensor tympani muscle (TTM) and the stapedius muscle. The TTM is attached to the malleus (hammer-shaped bone or ossicle in the middle ear) and is supplied by a branch of the Vth cranial nerve and palatal muscles



that open the Eustachian (Pharyngotympanic) tube. (ET). The TTM does not seem to respond to sound in man, but has been reported to respond to face stroking, puffs of air against the eyes, electrical stimulation of the tongue and swallowing. The tensor tympani muscle can move the eardrum inward, and is involved in most cases of voluntary middle ear muscle contractions. It has been suggested that the TT muscle contraction may be involved in the development of ear-related pathologies such as tinnitus and hyperacusis.

Have you ever heard a thumping, tapping or clicking noise in your ears that occurs randomly and seemingly for no reason? Although uncommon, you may be experiencing a condition known as Tensor Tympani Syndrome – TTS. While TTS is not considered dangerous, it may cause significant distress and frustration for anyone struggling to understand and manage the symptoms caused by the muscle spasm of the middle ear muscle (the Tensor Tympani).

The Stapedius Muscle (SM) - is supplied by the facial nerve, a branch of the VI nerve, and is attached to the stapes (stirrup) bone or ossicle) and helps stabilize the stapes bone and is involved in regulating sound and protecting your inner ear from damage due to loud sounds (incidentally the SM is the smallest muscle in the body at just over 1mm in length).

More commonly, people have contractions of the middle ear muscles of unknown origin. These can be of several types, but the most common is a paroxysmal 'fluttering' sound in the ear, like a butterfly flapping its wings. This is often thought to be from the stapedius muscle, although there is no concrete evidence for this. Stapedius muscle contraction can also move the eardrum outward.

Differential diagnosis is the distinguishing of a condition from others presenting with similar symptoms, and Professor Bance gave as an example "Typewriter Tinnitus". This a special kind of staccato tinnitus, mostly described by patients as Morse code, popcorn, or machine-gun, associated with facial spasms, paroxysmal dizziness or brought about by head movements. Another is palatal myoclonus which is characterized by involuntary contractions of the soft palate, causing bilateral clicking tinnitus. The myoclonus is rapid and irregular, and a stroke is the most common cause.

Eustachian tube dysfunctions

Patulous ET dysfunction is a disorder of the valve of the ET that causes it to remain open. When this valve remains open, sound can travel from the nasal-sinus cavity to the ears, allowing you to hear your own breathing (aerophony), popping or clicking noises, tinnitus, echoing of your own voice (autophony), or even the sound of blood pumping. Lying down or pressing on the neck can help, as well as pinching one nostril and breathing through the other.

Signs of obstructive ET dysfunction include middle ear fluid, scarring, sclerosis, and a retracted tympanic membrane. A test for a ET dysfunction would include the findings from multiple tests (inc. patient history, physical examination, audiogram, tympanogram and endoscopy etc).

Professor Bance finished with the following slide:

"So there is more in the ear than is dreamt of in most people's philosophy"

Most tinnitus is inner ear related, the majority related to nerve type hearing loss; however there are other causes of sound in the ear, which are much rarer, but at least potentially treatable.

As one of the UK's top otologists, we were extremely fortunate to have Professor Bance spare the time to come and give us a interesting talk about objective tinnitus; a topic that I suspect, like me, our audience knew very little about. After several questions he was given our usual enthusiastic round of applause.

Loss of auditory nerve fibres uncovered in individuals with tinnitus

(Edited from article in Mass General Brigham)

Massachusetts Eye and Ear researchers link tinnitus to auditory nerve degeneration in individuals with a normal hearing test

Researchers have uncovered that tinnitus might result from underlying auditory nerve damage that can't be detected on conventional hearing tests. The work builds upon previous research into cochlear synaptopathy or 'hidden hearing loss,' a difficulty hearing in noisy environments despite showing normal results on hearing tests. The researchers hope these new findings into the mechanisms underlying tinnitus could lead to treatment options.

A new study from Mass Eye and Ear investigators shows that individuals who report tinnitus are experiencing auditory nerve loss that is not picked up by conventional hearing tests. This work is part of a grant awarded by the National Institutes of Health (NIH) to these researchers for their work on cochlear synaptopathy, commonly referred to as "hidden hearing loss." The results from this study provide a better understanding on the origins of tinnitus and were published in Scientific Reports.

"Beyond the nuisance of having persistent ringing or other sounds in the ears, tinnitus symptoms are debilitating in many patients, and reduce significantly their quality of life," said principal investigator and senior author Dr Stéphane F. Maison. "We won't be able to cure tinnitus until we fully understand the mechanisms underlying its genesis. This work is a first step toward our ultimate goal of silencing tinnitus."

It's been a longstanding idea that these tinnitus symptoms arise as a result of a maladaptive plasticity of the brain. In other words, the brain tries to compensate for the loss of hearing by increasing its activity, resulting in the perception of a phantom sound, tinnitus.

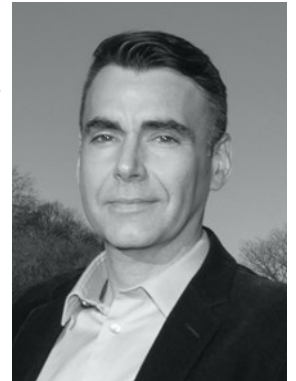
Until recently though, this idea was disputed as some

people with tinnitus have normal hearing.

However, the discovery of cochlear synaptopathy back in 2009 by Mass Eye and Ear investigators brought back to life this hypothesis as it was evidenced that patients with a normal hearing test can have a significant loss to the auditory nerve. In view of this paradigm shift in the way researchers and clinicians think about hearing loss, Maison and his team sought to determine if such hidden damage could be associated with the tinnitus symptoms experienced by a cohort of normal hearing participants. By measuring the response of their auditory nerve and brainstem, the researchers found that chronic tinnitus was not only associated with a loss of auditory nerve but that participants showed hyperactivity in the brainstem.

"Our work reconciles the idea that tinnitus may be triggered by a loss of auditory nerve, including in people with normal hearing," said Maison. In the future, the investigators aim to capitalize on recent work geared toward the regeneration of auditory nerve via the use of drugs called neurotrophins.

"The idea that, one day, researchers might be able to bring back the missing sound to the brain, and perhaps, reduce its hyperactivity in conjunction with retraining, definitely brings the hope of a cure closer to reality," Maison added.



Dr Stéphane F. Maison

Can you help?

Due to the negative effects of tinnitus, a group of researchers at Anglia Ruskin University in Cambridge in the UK are looking for ways to promote relaxation, known to improve tinnitus distress. They are running a research study involving watching videos that induce the ASMR response (a calm response that slows your heart rate). They are also investigating if levels of stress (cortisol) changes due to being relaxed.

Participation in this study can be an enjoyable experience and help identify ways of lessening tinnitus distress. You will be asked to complete:

A 10 -15 minute online questionnaire.

A 45-50 minute in-person session at Anglia Ruskin University in Cambridge to watch a relaxing video and collect a tiny sample of your hair (invisible) and three samples of your saliva

A 3 minute questionnaire to complete at the end of the session.

Who can help?

Both adults with tinnitus and without tinnitus (control group) are welcome to participate

Here is the link to register. <https://research.sc/participant/login/dynamic/9A32E3FB-6461-4F5E-A711-269929EB96F0>

To thank you, a £10 Amazon voucher will be given following participation.

For more information, contact ac1777@student.aru.ac.uk

**You asked.
We did!**

TINNITUS

Many of you have told us that you miss our downloadable leaflets—whether that's for personal use, or to give out to the people you see in clinics. So, we've heard you, and we've bought them back! We've published the most popular topics first of all, including self help for tinnitus, pulsatile tinnitus and tinnitus and stress, and plan to complete them all over the next few months.

You can find the leaflets on the appropriate page of our website, we've also pulled them altogether in one library.

Sound of silence - Story and Science by Claire Wilson Pt 2

(Edited from New Scientist by Martin Middleton)

Part one of this story - see June newsletter page 5 - set the scene of Rand, a DJ in Liverpool, and the medical understanding of his condition. In part two we are introduced to new developments and remedies to provide relief and ultimately a permanent solution.

The old idea, that the main effect of noise exposure is to kill hair cells, meant that to reverse the damage, new hair cells would have to be created. But repairing cochlear nerve may be more achievable. Work on animals has shown that the initial damage is to the nerve's synapses – the connections they make with the hair cells – progressing along to the first part of the fibre. What remains is a crucial part of the nerve cell called the cell body, along with the second half of the nerve fibre, which continues on to the brain. "The exciting thing is that the cell body and the rest of the fibre can remain alive, after the initial damage, for decades"

That is good news because previous work has shown that fibres and synapses can be coaxed to regrow by natural signalling molecules called neurotrophins. In



Dr Gabriel Corfas

the ear, focus has turned to one called neurotrophin-3, which normally promotes synapse formation in the ear of developing embryos. One hurdle is that neurotrophins are large protein molecules, which makes them hard to deliver to the inner ear, but there are possible workarounds.

Dr Gabriel Corfas and his colleagues have used gene therapies to boost levels of neurotrophin-3 in the inner ears of mice, which leads to synapse growth. Niliksha Gunewardene at the Bionics Institute in Melbourne, Australia, and her colleagues have recently

shown that in animals, an injection of neurotrophin-3-loaded nanoparticles into the ear releases the compound for several weeks.

Further along is a French firm called Cilcare, has a lead compound already shown to be safe in people when given orally for a different medical condition. The firm is due to start a trial in 2024 for people with hidden hearing loss, with or without tinnitus.



Dr N. Gunewardene

That chimes with Rand's experience. Contrary to his initial fears, his symptoms didn't interfere with his music career, and he has now come to terms with his tinnitus. "It doesn't feel that intrusive in the day and I have grown used to it at night," he says. At work in mixing studios, however, Rand is fastidious about making sure sound levels don't get too high and he advises everyone to wear hearing protection at clubs and concerts. "You get one pair of ears, so look after them," he says. Most people are aware that excessive noise exposure can lead to hearing loss and tinnitus. But it is hard for people to know exactly how loud is too loud.

"There are very clear noise exposure guidelines. My impression is they are ignored by most people, whether it's the listener or people who run concerts, clubs and bars," says Sedley.

He uses the "60-60" rule when using headphones, which means you should listen at no more than 60% of the maximum volume for no longer than 60 minutes.

Imaginary words

• Procaffeinating - *A tendency to not do anything until you have had a cup of coffee.* • Isotope - *A radioactive hairpiece* • Holipstic - *An organic cosmetic* • Afictionado - *A devotee of novels* • Tumblesweed - *A Scandinavian gymnast* • Astrollogy - *A walk under the stars* • Pediatricks - *Child doctor's technique to distract fearful patients*

Chatbot-based CBT app brings tinnitus improvement to 64% of test group subjects

A study by an international research team has reported that a new app - MindEar, is effective in decreasing tinnitus distress, and levels of anxiety and depression

The app uses internet-based delivery of cognitive behaviour therapy (CBT), which to date has proven the most efficacious way of reducing tinnitus distress. The authors of the study, whose findings were published in January 2024 in the journal *Frontiers in Audiology and Otolaryngology*, also state that while addition of telepsychology might be beneficial, it is not essential for the effectiveness of treatment, i.e. the chat-bot functions well unsupported by human intervention. MindEar, downloadable for iPhone and Android users, aims to tune out the annoying tinnitus sound by equipping the mind and body with the tools to suppress stress hormones and responses, reducing the brain's tendency to focus on the sound.

28 people completed the study. 14 used the app's virtual coach for 10 minutes a day for 8 weeks. The other 14 participants were given similar instructions with 4 half-hour video calls with a clinical psychologist.

At post-treatment, a clinically significant improvement was observed in 42% of the Tinnibot-only group and 64% of the hybrid-intervention group. At follow-up, this was 64% for both groups.

Publication of the findings was met with enthusiasm by the charity Tinnitus UK, which has followed the progress of the study team led by Dr. Fabrice Bardy of the University of Auckland, New Zealand.

Tinnitus UK Communications Manager Nic Wray said: "MindEar uses a new technology to delivery tinnitus management techniques that existing research has shown are effective for tinnitus. The results of this study are encouraging, and we hope that they can be repeated in larger scale trials. There is a huge need for affordable, accessible and effective tinnitus treatments for the one in seven adults living with this often overlooked and distressing condition."

'Semantic hearing' could help people suffering from sensory conditions such as misophonia.

Researchers in the US have used artificial intelligence to produce noise-cancelling headphones that allow users to select which sounds they want to hear – or don't. Using deep-learning algorithms that allow users to make choices in real time, "semantic hearing" has been evaluated on about 20 specific noises, including sirens, a baby's cry and a dog's bark. They believe that as their system can be trained to deal with any sound it could be of significant use to people who suffer from sensory conditions such as misophonia, in which a noise generally considered normal, such as the clicking of a pen, can force a person from the room.

"You're talking about augmenting human auditory perception with AI," said Shyam Gollakota, professor of computer science and engineering at the University of Washington. Eventually, users will have an app on their smartphone to control the sounds, but for the trial a laptop programmed to block or unblock half a dozen noises was utilized. The headsets can also be set to cancel all noises or none.

Dr Gollakota said the project aimed to do several things simultaneously: identify all sounds in an environment and separate the target sound, while preserving its direction so users know where it is coming from – and it needs to do it within a few milliseconds of audio. "We designed the first real-time neural network that can extract these target sounds and run in real

Misophonia is a disorder of decreased tolerance towards specific sounds, or the stimuli associated with them. These stimuli, known as "triggers", can be unpleasant or distressing, and tend to evoke strong negative emotional, physiological and behavioural responses. For those who have acute misophonia, it can be utterly debilitating, and is linked to a higher rate of depression and even suicide.

Cris Edwards, founder of the group *soQuiet*, says for some people – himself included – the sound of someone just crinkling a bag or eating biscuits might be enough to drive them from the room. Mr Edwards says his group has been in touch with the University of Washington team, and believes semantic hearing could be a huge help. "If it works as they say it does, this could be a miraculous assistive technology for people with misophonia," he said.

Zachary Rosenthal, professor of psychiatry and behavioural sciences at Duke University, Durham, North Carolina, and a leading expert in this little-known disorder, says a forthcoming paper suggests ~ 5% of people can have misophonia, and how it affects a person can vary greatly. He believes semantic hearing could be "transformational", allowing someone with the condition, for instance, to enjoy meals with their families or attend school without fear. "This could help reduce suffering for millions of people – it's that big of a deal" he said.

Chuckles

- A Yankee and a Scot are walking in the Scottish mountains. The Scot, wishing to impress his visitor, produces a famous echo to be heard in the place. The echo returns after nearly four minutes. The proud Scotsman turn to the Yankee and says, 'There, ye canna show anything like that in your country.' 'Oh, I don't know, says the American. 'Back in the Rockies, when I go to bed I just lean out of the window and shout, "Time to get up!" Eight hours later the echo returns and wakes me.'
- An anthropologist went to study the inhabitants of a far-flung tropical island. He found a guide with a canoe to take him upriver, and about noon on the second day of travel they began to hear drums. The anthropologist asked his guide, "What are those drums?" The guide says, 'Drums okay, but very bad when they stop.' As they travelled the drums grew louder and louder, making the anthropologist very nervous, but the guide merely repeated, 'Drums okay. When they stop, then Very Bad!' Then the drums suddenly stopped. Terrified, the anthropologist yelled to the guide: 'The drums have stopped! What now?' The guide crouched down, covered his head with his hands and said, 'Guitar solo.'
- Actor to fellow thespian: 'At the end of my last recitation it took the audience forty five minutes to leave the theatre.' Thespian: 'Goodness, was it very well attended?' Actor: 'No, he was on crutches.'

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](#)



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.

Our next meeting is on Saturday 16 November, and will feature our ever-popular Self- Help session, watched over by Rachel Knappett, followed by our yummy Bring & Share Brunch!