Cambs Tinnitus Support Group

No. 160 NEWSLETTER February 2022



Saturday 19 February

at

10.00 for 10.30 am

"Somatosensory Tinnitus"

Speaker: Rachel Knappett,

Head of Adult Auditory Rehabilitation

Addenbrookes Hospital

Rachel, and her colleague Dan Smith, will be talking about somatic (or somatosensory) tinnitus (ST). This is a subtype of subjective tinnitus, where changed somatosensory information from the cervical spine or jaw area causes or changes a patient's tinnitus perception.

Most of you will know Rachel either from Clinic 10 or from our meetings. But as well as her main role (see above). as a Specialist Audiologist she has extensive experience as the lead Audiologist for the tinnitus, teenage hearing services and single-sided deafness clinics. She also provides customised hearing protection and hearing therapy. Rachel worked with the International Nepal Fellowship to Nepal to provide Audiology support on one of their 'Ear Camps,' and also chairs the East of England professional tinnitus network.

Meadows Community Centre

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

(Link to directions to temporary C/P will be provided)

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EDITOR'S CHAT

May I belatedly wish all our members a very happy, safe and peaceful 2022. The pandemic has affected everyone in many different ways, but hopefully this year we will begin to see our lives recover to some form of, albeit altered, normality. It was so good to be back together in November at our annual self-help session. I think it was one of the best we have had, with everyone contributing to the mix of thoughts and opinions. We can now look forward to more 'proper' meetings this year, although currently we are still restricted on attendance at the Meadows. With luck more of you will be allowed to attend come our April meeting; let us hope! I hope you find something of interest in this month's newsletter; although I have to confess it was more difficult than usual to find suitable content to keep you interested. Cue here for my usual plea that it would nice if some of our members put pen to paper and wrote something about, or related to their tinnitus. After all, if one of our newest members contributed a piece in April 2021, why not you.

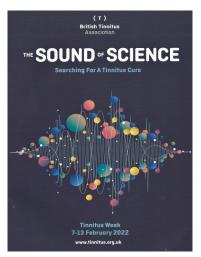
Thanks to David Stockdale for alerting me to the story of Gareth Malone's brush with tinnitus. This story can only help to increase the general public's awareness of tinnitus.

Tinnitus Week this year is 7-13 February, and the BTA have come up with a neat poster and a catchy title which is a play-on-words of the great 60s hit by Simon & Garfunkel (apologies to our younger members, or those who are not fans). At the time of writing the BTA haven't given any details beyond saying 'there will



Sue Peacock 'manning the fort' at Hinchingbrooke Hospital 2019

lots going on and different ways for you to get involved'; probably a lot involving social media. Although the Covid outlook is looking more positive (I hope that's not famous last words), a return to our usual CTSG promotional stand at Addenbrooke's won't be possible because of the current visiting restrictions. Although those 'awareness' sessions could be quite hard work, I personally found them very rewarding, and will miss the opportunity (for the third year on the trot) to talk to the public about their tinnitus experience.



Relationship between tinnitus and hyperacusis

Tinnitus increases the risk of also having hyperacusis, a study has found.

Having hyperacusis does not appear to contribute significantly to tinnitus severity, but having tinnitus contributes to the likelihood of having hyperacusis, a study found. In the study, about 6% of the respondents were classified as having hyperacusis. (Hyperacusis is a reduced tolerance and increased sensitivity to specific sounds and sound levels that are not normally regarded as loud.)

Tinnitus status

Of the respondents who completed the surveys in the study, 47% answered "Yes", while the rest of the respondents answered "No" (46%) or "Not sure" (7%)

to the question "Do you experience tinnitus, 'noise in the ears'?" Of those experiencing tinnitus, the 72% reported tinnitus perception in both ears.

Hearing loss

In the study, approximately 25% of the participants also reported having hearing loss, with most of them (18%) not being confident about their hearing loss status. The study did not examine the relationship between hearing loss and hyperacusis.

To investigate the association between the highly comorbid tinnitus and hyperacusis conditions, the study used questionnaires about tinnitus and hyperacusis. 616 persons, primarily students and staff at a large university, participated in the study which was published in the International Journal of Audiology.

JIM'S PIECE

I hope you were all able to enjoy a Covid-free Christmas with your loved ones. Although this whole Covid thing has been a curse, I think it has made us appreciate the things we have and encouraged us to live for, and make the most of, the moment. The future is always uncertain, but rather than be fearful let's focus on the present and keep positive.

On the personal front I will probably have retired by the time you read this, after 37 years working for the same high-tech software company. This is going to be a big change, but now I will have the freedom to spend my time as I choose. I'm planning to spend as much time as I can in the Dolomite mountains of northern Italy. It's always been my dream to live in or near the mountains, and these are some of the best. I'm busy learning Italian which should keep my brain ticking over, and I will be hiking up mountains to keep my body ticking over. I'll be spending time in the UK as well and will attend as many meetings as I can. Let's hope we can continue to have them face-to-face.

I hope you're all in good health and even better spirits, and wish you all the best for 2022.

Stay safe

Helping patients getting to grips with tinnitus

(Edited from her presentation by Dr Lucy Handscomb, Hearing Therapist, UCL Ear institute, London) at the BTA Virtual Conference 2020)

Lucy used this title because she thinks the whole aim of tinnitus therapy is to help patients to live with their condition in a more competent and skillful way. She introduced "Jack", a 35 year old working as a teaching assistant in a secondary school. A keen motorcyclist, he had a high frequency hearing loss and constant tinnitus for six years. He had bi-aural hearing aids (HAs) fitted two years ago, which he found useful for hearing but not perfect. He was also told they would help him with his tinnitus, which had enthused him, however he found they didn't help him. He was told by Audiology that this was unusual, and he should try them for a little longer; however he still found no improvement and was given no more suggestions to help him manage his tinnitus. This made him feel quite



Dr Lucy Handscomb

despondent.
Lucy met him when Jack
when he signed up to a 5
week course she runs at
City Lit college in London
called "Manage your
Tinnitus". This course had
no association with
hospitals or healthcare and
was funded purely by the
students.

This was the last course before Covid 19 intervened

in summer 2019, and had eight attendees including Jack. Before starting they all filled in the Tinnitus Functional index (TFI) questionnaire, and Jack scored 61%, which is relatively high.

At the end of the first class, Jack was clearly disappointed, expecting a quick fix ('my tinnitus is so bad that this isn't going to help'). She was doubtful whether he would return, but he did the second week, and over the next few weeks there were a few important turning points. The second week involved a talk about stress reduction, followed by a stress reduction exercise,

Jack became really involved, especially when the class discussed their stress points and how to alleviate them; particularly giving out suggestions rather than receiving them. The next week he said he had identified areas of stress within his life, was taking steps to improve the situation and felt things were improving.

Another turning point was in week 3, which involved everyone discussing negative thoughts. Lots of examples were discussed, but Jack thought there was nothing he could do about his own. Lucy then suggested trying to respond differently to these negative thoughts, rather than trying to stop them, and this idea chimed well with him. Week 4 involved listening to their tinnitus for 2 minutes; a powerful exercise, and it was only the fact that he was with others enabled Jack to participate. He didn't like it, but felt it might have changed his relationship with his noise a bit.

At the end of the course, Jack scored 40% on the TFI, a noticeable reduction. He was clearly much less anxious and upset, and felt better informed about his condition. Although he knew he had a long way to go, he felt he was heading in the right direction, and was glad he took part.

Learning points (picked up by Lucy)

- She reflected on the damaging effect of being told something should help, and when it doesn't, how confidence can be knocked.
- 2. Worth persisting with her approach; Jack's progress was gradual after a very difficult start.
- The value of having other people present in the same situation. Lucy felt that Jack with a one-toone with a therapist (without tinnitus), wouldn't have made the same progress. The class encouraged him and let him know he wasn't alone.

Professor David Baguley (our former president) catching up with tinnitus pioneer Jonathan Hazell on a chilly Norfolk day.

In the 90s, Pawel Jastreboff,* a Polish neuroscientist working in the USA and otologist Jonathan Hazell*, working with audiologist Jacqui Sheldrake, created a treatment called Tinnitus Retraining Therapy (TRT); essentially a mixture of education and counselling about tinnitus, together with sound therapy.

*Authors of the book: "Tinnitus Retraining Therapy: Implementing the Neurophysiological Model"



WIT of the NATION

• The length of a film should be directly related to the endurance of the human bladder. *Alfred Hitchcock* • It's not hard to understand modern art. If it hangs on a wall it's a painting, and if you can walk round it, it's a sculpture. *Tom Stoppard* • Acting is merely the art of keeping a large group of people from coughing. *Ralph Richardson* Fine art is that in which the hand, the head and the heart of a man go together. *John Ruskin* • History has remembered the kings and warriors because they destroyed; art has remembered the people because they created. *William Morris* • Lying in bed would be an altogether perfect and supreme experience if only one had a coloured pencil long enough to be able to draw on the ceiling. *G. K. Chesterton*

The 3 Best Tinnitus Remedies and 6 to Avoid

(edited from article in www.livingstrong.com January 2022) Neurotologist Dr Elina Kari, assistant professor of surgery at UC San Diego Health shares her thoughts on the do's and don'ts of tinnitus remedies.

Add Background Noise

One of the simplest way to help to live with your tinnitus is by avoiding silence. Turn on music, the TV, a fan or a white noise machine to distract you from your 'noise'. You can even get earplugs that emit a low level of white noise.

Try Meditation

If you are bothered by your tinnitus, it can lead to anxiety and stress which becomes a positive feed back; you have to break that cycle. Finding your zen is one way to do so. Emptying your mind in order to meditate, which can be stressful if you have tinnitus, but guided meditation is also helpful in managing tinnitus as well as improving your mood and sleep, and promoting a general state of wellbeing.

Get Enough Sleep

It's no surprise that tinnitus can affect your rest. After all, it's hard to snooze if you can't shut off the 'noise' in your ears. But it's worth the effort to get some solid shut-eye. Sleep loss leads to higher levels of the stress hormone cortisol, which can exacerbate tinnitus. Meditating at bedtime and having music etc. to listen to can help you reach dreamland sooner and sleep more deeply.

Avoiding certain foods

Although no specific foods or beverages have been scientifically-proven to worsen tinnitus, feel free to experiment and see if dietary changes have any

effect. Each case of tinnitus is individualized, so the contributing factors may differ from person to person. Generally caffeine is known to increase anxiety and excessive alcohol increase depression, which may impact on your tinnitus.

Ear drops

Ear drops won't do anything.

Jaw and Neck exercises

People with their temporo-mandibular joint (TMJ) problems are more likely to have tinnitus. A 2016 review found no high-quality evidence that jaw or neck exercises are effective.

What about Vitamins?

Vitamins D, B1, B2 (aka riboflavin) and B12 are often hailed as tinnitus cures. But before you pop a supplement, Dr Kali has never seen vitamin deficiency as a contributing factor for tinnitus.

• What about Lipoflavonoid?

Studies have shown that some of this family of antioxidants can be neurogenerative for the ear. Dr Kali's response is they are no better than eating an apple or choosing a salad for lunch. They are also expensive, and although side-effects are rare, a small 2016 study revealed that some people taking Lipoflavonoid for tinnitus reported problems, including stomach pain, bleeding and blurred vision.

Vick's VapoRub

Dr Kali thinks you should be careful of applying this to your ears in case of possible toxic effects.

The Marie and Jack Shapiro prize

The BTA are pleased to announce the award of the Marie and Jack Shapiro prize to a study that sought to investigate ways of increasing access to psychology-based tinnitus treatments. These have a strong evidence base for their effectiveness, and access to these treatments is patchy, so it is tremendous to see people thinking about new ways of delivering these interventions. This study provides both the clinical and research communities with a number of important learning points. These could help lead new research towards more effective accessible treatments for tinnitus.

The paper, "The TinMan study: feasibility trial of a psychologically- informed, audiologist-delivered manualised intervention for tinnitus" was led by Drs John Taylor and Dean Thompson from the NIHR Nottingham Biomedical Research Centre. Together with a team of patients, clinicians and researchers, they found that although the patients found the treatment acceptable and helpful, that will need to be addressed before it can be used in clinic.

The prize was judged by our Professional Advisors Committee, who commented that it was "A useful study to explore a newly emerging way of increasing access to psychologically-informed treatments for tinnitus. It is great to see robust feasibility studies being developed to explore how such approaches need to be designed and adapted and to consider if this type of intervention can be of use to patients. Although the findings may indicate that this approach has significant barriers, in the longer term, this type of work is likely to have an impact on how tinnitus care evolves".

Chief Investigator Dr Derek Hoare said, "On behalf of the team involved in this work, I would like to thank the BTA and say how delighted we are to be awarded this year's Shapiro prize. This work was funded by the NIHR and was a highly collaborative effort including patients and patient advocates, clinicians and researchers. Together we produced and tested a treatment manual that can be used by audiologists to provide psychological support for people with tinnitus. With a little more work, we plan to test the new treatment manual in a larger trial and make it ready for use in clinics".

David Stockdale, CEO of BTA, said: "There is currently no cure for tinnitus, but psychology-based treatments have a strong evidence base for their effectiveness. Access to these treatments is patchy and it is great to see people thinking about new ways of delivering these interventions."

The prize is named after the late Jack Shapiro, the founder of the BTA, and his wife Marie, (right) who both played an important role in the establishment of the charity and in raising awareness of tinnitus.



TV choirmaster Gareth Malone on how tinnitus made him 'panic' he was losing his hearing (Edited from *Newschain*) From David Stockdale via LinkedIn "Thanks to Gareth Malone for sharing his tinnitus story, and highlighting the importance of taking care of our hearing".

When Gareth Malone started hearing ringing sounds after recovering from a sinus infection, it took him a while to realise it was coming from inside his own ear. "There was a ringing in my right ear, really quiet and I didn't really notice at first. Then I kept thinking, 'I'm sure there's a fridge buzzing or something', just a very high-pitched squeak," recalls the TV choirmaster, 46. "Eventually, I turned all the electricals off in the house and thought, 'Ah ok, it's inside my ear'."

Tinnitus – when you hear sounds which have no external source – is actually quite common. About 30%

of people will experience it at some point, according to the BTA, with ca.13% of UK adults living with persistent tinnitus; however it's generally rare for tinnitus to be linked with serious underlying issues. For the London-born TV personality, who has been helping people hone their singing voices on shows such as The Choir since the mid-Noughties, his hearing is

arguably his most essential tool, and at the heart of his musical passions and identity (he also writes music and plays piano). So, as soon as he realised he had tinnitus, he went to see his doctor. A MRI scan and hearing tests followed, and thankfully, nothing sinister was found, and they confirmed he had lost very little of his hearing

For Malone, he feels lucky it didn't "impede my work or my life". "I've got other friends, who are musicians, that have damaged their hearing and that can be very distressing and difficult. It's there right now when I think about it, but most of the time, I just block it out. It took a while, but I've got used to it."

However, he admits: "I did panic at first and think, 'Is this the start of something?' And there was a period where I felt really angry about it." Malone says he'd always been "pretty careful about my hearing" – but acknowledges many of us aren't really aware of the risks of long-term hearing damage through exposure to loud noise, or just think these things will never

happen to us. "You hear a lot of people going, 'Oh my ears were ringing when I left the nightclub', but then think nothing of it and it goes away – but of course, that's a sign you're damaging your hearing."

"Tinnitus and hearing loss can have a big impact on your mental and emotional health," says Malone. "And the connection we get

with people through music – I think we've really seen that more than ever through particularly during the pandemic – that it's one of the things a lot of people have really missed." "Hearing also plays a core part in how we communicate, and that all-important sense of community and connection", say Malone.

Gareth is working with Specsavers to raise the importance of looking after our hearing.

JOKES

- A man goes into a remote Scottish pub and orders a whisky. 'That'll be 10 pence' says the landlord. 'That's cheap' says the man. 'A whisky would cost me over £2 pound in London.' 'Aye' says the landlord. 'But the folks here about willnae stand for prices like that.' 'The man takes his drink over to a table where two old men are playing dominoes. The man notices that neither of them has a glass. 'Why aren't you drinking' says the man. 'The prices are an absolute bargain.' One of the old boys says 'Well a Londoner might call them a bargain, but Hamish and I are waiting for Happy Hour.'
- The optimist says the glass is half full. The pessimist says the glass is half empty. The engineer says the glass is twice as big as it needs to be.
- What's the best way to kill a variety act? Go for the juggler. Boom Boom!
- The other day, my wife asked me to pass her lipstick, but I accidentally passed her a glue stick. She still isn't talking to me.
- What do you call a dinosaur with an extensive vocabulary? A thesaurus.

Michigan Tinnitus Device

A University of Michigan team led by Susan Shore, Ph.D., has developed the Michigan Tinnitus Device, a novel technology that alleviates tinnitus through a sequence of auditory and somatosensory stimuli to the face or neck. The treatment utilizes a stimulus protocol consisting of precisely timed sounds alternated with weak electrical pulses that activate touch-sensitive nerves, aimed at steering damaged nerve cells back to normal activity. The approach, called targeted bimodal auditory-somatosensory stimulation, shows promise in clinical trials.

Over the past decade, Dr Shore and her team of researchers have studied the contributions of multisensory systems to auditory processing. In particular, the lab discovered that somatosensory neurons in the brain, that receive input from the face and head, send neural projections to the auditory system. And these become hyperactive and synchronized with each other in guinea pigs and humans with tinnitus.

These projections terminate in the cochlear nucleus, which receives input directly from the cochlea. Their work has shown that these 'somatosensory' neurons can alter the cochlear nucleus response to sound. Most remarkably, after deafness, there is a strong enhancement in somatosensory influences on the cochlear nucleus, as if in compensation for the loss of input from the cochlea.

Cont. p6

Cont. from p5

An undesirable side effect of these somatosensory inputs, which are excitatory, is the development of tinnitus. The lab's past work demonstrated that in animals with tinnitus (tested behaviourally), the major change in the cochlear nucleus was increased



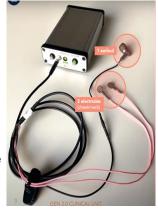
excitation from the somatosensory system. Work extending these findings is now focused on synaptic plasticity (process by which neuronal activity results in changes in the strength of connections (between neurons), as an underlying mechanism to explain the long-term nature of these changes. Ongoing work is laying the ground-

Dr Susan Shore

work for treatments that include specific, patterned stimulation that may reverse the increased excitation that contributes to tinnitus.

Fast forward to 09/21.....

Dr Susan Shore has set up a company called Auricle Inc. to market the Michigan Tinnitus Device (see picture). The official product description is: "A device that combines auditory frequencies and timed somatosensory stimuli to suppress tinnitus generating neurons that cause ringing in the ears. Auricle Inc. is a medical device venture (start-up) created to



commercialize Shore's tinnitus device and patents.

According to Jon Pearson, CEO and co-founder, " our device is nearly market-ready."

Tinnitus Talk Forum chat

I have mentioned this forum before, which features, among other things, a series of podcasts. They have interviewed some interesting people in the tinnitus world, including Dr Dirk de Ridder and David Stockdale CEO of the BTA.

For Xmas, they put out a couple of good news stories:

- 1. New treatments in the pipeline; some closer to market than others:
 - a. Professor Dirk de Ridder from the University of Otago Medical School in NZ is trialling the effect of the combination of ketamine and brain stimulation on tinnitus severity and distress (p. 5 June 21 Newsletter).
 - b. The Otonomy drug OTO 313 has entered Phase 1/2 trials. This is to determine the efficacy of the drug in subjects with single-sided tinnitus of at least moderate severity.

- A link to the abstract of the resulting paper:-(https://tinyurl.com/2p876st2).
- c. The treatment closest to market is probably Dr. Susan Shore's Michigan Tinnitus Device, which has been long awaited and is apparently nearly market-ready (see above and p.5).
- 2. More public awareness

There seems to be more awareness about tinnitus In the general public due to stories in the media. The donation of a \$1 million to tinnitus research by inXile founder, Brian Fargo, a very successful video game designer and programmer (company known as inXile) was one such story, and the news that the singer K T Tunstall had cancelled a series of concerts because of concern about her hearing loss and tinnitus also made headlines.

PS: And also the forum is 10 years old!



Another representation of tinnitus for you to look at and ponder.

WIT of INSULT

Auditors are the troops who watch a battle from the safety of a hillside and, when the battle is over, come down to count the dead and then bayonet the wounded. Anon

It represented the narrow and obscure taste of contemporary art mafia, out of touch with mainstream art and taste, obscure, self-serving and of dubious merit. Independent on Turner Prize

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. Reports and comments expressed in this newsletter do not necessarily reflect the views of CTSG.

Our next meeting is on Saturday 23 April at the Meadows Centre, where our speaker is Dr James Jackson, Reader in Psychology, from Leeds University. James will be talking about his involvement with the smartphone app Tinnibot.