

Cambs Tinnitus Support Group

No. 170

NEWSLETTER

February 2024

MEETING

Saturday 17 February

at

10.00 for 10.30 am

" How the OTO app can help those with tinnitus ".

Speaker: Anna Pugh
Therapy Lead
OTO

Anna Pugh is a highly experienced audiologist who has worked in the field for over 25 years. Anna has worked in a variety of settings, from private practices to large NHS trusts, and has gained a wealth of knowledge and experience. Anna is currently the Therapy Lead at Oto, an app-based tinnitus therapy service, and is also a Council Member of the British Society of Hearing Aid Audiologists (BSHAA). Anna has a keen interest in helping people to manage their hearing loss and tinnitus, and is passionate about making Oto the best possible service it can be.

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
(If details of the vehicle barrier entry protocol are required they will be sent out before the meeting)

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EDITOR'S CHAT

Belated greetings for a very happy and 'quiet' 2024. You will remember our June meeting when Dr James Jackson gave a superb talk on the use of mobile phone apps for people with tinnitus-in this case, Tinnibot. A lot of the programming covering mindfulness came out of his research. In February we get the chance to compare Tinnibot with another app called Oto, which Tinnitus UK (formerly BTA) has had an association with for a couple of years. Anna Pugh is the Therapy Lead for Oto, and will show how their app works, and possibly compare it with Tinnibot. These apps are becoming popular so come along and see how Oto works.

In our April 2023 newsletter we highlighted new research that was being undertaken by Dr Mehrmaz Shoushtarian of the Bionics Institute in Auckland, New Zealand. Her focus one of the major obstacles hampering tinnitus research - to find an objective way of measuring the condition. In this edition we highlight another research group being led by Dr Jason Mikiel-Hunter of Macquarie University of Sydney, Australia, who is using a different method to try and achieve the same aim.

The Marie & Jack Shapiro Prize (page 5) is given by Tinnitus UK to the piece of published research, by a UK based author, 'most likely to result in improved treatment or public awareness of tinnitus,' that is published in each calendar year. The prize is named after the late Jack Shapiro and his wife Marie, who both played an important role in the establishment of the charity and in raising awareness of tinnitus. This year's prize was won by Professor Frances Williams and her team.



Professor Frances Williams

I was not familiar with the term misophonia until it cropped up at our November self-help meeting. And then, by coincidence, I found two recent articles on the topic from different source and they appear on page 5.

The recent pandemic, and the transition of the BTA to Tinnitus UK are some of the reasons we haven't had a CTSG display during Tinnitus Week since 2020. We would have liked to put on a display at Addenbrookes this year, but it just didn't happen. Tinnitus UK have only just released dedicated posters and other information digitally, which hopefully we will be able to use next year. With luck, we will back for 2025!

I hope you find the newsletter interesting, and as ever, if you feel would like to contribute something, perhaps about your experiences of tinnitus? Any offering will be gratefully received.

Tinnitus Biomarkers & Therapeutic Targets

(Taken from an interview with Dr Daniel Polley by Tinnitus Hub)

Professor Daniel Polley, Director of Lauer Tinnitus Research Centre, Mass., USA was interviewed by the Tinnitus Hub, whose first question was, '*How well to animal models and tinnitus generally translate into human models.*'

I think the best way to think about what animals can do for tinnitus research is not to model the very complex, complete disorder of tinnitus, but rather to model a biomarker that is thought to be critical to the symptoms of the condition.

It is no longer really en vogue to say you have a mouse model of, say, autism, but rather there is a feature of it that's found in the brain of an autistic person, like an excitability feature or a certain circuit in the brain that is abnormal. And it is that abnormal mobility that you can model in a mouse.

The more complex behaviour and the sort of spectrum of mood, stress and perception that are a part of tinnitus, is, I think, implausibly modelled in a mouse. Even whether a mice can hear 'phantom sounds' is very much open to debate, and behavioural proof of tinnitus in a rodent is unconvincing to many people. What the animal models are great at is latching onto a biomarker that is seen in humans and showing that you can produce it in an animal, and then be able to drill down to cell types and the features that would be therapeutic targets. Animals do have a critical role to play in the search for an effective treatment for tinnitus, but more as modelling a biomarker and identifying therapeutic targets.

(Continued in next newsletter-Ed)

JIM'S PIECE

As I write, it has been extremely cold, and I've been wrapped up in many layers as I find it hard to deal with.

I hope you have been able to deal with this challenging weather, especially when venturing outside. Extremes of cold or heat can make it hard to think about anything else, as the discomfort seeps right into your body and mind.

It might feel unhelpful to say it's a just a state of mind, but in some ways it is, provided we're not getting hypothermia or severe sunburn ! As with any discomfort or pain the more attention we pay it, the worse it feels. I'm sure you know where I'm going with these thoughts! I have a busy life, even though I'm now retired, and fortunately I am unaware of my tinnitus until the rare moments when I stop ! Maybe I should do that more often, and practice meditation. That is another great technique for managing tinnitus. Have you had any success with that ?

I've just noticed that I wrote about the weather in my last piece ! I'll try and think of something different next time.

Apologies in advance that I will not be able to make the next meeting, which looks like it's going to be very good.

Wishing you all the best for 2024

Jim Infield
CTSG Chair

Developing a reliable objective measure of tinnitus

by Dr Jason Mikiel-Hunter, Macquarie University, Sydney, Australia

(Edited from *Quiet Magazine*)

Finding an audiological test that can objectively identify an individual with tinnitus, without needing people's self-reports of their sounds, remains a key goal of many audiologists and auditory researchers.

The usefulness of an objective measure could extend well beyond its ability to diagnose tinnitus: from improving our understanding of how these auditory illusions are generated in brains to identifying individuals who may be susceptible to more debilitating tinnitus in the future.

Furthermore, any tool that allows researchers to describe quantitatively how tinnitus is treated offers the prospect that novel therapies be introduced more quickly and effectively. Our work has been focused on how tinnitus affects auditory neurons in the early stages of the auditory system. By presenting click trains to individuals, we record auditory brainstem responses (ABRs) using non-invasive electroencephalogram (EEG).

The aim of our project is to determine whether artificial intelligence (AI) software can determine which ABRs come from individuals who have debilitating tinnitus. While our initial pilot study demonstrated that the AI

software had a high success rate of identifying these individuals, a larger, more inclusive dataset was required to train its machine-learning algorithm and validate its clinical merits.

Despite the impact of COVID, we have managed to acquire a large dataset for our test purposes, with the majority of our data coming from collaborators at Karolinska Institute who recorded ABRs from over 400 Swedish participants pre-COVID.

The dataset recorded at Macquarie University grows continually and after collecting data from the 25 participants all under the age of 35, we are now expanding our criteria to include older individuals with mild-to-moderate hearing loss and will be applying these data to test our AI diagnosis tool. In addition to the EEG recordings, our participants have also undergone common audiological tests, whose targets have been previously proposed as other tinnitus biomarkers.

The results of the Acoustic Reflex testing have proven particularly interesting in our young participants, pointing to decreased acoustic reflex recruitment with sound level in individuals who have tinnitus.

We hope to publish these results soon.

IMAGINARY WORDS

Flabotary: Research centre for diet products **Lunguini:** Pasta preferred by non-smokers **Spurghetti:** Cowboy pasta **Castroto:** A Cuban male with a high voice **Penvious:** Jealous of another writer's work **Scareenwriter:** An author of horror films **Countroversy:** Argument over Dracula **Violince:** A stringed instrument played with great passion **Nanachronism:** Granny attends a rave **Squintet:** Five longsighted singers **Paintaloons:** Outdoor sportswear on Mt. Fuji **Scabriolet:** A convertible driven across a picket line **Multitude:** A large number of stylish men **Pugeon:** Chubby bird

MARTIN'S UPDATE

It's been a while since I wrote anything for the newsletter and after last Saturday's support group open forum meeting, I thought I'd update my story/journey.

When I woke up the following Sunday morning I realised that my wake up routine had subtly changed. Many years ago, after consultation with Dr David Baguley, I started trying to better describe the different tinnitus sounds in my head. As mentioned in a previous newsletter, I had found 7 distinct sounds of which only 4 were ever resident at any one time. My usual wake up routine was to decide which 4 of the 7 were present, as an indicator of how my day might pan out.

This Sunday I realised that I'd stopped taking the sounds register and all that I "heard" were the two I'd described badly to Dr David all those years ago. I think I then had an epiphany. Stop at two, I can't use any more.

What had changed? As mentioned at the meeting, I have had a prostate problem that has been improved with an operation, so it no longer wakes me up in the night. When previously my tinnitus would then keep me awake, now it's the tinnitus that wakes me up. The upside being, I don't need to get out of bed. So what had changed? I've never really been patient enough with meditation and mindfulness routines to claim that they've had a direct benefit but subliminally I must have absorbed a quote I see every morning when leaving home. We have a little plaque by the front door with a quote by Reinhold Niebuhr:-

"God give us the serenity to accept what cannot be changed; the courage to change what should be changed, and the wisdom to distinguish one from the other."

Perhaps I've just accepted I have tinnitus and that getting help with things that can be treated is a better way to live.

I also think that Tinnitus UK, CTSG meetings and Alan's newsletters give hope that one day permanent relief will be found. With the current political climate, both at home and abroad increasing anxiety levels, even though we know we probably can't change things, I hope the photo on the right of a local busker puts a little smile on your face.



November meeting report

A damp start fortunately turned dry for those attending our November meeting, which comprised 25 members and two newcomers. We were again fortunate to have Rachel as our mentor again, as she really does make the session worthwhile.

First topic out of the blocks was somatosensory tinnitus, which Rachel explained was a complex topic, as we know from Matt Smith's excellent talk on the subject in February 2023. A subject that does require more research. Nerves in your spine send information (such as temperature etc.) to your jaw, neck and shoulders, and the nerve supply to the brain stem comes along the same pathway as your hearing nerve. As a result sometimes signals from the somatosensory system can interfere with the hearing nerve. This explains why sometimes movements such as pushing your jaw, chewing, or stretching when you yawn can alter your tinnitus.

Another question of a similar nature was pulsatile tinnitus. Rachel explained that this often involves disorders or malformation of the blood vessels and arteries, especially near the ears. A rhythmical noise (same as your heart rate), is down to blood flow (vascular). However pulsatile tinnitus is not normally vascular but can be somatosensory in origin.

The topic of ototoxic drugs and their potential to cause tinnitus was then discussed. This situation could occur during a potential operation, and also when medicines are prescribed, and doctors might be unaware of their potential to cause harm. Rachel mentioned that the doctors at Addenbrookes are well aware of this potential hazard and will get a patient's hearing checked before proceeding.

The possible effects of Covid regarding tinnitus was mentioned. Of those present some said it had made their 'sound' worse, but the majority had not been affected adversely.

Ways in which those present coped with their tinnitus were discussed, with each individual having a different approach. Most important is finding ways not to concentrate on it, by keeping busy, background music, relaxing etc. One member even suggested punching the hell out of a punchbag for 30 minutes to relieve their tension!

Sensitivity to noise and its effect on our tinnitus was another topic aired. Hyperacusis is condition whose effect varies from person to person. Some people have certain noises that they cannot stand - such as a whirring fan - while sometimes sudden sound ('flight and fight' reaction) that can be a problem. Misophonia was also mentioned, involving a strong negative reaction to certain triggering sounds [See the articles on page 5 of this newsletter – Ed].

Another topic which touched a 'communal' nerve was the perception, or lack of it, that people have of those with tinnitus (and/or deafness). Ignorance of the condition or an unsympathetic reaction can be a real problem leading to frustration on our part, which could make our tinnitus appear worse.

Hearing aids can be a real benefit to those with tinnitus, as it can help increase the input from outside relative to your 'inner' sound. We have had several examples within the group where hearing aids, when worn, have virtually eliminated the tinnitus sound. Rachel mentioned single-sided deafness with tinnitus can be a problem, as it can be difficult for the brain to work out which sounds are important.

Those present mentioned various other personal effects they have experienced: some can 'feel' their tinnitus, a sensation different from their tinnitus. Rachel says this is probably a middle ear problem, causing muscles to spasm ('butterfly effect'). The effect of changes in air pressure on tinnitus was also mentioned although few of us had experienced it. Apparently it can affect those with migraine.

The old favourite, wax in the ear, was discussed at some length. Rachel said that micro suction is by far the best removal method, however the downside is the equipment is bulky and expensive, and even some private clinics no longer provide the service. Theoretically it is available on the NHS, if you are lucky, but not that many clinics offer the service.

After an excellent session, and the raffle completed, we adjourned for our Bring & Share Brunch. This was a real treat after such a long break, due to the pandemic, and everyone tucked in to an amazing spread thanks to member's generosity. The mulled wine and mince pies had several eager for seconds!

- What's worse than finding a maggot in your apple? Finding half a maggot.
- How many ears did Davy Crockett have? Three - his left ear, his right ear and his wild front ear.
- Is it possible to be totally partial?

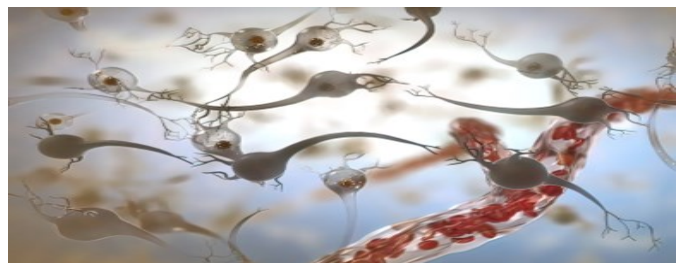
Basic science: Unravelling the mechanisms

Summary of one topic from last year's TRI conference in Dublin for Audiology Worldnews by Nic Wray

Brain Signals

One mechanism for tinnitus suggests that it is a result of neuronal activity not responding appropriately (maladaptive neural plasticity). One form of this is noise-induced reduction of cortical inhibition, where inhibitory neurons do not fully prevent other neurons firing messages. Shaowen Bao presented a neuroinflammation and neurodegeneration model of chronic tinnitus based on studies in mice and rats. TNF- α and calpain signalling pathways [associated with stress

response, cell death, and cell survival] appear to be involved in noise-induced tinnitus and that blocking them improved the tinnitus.



One in five people in the UK have Misphonia

(Taken from Quiet)

New research shows the scale of the burden of negative reactions to everyday sounds.

Misphonia describes an intense dislike or even a repulsion to a particular sound, often one generated by other people, such as chewing. These feelings can be very distressing, and people can feel powerful emotions, such as anger or panic, when they hear their trigger sounds.

Misphonia is a little researched condition, and it was unknown how many people experience it, until this study from King's College London. Study leader Dr D Vitoratou said "Most people with misphonia think they are alone, but they are not".

Chewing or snoring?

Participants in the study were asked about the sounds that they found triggering, such as chewing or snoring, and the impact of such sounds, as well as the type of emotional response participants felt to the sounds and the intensity of their emotions. The results revealed that more than 80% of participants had no particular

feelings towards sounds such as normal breathing or yawning. But more than three-quarters were bothered by sounds, including 'slurping', 'chewing gum', and 'sniffing'.

Emotional responses

However, Dr Vitoratou pointed out that not all those reporting a response had misphonia. "While there are lots of sounds that irritate many people, people with misphonia expressed different emotional responses," she said.

Although there is no definitive diagnosis of clinical misphonia disorder, the study concluded that 18.4% of participants experience misphonia to an extent that it was a significant burden on them.

While previously it was thought misphonia was more prevalent in females, the team found no difference by sex. The team is carrying out further research into the condition, including whether there are different types.

Mary & Jack Shapiro prize awarded for research into tinnitus genetics

(adapted from Tinnitus UK's website)

Tinnitus UK has announced the award of the Marie and Jack Shapiro Prize to a study that looked at a possible genetic component to tinnitus.

Teams based at King's College London and the Ear Institute, University College London using data from the UK Biobank found a number of interesting candidate genes which may be linked to tinnitus, notably the RCOR1 locus. The prize was judged by Tinnitus UK's Professional Advisers' Committee, who commented: "The authors of this study have used the records of over 170,000 participants in UK Biobank to identify a gene they newly link to the risk of developing tinnitus. Importantly, the gene was not linked to hearing loss, but seems to have an independent link to tinnitus. Future research on this gene might help to identify mechanisms of tinnitus or develop new treatments". Understanding the genetic factors underpinning tinnitus is one of the approaches we can use to identify the biological pathways of importance, and from this to develop targeted therapies.

The work was supported by a PhD studentship from the Royal National Institute for the Deaf and by NIHR funding to support the UCL Biomedical Research Centre.

The teams are indebted to the many volunteers at UK Biobank who gave so generously of their time and their samples and allowed research on large samples such as this to take place. We are building on this work by recruiting further cohorts and hope to expand our understanding of the genetics of tinnitus in the near future."

Deanne Thomas, Chief Executive of Tinnitus UK, said: "We're delighted to award the Marie and Jack Shapiro Prize to this useful study. This project's findings were very interesting and indicate that there are possible genetic risk factors for developing tinnitus. The study shows the potential benefits that a dedicated Tinnitus Biobank could bring, allowing us to understand the condition much better and answer many other questions that, thanks to chronic underinvestment, so far remain unanswered."

Professor Frances Williams, King's College London said: "The teams at Twin Research, King's College London and the Ear Institute, University College London are really delighted to be awarded the Shapiro prize by Tinnitus UK for our collaborative work on the genetics of tinnitus.

Misophonia research is Taking Off

(Opening extract for article in *Psychology Today*)

Misophonia research has increased dramatically over the last five years.

On May 16, 2023, an all-day online event entitled CARE for Misophonia took place. CARE stands for Conversations about Research for Everyone, and this title perfectly reflected the goals of the event, in which scientific information was presented in highly understandable ways.

Often conferences are for researchers to see the work of colleagues. This event went beyond that and focused on presenters communicating with those with misophonia and their families. Zach Rosenthal of the Duke Centre for Misophonia and Emotion Regulation (CMER,

along with the organizations such as soQuiet and the International Misophonia Research Network formed a planning committee including international misophonia advocacy groups, and invited moderators who helped ensure that attendees' questions were answered.

What is so exciting about the research? I will try to highlight as much of the work as I am able in a short post, but I encourage you to view the event for yourself and draw your own conclusions.

[For full article see <http://tinyurl.com/rv2p65z5> - Ed]

Basic science: Unravelling the mechanisms

Summaries of another two topics at last year's TRI conference in Dublin for Audiology Worldnews by Nic Wray

Sound Therapies

Sound therapies are still attracting attention, and progress is being made in characterising those people who are likely to respond. Novel apps are also being used to deliver sound therapy, and results were shared from two studies. One study from the University of Newcastle reported promising results from phase-modulated online sounds.

Another study from the team at Widex PureSound™ showed that tinnitus patients who used sound therapy for more hours a day than others, had improved outcomes. Those that listened to fractal tones (unpredictable harmonic and melodic tones) had a greater improvement in Tinnitus Handicap Inventory (THI) scores over those who used nature sounds, or a combination of nature and fractal sounds.

Computational modelling

Computational models of tinnitus use digital simulations to allow researchers to investigate their hypotheses. As modelling learns and refines its models, these may help bring together findings from different studies and help categorise potential sub-types of tinnitus.

As each tinnitus sub-type may respond to treatments in a different way, studies on a homogeneous rather than a heterogeneous cohort (people with a shared characteristics) may identify more effective treatments. Additionally, the use of computational modelling in developing personalised management techniques shows promising potential.

CHUCKLES

- One of the airlines recently introduced special half-fare rates for wives accompanying their husbands on business trips. Anticipating some valuable testimonials, the airlines sent out letters to all the businessman's wives who used the special rates, asking how they enjoyed their trip. Responses are still pouring in, asking, 'What trip?....'
- A man always buys his wife anemones on her birthday, but one day he goes to the florist to get one, only to find that they have run out. There's no time to go anywhere else so the man buys the only plant they've got left, a large fern. As luck would have it his wife is delighted by the gift. 'With fronds like these,' she says. 'Who needs anemones.'

The Alexander Technique and tinnitus

Every day brings with it many challenges that lead to the accumulation of stress, adversely affecting both the mind and body. Sometimes all you need is time to relax and ease the stressors that exacerbate your tinnitus. By incorporating relaxation techniques into your daily routine, you can improve your quality of life. Making the time to practice a few relaxation techniques throughout the day can make all the difference.

The Alexander technique is a way to feel better and move in a more relaxed and comfortable way. This technique allows the muscles around the head, neck, and back to work in a coordinated and free manner, and helps to relieve tension that has built up in those muscles.

In the 1930's, Fredrick Alexander (from which the technique takes its name) believed that a majority of physical ailments, including tinnitus, were caused by the misuse of our muscular skeletal system. Practitioners say it does work and would certainly help in cases of Temporomandibular Joint (TMJ), pinched nerves, stressed face muscles and overall stress all of which can affect sound in our ears. It is not an easy technique to learn, and takes a lot of effort (similar to that needed work like learning Tinnitus Retraining Therapy (TRT). Incidentally, It is a technique practiced by many classical musicians.

[We tried to get a practitioner to talk to us in 2024, unfortunately without success - Ed]

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 alanyeo70@gmail)

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 20 April at the Meadows Community Centre, where Dr Kathryn Fackrell will give a talk entitled " An update on my tinnitus and hyperacusis research". Kathryn has talked to us before, and her talks are always very interesting. Don't miss the opportunity to listen to an established tinnitus and hyperacusis researcher.