Cambs Tinnitus Support Group

No. 171 NEWSLETTER April 2024

MEETING

Saturday 17 April 20

at

10.00 for 10.30 am

" An update on my tinnitus and hyperacusis research"

Speaker: **Dr Kathryn Fackrell**
Research Fellow (Tinnitus and Hyperacusis),
National Research Institute for Health Research,
Nottingham Biomedical Research Centre (NBRC)

Kathryn is a Senior Research Fellow leading a programme of research in hyperacusis at the NIHR Nottingham Biomedical Research Centre (BRC). She studied at Nottingham Trent University achieving a first-class BSc (Hons) degree in Psychology, before completing her PhD on measuring tinnitus and evaluating outcome measurement tools in 2016 at the University of Nottingham. She has continued to work in tinnitus and hyperacusis, working closely with clinicians, patients and academic colleagues to explore new measurement techniques, improve knowledge and establish standards in measurement for tinnitus and hyperacusis. From May 2017 to July 2018, Kathryn lead and co-ordinated the James Lind Alliance Priority Setting Partnership for hyperacusis to identify the top research priorities for hyperacusis. In 2018, Kathryn successfully obtained an NIHR Post-doctoral Research Fellow award to develop a digital intervention to provide self-help, understanding and support for hyperacusis (iSHUSH). She is also working with researchers from University College London and Manchester BRC to deliver an DHSC/NHS England Research Action Plan for Hearing Loss and Tinnitus.

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
(Details of the vehicle barrier entry protocol will be sent out before the meeting)
NB: Other free parking is available in St Albans Road. Turn R out of car park, St Albans Rd is next R.
Parking is free and the Centre is just across the green space

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Refreshments and Raffle

EDITOR'S CHAT

You will have read the very good news from my covering e-mail that the potential threat of having to pay car-parking charges at the Meadows Centre has been lifted. It has been a worrying time for your committee, and particularly for your hon. sec., who was faced with the prospect of having to find another venue. The term 'weight off the shoulders' comes to mind! Things are still not perfect at the Meadows - we are still waiting for neck and hand mikes to be plumbed into the loop system - but I believe that they are on their way.

You may have read recently that Caroline Savage, the recently appointed Chief Executive at Tinnitus UK, left the organisation in February. Caroline headed the organisation through a period of substantial change leading to the rebranding from the British Tinnitus Association last year, and secured some of the largest grants in the charity's history. Hot off the press - 20th March - Robin Greenwood is the new interim CEO who will lead the team while a permanent CEO is recruited. Robin has a strong track record of leadership within the charity sector having served as a CEO, trustee and senior executive in his previous career.

If you were watching Sunday's BBC's Breakfast on 4th February, then you had a treat, because Dr James Jackson was on the couch to talk about Tinnitus Week 2024. According to Nic Wray, Tinnitus UK's communication's manager, who was listening 'down the line', she was just blown away and said, "I know he is a great speaker, but I've heard him at conferences with his 'professional' hat on, but this was something altogether more personal and had a big impact. I think it will have really resonated with people." Unfortunately, I missed it, and also missed it on iPlayer. James then flew off to give 3 lectures at a conference in South Africa!

Revealing the struggle for silence - from Tinnitus UK

- Tinnitus impacts 1 in 7 adults in the UK and severely diminishes the quality of life for 1 in 6 of those individuals.
- In December 2023, we conducted a study involving 478 people living with tinnitus to delve into your experiences and the challenges you encounter in accessing healthcare support for the condition. The findings were frankly distressing but backed up by what we're hearing from you via our helpline and support services:
- Over one in five respondents to our survey experienced thoughts of suicide or self-harm in the last year.
- More than 8 out of 10 reported low mood or anxiety, with 7 out of 10 feeling hopeless or helpless. 85.7% reported sleep disturbances.
- The emotional toll is significant, with 68.4% reporting low self-esteem and 54.9% struggling to think rationally.
- Tinnitus is also linked to social isolation, impacting relationships and daily life, with two-thirds of respondents avoiding contact with friends, minimising social activities, or facing difficulties at work.

Summary of Report released during Tinnitus Week 2024

- Despite NICE guidelines introduced in March 2020, substantial challenges persist in healthcare support for those with tinnitus.
- Referrals to secondary care decreased to 57.9%, with 11.7% not offered a referral.
- Waiting times for secondary care appointments have increased, with the number of people waiting over a year tripling from 2019 to 2023, to 1 in 6 facing waits of more than 12 months.
- Limited mental health support is available, with only 5% offered Cognitive Behavioural Therapy (CBT).
- In response to these alarming findings, we're calling for immediate action.
- An evaluation of secondary care services and increased investment from commissioning bodies where necessary.
- Implementation of a standardized nationwide management model for tinnitus.
- Increased tinnitus education for medical professionals.

JIM'S PIECE

I hope you are enjoying this edition of our newsletter. Is it something you look forward to reading ? There is a wealth of information, and always a good summary of our last speaker in case you missed the meeting, or a helpful recap if you did attend. The amusing quotes Alan discovers always make me smile, and lighten the sometimes heavy reading material. Over the years I've learned so much from our varied and knowledgeable speakers. It takes a lot of effort behind the scenes to find them and arrange their visit, and we can be enormously grateful to Alan and Rachel for the work they put into this, as well as the speakers themselves for making the time to travel all the way to Cambridge. The information they impart and the interest they generate make our meetings so much richer than just a social gathering.

Being an engineer who likes to know how things work, and solving problems when they don't, it is very important to understand what is going on when I have a body malfunction. I was privileged, as many of us were, to have met Dr Baguley who explained it so well. Today, we are very fortunate to have Rachel, Head of Adult Auditory Rehabilitation at Addenbrookes, so actively involved with the group, and she is the one who now helps people to understand the possible mechanisms behind their newly developed tinnitus.

The Newsletters are a great resource and if you want to read older copies, they are available from our CTSG website here, under the 'About Us' tab (https://www.cambstsg.com/members-newsletters).

Apologies for missing the April meeting, which I am frustrated to miss as it looks like a good one. Enjoy !

Spring is in the air, and the cold of winter is mostly behind us.

Jim Infield
CTSG Chair

February Meeting Report by Alan Yeo

Anna began by confessing that her tinnitus was going 'a bit bananas' as result of her hectic search trying to find our venue. All due to Arbury Rd being closed shortly before the meeting, which bamboozled her car's sat. nav. As she said, the worst thing for tinnitus is stress, and this was a classic example!

She has been a hearing therapist and audiologist for 40 years and had tinnitus in both ears for 25. Hers was a result of a mugger attack in London which resulted in a head injury that damaged her cochlea. Although a hearing therapist for about 15 years, she found that all the things that were supposed to help, didn't. Her 'light bulb' moment came when she heard a neurologist say that the brain sees tinnitus as it does pain. Familiar with pain management, this led via a pain specialist to a research paper on phantom limb pain (PLP), which compared the neurological network associated with PLP with the similar network associated with tinnitus. She realised that that tinnitus affects us as a whole, and therefore one type of therapy is unlikely to be sufficient. Shortly before lockdown, fortuitously she was approached by two ex-military doctors (Edmund Farrar and George Leidig), both with tinnitus, who were looking to develop an app. to help people with the condition. Their work together was to result in the app. called Oto.

Our speaker at work!

How can Oto help you?

No special kit is required, just a mobile phone. All material used in the app is evidence-based and proven. The NICE guidelines show that there only two tinnitus treatment pathways that are proven; hearing aids, if associated with hearing loss, and counselling/therapy. The app is not cheap, although a lot cheaper that using a private therapist, or a local authority paying a therapist. It is a new way of thinking about tinnitus, and the reason is you control it, choosing which bits of the therapy work for you. There is a pathway consisting of a spiral curriculum format, and you will find exercises that work for you as you progress, rather than a rigid structure.

The Therapy - their blended approach

Based on person centred principles, Oto's blended approach draws from the best practice currently available in counselling to help people to regain a sense of ownership and control over a condition which is often uncontrollable.

All the main therapies the app uses are based on Cognitive Behavioural Therapy (CBT), which neurological research shows is that what you feel and what you think can really influence how you behave and respond, particularly with tinnitus. The more we concentrate on our 'noise', the worse it seems to become (vicious circle etc.), and this is probably because our brain doesn't necessarily recognise the difference between what we are feeling and what we are thinking.

Therapies that are used

Tinnitus Retraining Therapy (TRT), because it is fundamentally important, involving counselling and sound therapy to train your brain to ignore your tinnitus.

Other therapies used include:

Cognitive Behavioural Therapy (CBT) - thinking differently, challenging your thoughts. Acceptance and Commitment Therapy (ACT) – rather than keep fighting, let go of the rope. Dialectical Behavioural Therapy (DBT) – changing the language you use, and the way you think. Relational Frame Therapy (RFT) - says that humans can create links between concepts, words and images and that this is an essential building block of the human ability to connect.

Other therapies in the app

Somatic therapy is therapy for the body – when we are stressed it's a human trait to hold ourselves to gain comfort, but if we do stretching exercises it can help release the tension.

Sleep therapy is a major issue. We all have a sleep cycle and if this is interrupted then we are not properly rested, making it difficult to resume the cycle. A sleep management programme is included.

Breathwork is also fundamental to helping us cope with tension etc. It has been proved that the CO2/02 exchange is vital in managing the flight and fight response in the brain, and Anna always recommends breathwork as the starting point.

Mindfulness is a newer concept which consists of two strands. With the first you spend all our time trying to distract ourselves and ignore the tinnitus. The other strand is newer, and slightly controversial, in that you listen to your tinnitus, and see where it takes you. It's hard, and counterintuitive, but works for some people.

Loss Therapy is about having a sense of self, a sense of awareness and change; that we are not necessarily the people we once were.

Other concepts

Self-kindness – traditionally we aren't very good at looking after or taking care of ourselves. There are comfort exercises on the app.

Person – about finding coping strategies from previous experiences to combat your tinnitus.

Journalling - Spend a few minutes each evening to write down/record a list of small wins/little victories you have claimed over your tinnitus during the day. It can also be therapeutic to talk about them as well.

Sisu (Norwegian) – about inner resilience. Bragging about climbing a mountain or completing a severe challenge.

Kintsugi (Japanese) – literally 'repairing broken

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ceramics.' They guild the cracks with gold, ending with a beautiful new object. Likewise with tinnitus, although 'broken' we can still be ourselves. This one of Anna's favourite concepts.

Other exercises in the app.

There's lots about tinnitus, hearing, how your ears work etc. Aspects of sound therapy, such as distraction, notch, noise, comfort, binaural beat and sleep stories (You will need to try the app. to get more details!) and also mindfulness exercises as well.

Oto are very proud of their spatial sound refocusing exercises, which are unique to the app. Using headphones you train yourself to listen to other sounds (birdsong, traffic etc.) than your tinnitus. Anna was very keen to see this included in the app.

Imagineering comes from a programme called visualization used by pain therapists. Anna can visualize her tinnitus has a big orange ball in front of her, which she imagines gradually getting smaller and eventually disappearing. This concept is extremely difficult to master, and takes a lot of practice. And like most ideas involving tinnitus, doesn't work for everyone.

Cost

Subscription based	Free 7 day trial
£107.99 for three months	www.joinoto.com

After her talk Anna spent a lot of time answering the numerous questions and she was giving a well - earned round of applause. She was an excellent speaker, and I hope she will come and talk to us in the future about her role as a hearing therapist.

[*If anyone has tried, or are thinking of trying the app. in the future I would love to have your feedback*—Ed]

CHEAP SHOTS

• The right honourable gentleman is reminiscent of a poker. The only difference is that a poker gives off the occasional signs of warmth. *Benjamin Disraeli on Robert Peel* • He couldn't see a belt without hitting below it. *Margot Asquith on David Lloyd George* • Only dull people are brilliant at breakfast. *Oscar Wilde* • Why don't you write books that people can read? *Nora Joyce to her husband James Joyce* • He would kill his own mother just so that he could use her skin to make a drum to beat his own praises. *Margot Asquith on Winston Churchill*

Blanking out that awful buzz with a tinnitus therapy chatbot. (Edited from a Sunday Times piece by John Fullerton)

"You are not alone." My iPhone is speaking to me in a friendly female Australian accent. "You're capable of overcoming anything you set your mind to, so take your time, don't give up, and if you are patient with yourself, progress will come." Along with this calming voice, I'm hearing a high frequency - ringing, like a television on standby. It isn't coming from my iPhone though. I have been hearing it for 20 (many) years, a never ending Eeeeeeeeeeeeeee…….

I've had tinnitus since I was 21, a condition that means you hear "phantom" noise not created by external sources. It is often a constant ringing but for some it's a hum, whoosh or buzz etc. It can arise from injury and trauma, but is more often caused by exposure to loud noise, from machinery to gunfire to Guns N' Roses.

In my case, it was primarily the latter; I didn't even know what tinnitus was until I had it. As a student in the early 2000s, I went to rock gigs every week and I assumed it was normal for my ears to ring afterwards, like an oral hangover. That ringing was your body telling you it was damaged," an audiologist told me when it didn't subside.

So I was heartened by recent news that a tinnitus therapy app called MindEar, based on cognitive behavioural therapy (CBT), has been shown to decrease distress caused by tinnitus among participants in a study published in the journal Frontiers in Audiology and Otology. The app uses a chatbot called Tinnibot to deliver the therapy, which can help to manage the distress by "rewiring" your brain to stop associating tinnitus with stress. The 14 participants in the study used the app for 10 minutes a day for 16 weeks, after which nine of them showed a clinically significant decrease in the distress caused by their tinnitus.

Tinnitus is thought to start when tiny hair like structures called cilia, found on auditory cells in the inner ear, become damaged by injury or prolonged exposure to loud noise, affecting the signal they send to the brain.

The signals are interpreted by the brain as sound, and researchers believe that if cilia stop sending these signals, the brain may adjust itself to try and make up for the lost perceived sound.

Most of us go about our lives exposing our ears, which have not evolved to deal properly with amplified sound, or the racket of modern life. It is the equivalent of staring at the sun, but we aren't aware of the danger. I bought professional - level ear plugs for gigs and suddenly became tuned into just how abnormally loud modern life actually is.

Dr Fabrice Bardy, the co-founder of MindEar, agrees the lack of public awareness of tinnitus is a problem and suggests school children be taught about noise damage. It is, after all, biology. Many older people have tinnitus and it has been linked to deafness and early-onset dementia.

It took me years to fully accept the condition and learn to not panic when it flares. I've found the most effective way to deal with it is to distract myself from my noise. On a busy day, I might not notice the phantom sound once. But on quiet Sunday mornings, ears roaring, I've fantasised about my tinnitus as a ball of light, which I pull from my head and bury in a graveyard. On days like these I use a sound app that chirps like a cricket and turn it up until it is louder than the ghost wasp in my head.

Dr Bardy believes there could one day be a cure, possibly using drugs, "But not in the next five years or so," he cautions. "There's work being done on the regeneration of hair cells. By using digital therapeutics now, we'll better understand the complexity of tinnitus.

Until the cure arrives, I'll keep chatting to Tinnibot.

Current perspectives of tinnitus and its management (From ENT and audiology)

by Don McFerran, Marc Fagelson and Gerhard Andersson

Tinnitus - *the perception of sound in the absence of an external source - continues to intrigue, perplex, and infuriate clinicians, researchers and those with the condition. The authors here present an overview of the current approaches to tinnitus.*

Whilst there are various therapeutic options for easing the impact of tinnitus, there is no current approved treatment for eradicating, or even for reducing, the loudness of tinnitus. Various reasons have been suggested to try and explain why searching for a tinnitus cure has proved so unproductive.

The pathophysiology (the study of abnormal changes in body functions that are the causes, consequences, or concomitants of disease processes) is incompletely understood, and the size of the problem is unclear. Prevalence estimates have varied from 5% to 42% of the population; there are multiple subtypes of tinnitus; animal models exist but research using these models often fails to translate to human tinnitus; there is no objective way of measuring tinnitus and no known biomarker for the condition; even the definition of tinnitus has come in for criticism. Modern research has clarified some of these areas but there are still many questions to be answered.

Epidemiology and big data

The ability to collect, manipulate and analyse large quantities of data has improved enormously over the last quarter of the century, and these skills have been adopted by tinnitus researchers. Exploring the heterogeneity of tinnitus requires studying the characteristics of large numbers of those with tinnitus. Some work has been done using existing general biobanks, but tinnitus-relevant information is often lacking in these resources. Use of big data is also helping to produce more accurate estimates of tinnitus prevalence and incidence, and is allowing us to better explore the association of tinnitus with other medical conditions. Development of large-scale clinical databases and/or tinnitus-specific biobanks is urgently required.

(See this topic on the Tinnitus UK website - reference:- http://tinytinyurl.com/3kfwz2tv).

Positive causal associations (the stronger the association between a risk factor and outcome, the more likely the relationship is to be causal) were found for various hearing-related factors and several non-otological (ear-related) risk factors including temporo-mandibular joint disorder (TMJ), depression, chronic obstructive pulmonary disease, and hyperlipidaemia (high-cholesterol). Negative, possibly protective, associations were found for diabetes and high alcohol consumption. No associations were found for low alcohol consumption, body mass index, head injury, heart failure, hypertension, leisure noise exposure, migraine, rheumatoid arthritis, sex, smoking, stroke, and whiplash.

(*continued in the June newsletter* - Ed)

CHUCKLES

- An ageing playboy visits his doctor after a lifetime of wine, women and song. 'Well,' says the doctor. 'The good news is that you don't have to give up singing.'
- Boy, to father, 'Daddy, why does Grandma spend so much time reading the Bible?' Father, 'Shhh, son, she's cramming for her finals.'
- Remember that age and treachery will always triumph over youth and ability.
- She asked a famous artist if he would paint her in the nude. He said that's fine, but he would have to leave his socks on otherwise he'd have nowhere to put his brushes.
- Have you heard of the Viagra computer virus? It turns your 3½" floppy into a hard disc.
- A writer sends his manuscript to a publisher with a note saying, 'None of the characters in the story bear any resemblance to any person, living or dead.' The publisher sends back the book with a note saying, 'That's the problem with it.'
- Thousands of years ago cats were worshipped as gods. Cats have never forgotten this.

BATTY BOOKS

- Challenging Uncertainty – by R U Shaw
- Keeping Caged Birds – by Ken Airey
- Eating Cheap – by Roland Marge
- The Expectant Bride – by Marius Ina Hurrie
- Dealing with Alcoholism – by Carrie M Home
- Sailing for Beginners – by Abal C Man
- The Haunted House - by Hugo First

Two more topics from last year's TRI conference in Dublin for *Audiology Worldnews* summarised by Nic Wray

Cognitive Behaviour Therapy CBT is often cited as the most efficacious of current tinnitus treatments, but access to this form of treatment can be limited in availability or expensive to access. Gerhard Andersson provided an overview of the research into internet-based CBT conducted in different countries and concluded that the early positive findings from Sweden (2008, 2016, 2018 and 2022) have been replicated, and that internet-based CBT has an effect in reducing tinnitus distress. As internet-based CBT can be delivered to greater numbers at reduced cost, this mean that more people can be helped. Similarly, the teams behind mobile 'apps' which use a CBT– based component, such as Tinnibot, Oto and SilentCloud, claimed that using these apps have also shown positive results.

Sleep & Tinnitus It is known that tinnitus can impact on sleep quality. However, Robin Guillard demonstrated that napping may also increase tinnitus loudness upon wakening, and that this is related to nap-time duration. Whilst napping may exacerbate tinnitus, a study from Hasselt University showed that people who undertook vigorous or moderate physical activity were a lot less likely to experience tinnitus, and that this risk reduced with every hour of physical activity. However, sitting for more than seven hours per day increased the risk of tinnitus by 92.1%. Smoking, ageing, an increase in BMI and noise exposure also increased the likelihood of developing tinnitus. Understanding these lifestyle factors will contribute to developing tailored strategies for individuals with tinnitus and hopefully lead to better outcomes.

Tinnitus Biomarkers & Therapeutic Targets cont.

Professor Daniel Polley, Director of Lauer Tinnitus Research Centre, Mass., USA, continues his interview with the Tinnitus Hub answering this question:
"What do you think could be appropriate therapeutic targets to investigate more deeply for tinnitus"

Well there is an ocean of possibilities and options, that's for sure. But if you look at where the points of consensus are in the field, there is a lot of folks who buy into the idea that there is a loss of input from the air as a triggering feature in tinnitus. That doesn't always show up on an audiogram, but is sort of occult or hidden. And it can be seen with some types of measurements, or inferred through some types of measurements, but that loss of afferent channels that convey acoustic signals from the ear to the brain, sets up problems in the brain.

And that if you were to regenerate those afferent transmission channels through synapse (the space between a nerve cell another cell) repair, you could turn down or eliminate the phantom percept. I'm certain the evidence from cochlear implant recipients who have tinnitus shows good, strong evidence for boosting the peripheral signals as one way to turn down the amplifier and get rid of the tinnitus.

Secondly, there is broad consensus that some important aspects of the tinnitus pathology is related to hyper-excitability or hyper-synchrony, which are themselves sort of byproducts of reduced inhibition. So, finding ways to reinvigorate inhibition would be a really important target, or the flip side would be to reduce hyperactivity. So, like the work on potassium channel modulators and intrinsic excitability, all those seem like worthwhile targets.

But for the third area, I think it is important to remember that the burden of tinnitus is not highly correlated to whether you hear the phantom sound or not. There are a lot of people that have a tinnitus percept. I have tinnitus myself, and I'm among the fortunate in that it doesn't really bother me.

For others it can be debilitating. And all these things we are talking about, that we researchers are keen on studying, don't really relate to how disruptive tinnitus can be in life.

It's all very upstream, very early, looked on as a purely audiological disorder. But for people who do experience mood dysregulation, anxiety and so forth, there is another important target. I think the problem is that the things that we measure in animals and humans are less related to burden, even though burden is the sort of outcome that the clinicians and the patients care most about. So I think that's a really important area of research.

Did COVID-19 make tinnitus worse? (Edited from study in J. of the American Academy of Audiology)

Researchers compare patients with tinnitus before and during the pandemic

Researchers from Florida Atlantic University, the Royal Surrey NHS Foundation Trust in the United Kingdom, and the University of Cambridge conducted a study that focused on the potential indirect effects of COVID-19 on the experience of tinnitus. They assessed whether the severity of tinnitus, as measured using ratings of tinnitus loudness, annoyance, and effect on life, was influenced by the lockdown related to pandemic.

For the study, researchers compared two independent groups of new patients; one group assessed during three months of lockdown in the United Kingdom and one group assessed during the same period in the preceding year. They examined patients' pure-tone audiometry, and their score on visual analogue scale (VAS) of tinnitus loudness, annoyance, and effect on life, which were imported from their records. Researchers compared VAS ratings from both groups. All patients were seeking help for their tinnitus for the first time.

Many people impacted by COVID-19 experienced changes in their sense of smell, taste, hearing, balance and in some cases, tinnitus. Among the various causes of tinnitus is stress; what is unclear, however, is whether the psychological impacts of the pandemic such as stress actually worsened tinnitus. Results do not support the idea that the pandemic led to a worsening of tinnitus and the mean scores did not differ significantly for the groups seen prior to the pandemic and during lockdown.

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** 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.

Our next meeting is on Saturday 15 June at the Meadows Community Centre, where we welcome Dr Manohar Bance, ENT specialist. He is one of the UK's top otologists, so this is one meeting you do not want to miss.