Cambs Tinnitus Support Group

No. 177 NEWSLETTER September 2025

MEETING

Saturday 20th September 2025

at

10.00 for 10.30 am

" Our tinnitus and hyperacusis research update "

Speaker: Dr Kathryn Fackrell
National Research Institute for Health Research
Nottingham Biomedical Research Centre (NBRC)

Kathryn has a first-class BSc (Hons) degree in Psychology from Nottingham Trent University. She started her translational hearing research career when she completed a summer internship working on tinnitus research. Since then she has continued to work with the tinnitus and hyperacusis team, working closely with clinicians and academic colleagues and gaining her PhD in tinnitus outcome measurement from the University of Nottingham in 2015.
In May 2017 Kathryn initiated the James Lind Alliance Priority Setting Partnership for hyperacusis with colleagues at NBRC (Dr Derek Hoare) and the patient representatives to identify the top priorities in research. Their research aims to explore new treatments, measurement and to look at how to maximise the benefits of current NHS Management options.

New Meadows Community Centre

299 Arbury Road, Cambridge, CB4 2JL

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

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Refreshment & Raffle

EDITOR'S CHAT

In May Danny Knight, Tinnitus UK's partnerships manager, was on the 'red couch' at the BBC and explained that Dr Will Sedley from Newcastle University had been doing some revolutionary work to try and help combat early onset tinnitus. This work was featured in a short BBC video which can be accessed via the Tinnitus UK website. An outline of this study is given below.

'Chronic tinnitus has to start somewhere, and we believe that this initial period when tinnitus first begins may hold a lot of insight into the causes and mechanisms of the condition, which may become all but undetectable once the tinnitus has become chronic.

In this innovative research study, funded by Tinnitus UK and RNID, we are studying volunteers whose tinnitus began less than four weeks ago, and comparing the results obtained to matched groups of people without tinnitus at all, or with chronic tinnitus, and also to the same individuals after six months, once their tinnitus has become chronic. This ability to study the same individuals at multiple time points of their tinnitus course is particularly powerful. We are taking a variety of measures, including tinnitus symptoms, perception of external sounds, resting-state brain activity, and brain responses to sounds at frequencies similar to, and different to, individuals' tinnitus. The first study is nearing completion, with all participants already studied for their first set of measurements, and the new-onset tinnitus group are mid-way through returning for their repeat testing after 6 months from tinnitus onset.

We will present preliminary findings at the Tinnitus Research Initiative conference in Dublin in June 2023, and aim to publish a first full set of findings before the end of the year. Further similar studies will follow, following on from the results of this first study.'

Recently members of the Tinnitus UK team visited the NIHR Nottingham Biomedical Research Centre, (BRC) long-time collaborators and a prolific hub for tinnitus research. The BRC is a leading force in the quest to better understand, manage, and ultimately cure tinnitus. It is part of a wider network of biomedical centres in the UK and is dedicated to translating scientific discoveries into real-world treatments. During their visit, they were shown the sheer breadth and ambition of their work on hearing conditions – particularly tinnitus. Their hosts were Dr Derek Hoare, who visited us in June, and gave us a fascinating lecture, and Dr Kathryn Fackrell, who will be coming to see us in September (see the front page). We try our best to bring you the most interesting speakers from the 'tinnitus research environment'. Hopefully in the future we may be able to persuade Dr Sedley to come and give us a talk in Cambridge!

WRINKLIES'S WIT & WISDOM

• There's no law that decrees when and when not to whinge, but you reach a certain age - 80 sounds about right - when you are expected to manifest querulousness - the coffee's too hot, the boiled eggs too soft etc. *Clement Freud* • A few perks of old age is: things I buy now won't wear out; I enjoy hearing about pensions; my secrets are safe with friends because they can't remember them either *Felicity Muir* • The older you get, the better you get – unless you are a banana *Anon* • Good days are to be gathered like sunshine in grapes, to be trodden and bottled into wine and kept for age to sip at ease beside the fire. If the traveller has vintaged well, he need trouble to wander no longer, the ruby moments glow in his glass at will. *Freya Stark* • Old books that have ceased to be of service should no more be abandoned than should old friends who have ceased to give pleasure. *Bernard M. Baruch* • The secret of staying young is to live honestly, eat slowly, and lie about your age. *Lucille Ball*

MARTIN'S MISSIVE - September

Some time ago I started including photos to illustrate how tinnitus manifests itself. I titled that picture "A Pictorial Metaphor for Tinnitus".

"Nobody seemed to get distracted by the ghostly image in the bright square on the left"

Walking around London with Rich, an experienced street photographer in my photographic club, I happened to spot what looked like an interesting shot. Rich waited patiently for me to compose the subject before offering any advice. Looking at the screen on the back of camera he suggested, removing the bottles on the desk and reflections in the window. I did some preliminary edits, cropping and converting to black and white and posted it to other members of the club's critique group to see what they thought. Someone made further edits, along the line Rich suggested, and commented on why they had re cropped the left side of the picture. Why had I left the black area in the top left corner which looked dark and sinister?

Remembering my thoughts on "A Pictorial Metaphor", in this picture I'm trying to explain the concept of negative space. Nearly everything above and behind the girl balancing on the stool is negative space. Unlike editing a photo and removing distracting items, bottles & reflections etc., we can't just unhear sounds and some times you can't even walk away from a very noisy environment. It's not a quiet place we seek, like a library, it's a negative space, a place where the Tinnitus isn't."

With Best wishes

Martin Middleton
CTSG Chair

June report

Faradena (please call me Fara) is a Tai Chi Chuan teacher, massage therapist and community musician, (and has been a musician her whole life). This is Fara's third visit to us and she always makes it clear that that the session will be minimal talking about her demonstrating and more about us exercising! She explained as a group we would be exploring stillness, awareness, whole body movement, posture, balance and relaxation using gentle exercises.

The important things to focus on while doing the basic exercises was to be relaxed, have awareness of good alignment during the movements – both internally and externally - and have good contact with the ground. Fara finds these movements, which she practices every day, helps certain of her conditions, including tinnitus! She started with some basic exercises to relax the muscles (which could also be replicated sitting down). This involved steady breathing in and out, with chin tucked in, the spine straight and the head floating (?). We gradually worked our way around and gently exercised arms, legs and back.

One of our members commented: "I found the Tai Chi session excellent. In a relatively short time Fara managed to get us to gently exercise nearly every part of our body. I have arthritis in my neck and it was quite painful before the session. It felt much more comfortable at the end. Since our meeting I have tried to regularly do some of the exercises. It's very calming and stress - releasing. Another remarked: "My memory was of a very relaxing almost tinnitus-free experience which lasted for most of the journey home. I put it down to the controlled breathing but subsequently if I just breathe slowly the tinnitus isn't sublimated in the same way. So I concluded coordinating moving and breathing is the way to go.

It was very fortunate that our exercises were slow and gentle because although we had been given the use of two rooms (1 & 2) combined, and we had the use of two chillers, it was still fairly warm work! (and noisy). And unfortunately unlike previous sessions in the old building, we were unable to access the grassed area outside as we were stuck on the first floor!

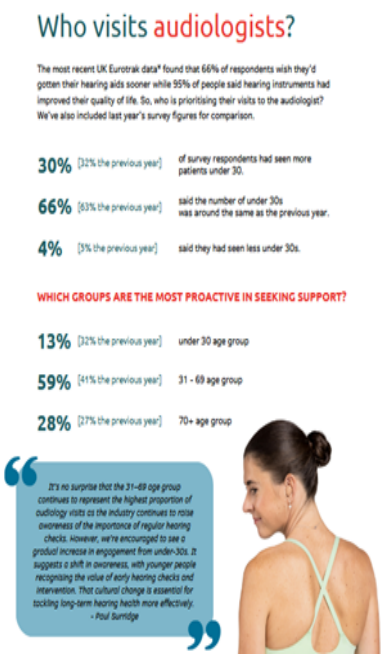
Towards the end of our series of the session Fara combined some of our basic stretches into a few more elaborate movements, those which we more typically associate with T'ai Chi. The movements form part of the Beijing 24 step set which is the short version of Tai Chi Ch'uan that she teaches. You can get a good appreciation of these moves in the Beijing 24 step sequence by going to the link: https://tinyurl.com/dx96fbkn.

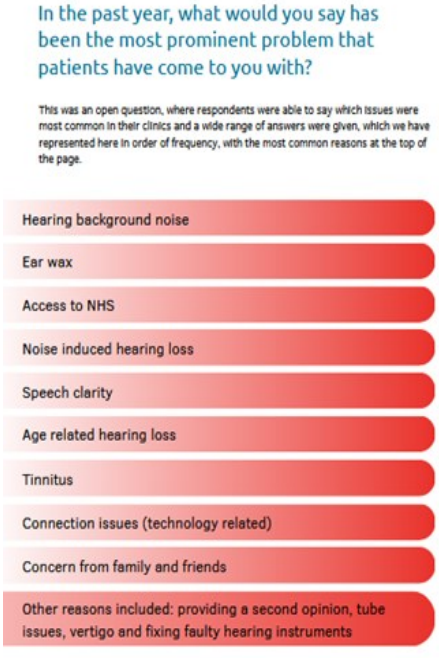
Audiologist survey report 2024 - 5 (See full report on Tinnitus UK website)

The British and Irish Hearing Instrument Manufacturers Association (BIHIMA) has released a report detailing the findings from its annual audiologist survey, offering valuable insights into the mounting challenges facing the UK's hearing care sector. Notably, a third of respondents said they had seen a rise in cases of tinnitus in the last 12 months and many commented on more people opening discussions about the condition.

One response highlighted the increasing rates of tinnitus in younger generations, saying "I am seeing more cases of tinnitus in under 50s, mainly due to the use of headphones or music ear buds." 65% of those surveyed across all audiology cases also highlighted NHS wait times as a barrier to patients receiving support.

The survey covers a broad range of issues facing professionals, including escalating wait times, staffing shortages, limited access to care, the gaps between public and private care and ear wax removal.





New tinnitus treatment emerges from blocking back-channels in the ear (From New Atlas by Michael Irving)

If some speakers in your sound system were broken, you might try to compensate by cranking up the volume on the ones that still work. It turns out that the brain does the same thing when damaged hair cells in the ear lead to hearing loss – and this could be causing your tinnitus. Sensory hair cells are tiny structures in the cochlea that wave like blades of grass in the wind – but in this case, it's the pressure of sound waves that gets them moving. When they do, they create electrical signals that are funnelled through nerve fibres to the brain, to process what you're hearing.

But a small percentage of these nerves actually run in the opposite direction, from the brain to the cochlea. Scientists have long been puzzled by the function of these backwards channels, and it's hard to study their activity while people or animals are awake.

In the new study, scientists at the University of Southern California (USC) used an intriguing imaging tool to see what's going on in there. The technique is called optical coherence tomography (OCT), which involves creating a 3D image of tissue using light waves. It's currently used to scan the retina to diagnose conditions like glaucoma, but the team adapted it for use in the ear.

"OCT lets us look down the ear canal, through the eardrum and bone into the cochlea, and measure how it's working – non-invasively and without pain," said John Oghalai, lead author of the study. "What's exciting about this is it lets us study how the brain is controlling the cochlea in real time."

The researchers genetically engineered mice to have impaired hearing, by disabling some of the nerves that carry signals from their ears to their brains. They then used OCT to monitor the activity of the cochlea and found that it was working harder than usual.

"As humans age and our hair cells die off, we start to lose our hearing," said Oghalai. "These findings suggest that the brain can send signals to the remaining hair cells, essentially telling them to turn up the volume."

As useful as this mechanism might be to compensate for hearing loss, the team suggests that it might have unwanted side effects: namely, it could contribute to conditions like tinnitus. The brain cranking the cochlea's volume could produce that annoying ringing associated with tinnitus. On the positive side, the team now plans to test drugs that could block these backwards nerve fibres as a potential treatment for tinnitus, and related conditions like hyperacusis, where everyday sounds seem uncomfortably loud.

(*Research originally published in Journal of Neuroscience*

* [An OCT scan is a safe procedure that involves using reflected visible light from a low-power laser to obtain images – Ed]

Tinnitus UK's transformation continues with new Chair and Trustees joining the Board

Tinnitus UK have announced new Board members as they continue to rebuild and strengthen following some difficult years. The charity has undergone a significant transformation in the past nine months, creating a new strategic plan helped by the UK's tinnitus community, and will be further aided by new expertise joining a refreshed and rejuvenated Board of Trustees.

Tinnitus UK have also appointed a new Chair of the Board of Trustees, Pierre Espinasse. Pierre is a former Chief Executive of a medical research funding foundation and brings extensive experience of charity governance and strategy development having served on the Board of other charities, including the UK Research Integrity Office. Pierre has been learning to live with tinnitus over the last few years.

Pierre said, "I am honoured to be appointed as Chair of Tinnitus UK and to support it at such an important stage as we embark on our new strategy. Tinnitus is an insidious, hidden condition which affects so many people in so many different ways.", he added, "I am fortunate in that I am, gradually, learning to live with tinnitus but I am acutely aware that, for many, tinnitus has a huge impact on their life and their mental well-being. Together we can work to alleviate that burden and strive towards a world without tinnitus."

Pierre is joined by two other new Trustees. Pete Byrom has over 20 years' experience in the NHS as an Audiologist including paediatrics and working in ENT and Audio-Vestibular consultant - led clinics and now runs a very successful and widely acclaimed private audiology practice.

Emma Stone is an FCA Chartered Accountant with more than 15 years of experience in Finance, Risk, Compliance and Assurance roles within professional practice, the FTSE 50 and the non-profit sector. Emma chairs the Tinnitus UK Finance Committee and supports the Board on matters of finance, governance and risk.

Alex Brooks-Johnson, Tinnitus UK CEO, said, "Tinnitus UK continues to forge ahead with our transformation plans, led by a new strategy created together with the tinnitus community".

He continued, "Being joined by people with the calibre and experience of Pierre, Emma and Pete will significantly improve our ability to help more people with tinnitus and represents our ambitions for the future as we work towards a world without tinnitus".

The three new approaches for treating tinnitus (Edited from an Everyday Science article by Claire Wilson)

We may dismiss messages warning that the music is too loud, but I've recently started paying attention and turning the sound back down, after learning that hearing loss can also lead to tinnitus. Hearing loss would of course be devastating, but for some reason, for me, the threat of tinnitus is even more of a deterrent.
While it has long been linked with hearing loss, we don't know exactly how one leads to the other. But the dearth of highly effective therapies may not be for much longer. As scientists have been learning more about what causes tinnitus, they have been developing a raft of new treatment approaches.

What leads to tinnitus?

We hear by means of the cochlea in the inner ear, whose hair cells can detect different frequencies of sounds. Nerve cells then send messages from the hair cells into the brain, where they are interpreted as sounds. Supporting the link between hearing loss and tinnitus, people often have hearing loss at only some frequencies and the sounds of their tinnitus are at the same pitch. The theory is that damage to some of the cochlea hair cells or their nerve fibres means there is weaker input into the brain at those frequencies. In response, the receiving brain cells get turned up in sensitivity. So, background and random nerve cell firing that should be undetectable can now lead to the perception of sounds when there are none there.

Retraining the brain

One approach is to retrain or rewire the brain, so it gets less sensitive. A basic version, offered through some NHS clinics, is called tinnitus retraining therapy. This involves a combination of counselling and sound therapy to train your brain to gradually habituate to the sound of your tinnitus.
But there are three other approaches to brain retraining that may be more effective. One involves people listening to sounds while holding a small paddle in their mouth that gives mild electrical stimulation to the tongue. Sold as a device called Lenire, by Neuromod Devices, this is designed to exploit the fact that some sensory nerves from the mouth and jaw lead into the same brain region as those from the ear. This boosts brain rewiring and so enhances retraining therapy.
While approved in the US, it is not yet available through the NHS but is available at private audiology clinics. Results from 250 patients at a US audiology clinic, presented at a recent medical conference, had people reporting significant benefits.
Dr Will Sedley, a neurologist at Newcastle University, said the results would be more convincing if the firm had compared the device against a placebo version.
US firm called Auricle has a similar approach except the electrical stimulus is given by small skin pads on the jaw. However the sounds are delivered as repeated pulses at the same pitch as the person's tinnitus, which is said to be more effective because it targets precisely the brain cells linked to the damage hair cells.

Musical modulation

Another technique at an earlier stage of development aims to encourage brain rewiring by using sound in a slightly different way. The higher sensitivity that people with tinnitus experience may involve their brain cells firing in synchrony with each other too much, which is interpreted as false sounds. One way to disrupt that synchrony is to play electronically altered sounds. Dr Sedley said, "We modify synthetic musical notes so that we keep activating neurons representing different frequencies at slightly different times" The alteration to the music is barely noticeable.
"So if this works, it could be turned into an app that does this kind of modification to ordinary music. In principle, this can be implemented freely or cheaply on an unlimited scale," he said.

Cause for optimism

While any of these approaches would be good news if they work, Dr Sedley said there is another cause for optimism. Many people assume their symptoms will get progressively worse. But in a study of 51 people with new tinnitus, most reported improvement over six months in how much the sounds bothered them, and that they reduced in volume. The condition can certainly affect some people badly, and they need specialist help, he said. "But there's a distinction between benign tinnitus, which thankfully is the majority [of cases], and people who are very badly affected.

Nevertheless, GPs should still take it seriously when patients develop tinnitus symptoms, said Don McFerron, a retired ENT surgeon and president of Tinnitus UK. "People are often told there's nothing that can be done about this and they should just go away," he said. "There's loads that can be done. It is infuriating."

Even current talking therapies can give more benefit than people expect, as they could be working by a kind of brain rewiring, said Dr Sedley. "What you could achieve is going from something that you're aware of most of the time and highly distressed by, to something like hearing an air conditioner in the office. It's always there if you listen for it, but you barely ever think about it. "It is a realistic treatment goal for anybody struggling with tinnitus to at least try and achieve that. And sometimes it works."

JOKE

St Peter is at the Pearly Gates when a cat shows up. St Peter says. 'I know you! You were a very nice cat and caused no trouble, so I want to offer you a gift of something you have always wanted.' Cat: 'Well, I always wanted a nice satin pillow to lie on like my master had'. St Peter: 'That's easy. Granted. You shall have the satin pillow after you enter in. Then a group of mice appeared. St Peter: 'Ah, I remember you, you were such good mice on earth, therefore I want to grant you a special wish you always wanted.' The Chief Mouse replied, 'Well we always watched the children playing and saw them their roller skate, and it looked like so much fun, so we would like some roller skates, if we could?' St Peter: 'Granted. You will have your wish.' Next day, St Peter is making the rounds inside heaven and sees the cat. 'Well, Cat….Did you enjoy the satin pillow?' Cat: 'Oh, indeed I did. And I have to say the Meals on Wheels thing was a nice touch too!'

Do You Have Tinnitus - The Answer Might Be Written In Your Face From Health Day Reporter

Subtle facial gestures linked to the body's fight-or-flight response could be used to help diagnose people with tinnitus, a new study says.

Video recordings showed that people with tinnitus experienced facial twitches and pupil dilation in response to certain sounds, researchers reported in Science Translational Medicine (April 30 2025).

This is the first time researchers have found a marker that could be used to identify tinnitus in people with the hearing problem, researchers said.

"Imagine if cancer severity were determined by giving patients a questionnaire – this is the state of affairs for some common neurological disorders like tinnitus," said senior investigator Daniel Polley, director of Mass Eye and Ear's Lauer Tinnitus Research Centre in Boston, in a news release.

"For the first time, we directly observed a signature of tinnitus severity, "Polley said. "When we began this study, we didn't know if sounds would elicit facial movements; so, to discover that these movements not only occur, but can provide the most informative measure to date of tinnitus distress, is quite surprising."

Tinnitus is the medical term for ringing in the ears, but it also can present as other persistent phantom sounds like buzzing or clicking, researchers said in background notes. It affects about 12% of people*, including 25% of seniors 65 and older. Most learn to live with the it, but about 15% of people have tinnitus so severe that it disrupts their sleep, mental health and everyday function, researchers said.

For this study, researchers hypothesized that people with debilitating tinnitus might exist in constant fight-or-flight mode, reacting to everyday sounds as though they were threats.

The team recruited 47 folks with varying levels of tinnitus and compared them to 50 healthy people who served as a control group.

The people were videotaped as they listened to pleasant, neutral or distressing sounds. The unpleasant sounds included coughing fits, yelling or a baby crying.

Using artificial intelligence (AI) software, they looked for rapid and subtle involuntary facial movements, like twitches in the cheeks, eyebrows or nostrils.

*[*Please note these will be American stats* - Ed]

HEALTH CHUCKLES

• The only way to keep your health is to eat what you don't want, drink what you don't like and do what you'd rather not. *Mark Twain* • I personally stay away from health foods. At my age I need all the preservatives I can get! *George Burns* • The doctor said I could get rid of my cold by drinking a glass of freezing orange juice after hot bath. Really? And did it work? I don't know. I haven't finishing drinking the hot bath yet. *Anon* • Attention to health is the greatest hindrance to life….*Anon* • An osteopath works his fingers to the bone *Anon*

Tinnitus and Sleep: Nap or not? (Edited from article from Danny Knight on Tinnitus UK website)

Tinnitus can cause us to have trouble sleeping, so a nap is a common tactic to get a bit of much-needed rest! But if you've ever woken up thinking your tinnitus is even louder than before, you're not alone. Previous studies have suggested that this clinical pattern could be attributed to a somatosensory modulation of tinnitus. A study led by Dr Robin Guillard was published in Hearing Research earlier this year, exploring why our perception of tinnitus often increases after naps.

37 participants undergoing six carefully monitored and measured nap sessions (197 naps were collected).

Findings revealed that nap duration, snoring, and sleep apnea (temporary cessation of breathing, especially during sleep) episodes correlated with heightened tinnitus perception. No direct link was found between these changes and somatosensory factors like jaw or neck movements, which can be associated with waking tinnitus.

To learn more about tinnitus, naps and the science of sleep, Tinnitus UK members were invited to join Robin for a special live webinar on Wednesday 9 July. [*A pity we weren't aware of this at the time!* - 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 alan.yeo622@outlook.com)

CONNECTIONS CTSG website: **www.cambstsg.com** Facebook: **Cambs Tinnitus Support Group** TINNITUS UK REGISTERED TINNITUS SUPPORT GROUP

CTSG is an independent voluntary organisation with a good supporting relationship with the Audiology Department at Addenbrookes Hospital. It is also a Tinnitus UK-registered tinnitus support group. We receive no financial support other than from membership subs, donations and sales. This pays for the hire of the meeting room, printing and postage of newsletters, replacement equipment and associated activities. Reports and comments expressed in this newsletter do not necessarily reflect the views of CTSG.

Our next meeting is on Saturday 15 November, and will feature our ever-popular Self- Help session, watched over by our Rachel Knappett, followed by our yummy Bring & Share Brunch!