Cambs Tinnitus Support Group

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NEWSLETTER

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Saturday 21 September

10.00 for 10.30 am

"Ménière's Society and it's role in supporting patients "

Speaker: Laura Fulco Administration & Groups Liaison Officer Ménière's Society

Laura works for the Ménière's Society having come from a varied background including, latterly, nursing. She says, "It is a special place to work, being able to communicate with people from all walks of life, offering them support and giving them information, whilst still maintaining my interest in healthcare." During her talk Laura will explain about Ménière's and also mention some of the other vestibular conditions. She will be happy to answer questions at the end of her presentation.

Meadows Community Centre

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

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EDITOR'S CHAT

NICE (The National Institute of Health and Care Excellence) are currently working on a set of guidelines for the treatment of tinnitus (see page 5 of the newsletter). The BTA is a stakeholder in these guidelines, and they have been invited to offer feedback. The draft guidelines are due to be published on 20 September, and as soon as the draft guidelines are available, the BTA will circulate a link to them, and also to their online survey for feedback. Check their social media streams for the latest news, and links to the draft guidelines and survey: <u>www.facebook.com/BritishTinnitusAssociation</u> <u>www.twitter.com/BritishTinnitus</u>. They will then use your comment in their official response to NICE, which will be available to all on their website from late October. E-mail me if you would like to be sent any other information I receive from the BTA regarding this matter.

Ménière's disease is a vestibular condition with four major symptoms: vertigo, hearing loss, tinnitus and fullness in the ear. According to one study, one in three Ménière's patients experience either mild, moderate or severe tinnitus, and it usually affects only one ear. In September we welcome Laura Falco from the Ménière's Society as our speaker, and look forward to learning more about this rare condition.

JIM'S PIECE

I have some good news. I think it's true to say that after about 10 years I really have come to terms with my tinnitus - or as the audiologists would say, I have become habituated to it. I am also fortunate that my 'noise' is relatively mild compared to many with the condition. However, although it rarely bothers me now, if I stop to think about it, my old 'friend' is still there. I want to share this knowledge so as to give hope to those who have recently experienced tinnitus and who maybe wonder if it will ever become less troublesome,

My hyperacusis and deafness in one ear on the other hand are challenging at times, but then so are other things in life! We must to try to be positive, and be appreciative of the many good things we maybe take for granted. One of them is the wonderfully supportive group we have and our welcoming, warm and informative meetings. I look forward to seeing you in September.

Enjoy the summer days, Best wishes Jim Infield, Chair

Introduction to tinnitus treatments (a new part of the BTA website - see https://tinyurl.com/yyblzlzv) Everyone who suffers from bothersome tinnitus wants something that will make their tinnitus go away. If you browse the internet or read newspapers and magazines, you can easily find people or organisations who will offer a method that claims to cure, or at least reduce, tinnitus.

This could be in the form of medication, such as pills or injections; herbal supplements; devices and gadgets or different types of therapy and hypnosis. The list of "cures" is long, and getting longer. Some of the information you read will be about effective, evidence based treatments. And some will be about treatments which haven't even been tested. There may even be suggestions you try treatments that are dangerous.

The page lists a number of treatments and gives our verdict on them. If you click on the treatment name, you can see the decision making tool we used to come to that verdict. We provide verdicts on two aspects of each treatment:

| | • Safety - | whether the treatment will do y | ou any harm |
|-----------|---|----------------------------------|-------------------------------|
| KEY | Efficacy - whether the treatment works for tinnitus | | |
| Safety | Evidence of harm | Limited potential for harm | Regarded as safe |
| | | 38 ; | 18 ; |
| Efficacy | Evidence there is NO effect | No evidence it is effective | Evidence that it is effective |
| | Tinnit | us Treatments (3 of 31 examples) | |
| Treatment | Ginkgo Biloba | Melatonin | Cognitive Behaviour Therapy |
| Safety | 18: | 18 ; | |
| Efficacy | 18 ; | 38 ; | |

"Read all about it - New breakthrough pill could cure tinnitus!"

Perhaps you have recently seen in the newspapers or online a similar-looking headline. A eureka moment if true, but what's the real story behind the headline?

The headlines were in response to an article by a research team from the University of Arizona (published in the journal *PLoS Biology*) that suggested that neuroinflammation (inflammation within the brain or spinal cord) may cause tinnitus. Inflammation is the body's response to damage or infection, so noise induced hearing loss (NIHL) could cause inflammation in the auditory pathway, triggering tinnitus.

The researchers looked at mice who had NIHL and tinnitus, and found higher levels of molecules and cells known to be involved when neuroinflammation occurs. One of these molecules is called tumour necrosis factor alpha (TNF), and when the researchers deactivated the gene responsible for TNF, they found that no neuroinflammation was present, and the mice no longer showed signs of tinnitus. When TNF was block–ed using drugs in another group of mice, they also showed no signs of tinnitus after being exposed to loud noise. To double check the connection, further groups of mice received infusions of TNF, and this was shown to trigger the condition.

Now this is where the stories and the headlines depart somewhat. In order for there to be a pill for tinnitus, these results need to translate over to humans, and such work has not yet been carried out. Although there are a number of drugs that block TNF in humans, each would need to be rigorously tested and this process could take a number of years.

ENT surgeon Don McFerran, the leading tinnitus expert, explained: "The name (TNF) Tumour Necrosis Factor is not very helpful, suggesting that it is only associated with disease processes. In fact, TNF is a chemical that is produced by many cells in the body and it contributes to normal body processes, particularly processes related to the immune system, such as fighting off infections. It is one of a family of normal cellular chemicals called cytokines and most of the time it is a normal, helpful part of us. There are certain diseases in which abnormal TNF activity is thought to contribute to the disease and anti-TNF drugs have been in use in selected patients for around twenty years. There are no reports in this time period that these drugs help tinnitus - indeed, the opposite is true - there are reports that tinnitus can develop in people being treated with anti-TNF drugs.

This is not to say that anti-TNF drugs definitely have no role in tinnitus - just that the ones that we have already produced do not seem to help. Different anti-TNF drugs work in different ways and it is still possible that there is an anti-TNF drug that may help tinnitus."

He also added this warning: "There is a salutary tale regarding anti-TNF drugs in a different condition - multiple sclerosis (MS). Initial animal experiments suggested that anti-TNF drugs could be very helpful in counteracting inflammation of the brain and nervous system. When these drugs were tried in humans, not only did they not help, but they actually made the MS worse. Unfortunately, optimistic animal research does not always translate into success in humans."

Sadly, in the interests of selling newspapers etc., a dramatic and misleading headline has been used. Whilst this study is interesting, and we look forward to further work happening to follow up these results, the breakthrough treatment we're all hoping for is still some way off.



(Edited from Quiet article by Nic Wray)

CHUCKLES 1

An anthropologist is travelling the world filming tribal dances when he hears of a mystic Australian Aboriginal ceremony called the Butcher Dance, which is only performed at one remote settlement and has never been seen by outsiders. So he travels to the Australian outback and puts together an expedition to try and find this tribe. They drive out into the bush, but bad luck strikes and their vehicle packs up, forcing them to walk. They walk for many days and the expedition members gradually drop through exhaustion, sunstroke and thirst until only the anthropologist is left struggling along with his camera. Finally he too collapses in the dust, but awakes that evening to find he's been rescued.

He is in a tribal encampment and is delighted to discover that his saviours are the very tribe that perform the fabled Butcher Dance. It turns out it is usually only performed once every ten years, but since the anthropologist has suffered so much the tribal elders agree to put on a performance especially for him. He sets up his video camera and the tribal dancers get into a circle. The tribal chief claps his hands, the anthropologist starts recording, and the Aborigines start their mystic dance, 'You butcher left arm in. You butcher left arm out. In. Out...'

CHUCKLES 2

- My wife has an toaster, a blender and an electric bread maker. Then she says 'There are too many gadgets, and no place to sit down!' So I bought her an electric chair.
- A man goes into a pet shop and asks for a big bag of bird seed. 'How many birds have you got?' asks the shopkeeper, 'None, replies the man, 'I was hoping to grow some.'
- A chicken crossing the road is poultry in motion.
- Why are woodpeckers smarter than chickens? Ever heard of Kentucky Fried Woodpecker?
- A newspaper man is captured by cannibals What was your job?' asks the chief cannibal. 'I was a sub editor,' replies the man. 'Well look forward to a promotion then,' replies the cannibal.' 'You are about to become editor-in -chief.'

Scientists create mind-controlled hearing aid

(Edited from Action on Hearing Loss Soundbite article)

Development could transform ability of the hearing-impaired to cope with noisy environments

A mind-controlled hearing aid (HA) that allows the wearer to focus on particular voices has been created by scientists, who say it could transform the ability of those with hearing impairments to cope with noisy environments. Scientists have been working for years to resolve this problem, known as the 'cocktail party' effect. The device mimics the brain's natural ability to single out and amplify one voice against background conversation.

Nima Mesgarani, from Columbia University in New York, said: "The brain area that processes sound is extraordinarily sensitive and powerful. It can amplify one voice over others, seemingly effortlessly, while

The device was tested on epilepsy patients who already had electrodes implanted in their brain to monitor seizure activity ahead of planned brain surgery. The audio of different speakers who were not known were played while the patient's brain waves were monitored via the implanted electrodes.

An algorithm tracked the patients' attention, and when they focused on one speaker the system automatically amplified that voice, with very little lag. When their attention shifted to a different speaker, the volume levels changed to reflect that shift.

The current version of the hearing aid, involving direct implants into the brain, would be unsuitable for mainstream use. But

today's HAs still pale in comparison." The brain-controlled HA uses a combination of artificial intelligence and sensors designed to monitor the listener's brain activity.

An algorithm automatically separates the voices of multiple speakers, which then compares these audio tracks to the brain activity of



the listener. Previous work by the researchers found that it is possible to identify which person someone is paying attention to, as their brain activity tracks the sound waves of that voice most closely.

The audio of each speaker is compared to the brain waves of the person wearing the HA. The speaker whose voice pattern most closely matches the listener's brain waves is amplified over the others, allowing them to effortlessly tune in to that person. Crucially, unlike an earlier version of the system, this latest device works for voices it has never heard before.

the team believe it will be possible to create a noninvasive version of the device within the next five years, which would monitor brain activity using electrodes placed inside the ear, or under the skin of the scalp. The next step will be testing the technology in those

with hearing impairments. One question is whether it will be as easy to match up brain activity in people who are partially deaf with sound waves from speech. According to Jesal Vishnuram, technology manager at the charity Action on Hearing Loss, "One of the reasons people struggle with conventional HAs is that they often wait a long time before getting a hearing aid and in that time the brain forgets how to filter out the noise and focus on the speech. This is really interesting research and I'd love to see the real world impacts of it."

WORDPLAY

- **Dopeler Effect**: The tendency of stupid ideas to seem smarter when they come at you rapidly.
- **Decafalon (n):** The gruelling events of getting through the day consuming only things that are good for you. **Osteopornosis** : a degenerate disease.

Physiological mechanisms of hyperacusis: an update

Hyperacusis is a debilitating hearing disorder that affects up to 10% of the general population. Advancing diagnosis and treatment of hyperacusis requires a better understanding of its underlying neural mechanisms. This is complicated by the diversity in both its cause and clinical presentation. This update will discuss recent efforts to model distinct forms of hyperacusis in animals to help elucidate potential mechanisms underlying this

diverse disorder. Hyperacusis encompasses a wide range of reactions to sound and, as such, its definition has been amorphous. Four subtypes of hyperacusis have recently been identified based on clinical presentation: excessive loudness, annoyance, fear, and pain. Hyperacusis is often associated with hearing loss and the phantom sensation of tinnitus. Sound tolerance disturbances are observed, however, across a wide range of neurological disorders. These include neurodevelopmental disorders like Williams syndrome and autism spectrum disorders (ASD), psychiatric disorders like depression and post-traumatic stress disorder (PTSD), as well as chronic pain disorders like migraine, and complex regional pain



syndrome. Thus, hyperacusis is diverse in both its aetiology (the study of causation) and expression, and it is imperative to consider this diversity when attempting to define its physiological mechanisms.

(From NT & Audiology News)

June meeting report: Self-help session

Report by Alan Yeo

We were so sorry to learn of our original speaker Claire Gatenby's accident, and our thoughts are with her as she recovers from her broken hip. We hope she makes a speedy recovery so that she will be well enough to talk to us in November. As this happened less than 2 weeks before this meeting, we were very fortunate that Rachel was

available to be facilitator for our hastily rearranged self-help session. The weather gods were smiling on us as usual and blue sky and sunshine greeted some 27 attendees, 10 of whom we had not seen before. Some had contacted me beforehand and were expected, but several had just come along after visiting the CTSG website, which is very encouraging (keep up the good work, Jim!) Even better, we gained five new members on the day welcome Sally, Mike, Rod, Sally and Rean!

Rachel got the ball rolling by posing the question: what do you do to help manage your tinnitus? Answers ranged from gardening, walking to the dog, tai chi and classical music, to riding their motorbike and hoovering - quite an eclectic mix! One of our newcomers who used a library a lot in his work found his 'noise' distracting at times and another who enjoys singing was initially frightened of her tinnitus, but has begun to adapt to the condition and finds gardening helps her a lot.



Jim infield, our chair, on the mike!

Rachel explained that how you feel about your tinnitus makes a huge difference to how you cope with it, and cognitive behavioural therapy (CBT) is proving to be very popular as a therapy; so much so that NICE (The National Institute for Health and Care Excellence) will be including CBT in itare s guidelines that to be published soon. Rachel explained that unfortunately a psychologist is not an audiologist and may not appreciate the problems that troublesome tinnitus can cause patients. It is also difficult to obtain CBT on the NHS, especially with practioners who are not particularly knowledgeable about the condition.

Rachel then finished with a brief roundup of the latest tinnitus research. Many thanks to all those present, particularly Rachel, and the newcomers who joined in and helped make it one of our best sessions we have had.

Chronic pain - how it might help us find a treatment for tinnitus

Action on Hearing Loss (AoHL) is funding a project at King's College London and the University of Nottingham to test if it is possible to lessen or even silence tinnitus, by blocking the activity of an ion channel associated with chronic pain.

Although the underlying biological processes and drivers of tinnitus are still not completely clear, scientists believe that tinnitus is associated with changes to the auditory system, which in turn cause increased activity in the hearing brain and the consequent perception of a phantom sound.

Neuropathic pain is a type of chronic pain where

patients experience shooting or burning pains without an external reason for the pain. This appears to be a result of increased activity in the nervous system, leading to the continuous activation of pain-sensitive nerve fibres and leads to persistent, phantom pain sensations. Similarly tinnitus patients experience persistent, phantom sound perceptions. Several studies have shown that there are similarities between the biological

processes involved in chronic pain and tinnitus. So AoHL are funding a project to look more closely at these similarities, and explore whether approaches to treating chronic pain may also help to treat tinnitus.

Testing if treatments for chronic pain can silence tinnitus Professor Peter McNaughton's team, based at King's College London (KCL), has identified that a type of ion channel, called HCN2, is responsible for driving neuropathic pain. Ion channels are proteins that allow charged particles (such as potassium and sodium ions) to pass in and put of nerve cells. Without these channels, ions cannot move across the cell's surface. The researchers have shown that ions flowing through the HCN2 channels trigger the activation of pain-sensitive



nerve fibres, creating a constant sensation of pain. When these ion channels in mice were blocked, they were able to eliminate pain in a mouse model of chronic pain.

HCN2 channels are also found in the auditory system nerve fibres, which carry information from the ear to the brain. These fibres are often damaged after

> exposure to loud noise, which can lead to tinnitus. Some preliminary studies by the KCL team have shown that blocking HCN2 channels with selective drugs significantly reduces tinnitus in animal models.

> The researchers now want to study the role of HCN2 channels in tinnitus in more detail. Professor McNaughton's team, working with experts in tinnitus

from the University of Nottingham, will test the effectiveness of different drugs that block HCN2 channels in reducing tinnitus in animals.

Why is this project important?

We have only a limited understanding of the biological processes and molecular drivers that underlie tinnitus - this is one reason why there are currently no effective treatments. It is vital that we discover more processes and molecules that can be targeted with drugs to silence tinnitus. This project is looking at a new approach to treating tinnitus, and could ultimately lead to the development of new and effective treatments.

(Edited from AoHL Soundbite article)

Younger and older people respond differently to sound

By exploring differences in the way younger and older adults respond to sounds, neuroscientists at Western University in Canada have found that our brains become more sensitive to sounds as we age, which suggests this may help explain why older people can have problems hearing in certain situations

The researchers examined the auditory cortex responses of participants in their 20s and 60s (with clinically normal hearing), and looked at how their brain's ability to adjust its sensitivity to sound levels was affected by aging. Postdoctoral scholar Björn Herrmann, the study's lead writer, said "What we observed is that older individuals don't adapt as well to their sound environment."

Older people more over-sensitive to sounds

The study revealed that when young adults are in a loud environment – such as a rock concert – their brains become less sensitive to relatively quiet sounds. This allows the listener to hear the relevant sounds (like a guitar riff) better without being distracted by irrelevant sounds. However researchers found that the older listeners become over-sensitive to sounds, hearing both quiet and loud sounds without the ability to ignore or tune out irrelevant auditory information. Without the ability to reduce sensitivity to unimportant sounds, the individual experiences hearing challenges. "When the sound environment is loud, the brain activity in younger adults loses sensitivity to really quiet sounds because they're not that important," Herrmann said. "Whereas older individuals still stay sensitive to these relatively quiet sounds, even though they're not important at the time."

Unpleasant and annoying sounds

The study suggests that this over-sensitivity to sounds is one reason why older adults may find certain situations, like a loud restaurant, unpleasantly distracting. It may also explain why they may find some sounds more annoying.

"It's a fundamental property of the auditory system to be able to adjust really fast to any environment a person goes into. If you cannot do that anymore, then in each situation your auditory system might be a little off. This means older individuals may be easily distracted and overwhelmed by sounds, or find them too loud," Herrmann explained.

(Edited from www.hear-it.org article)

INSULTS! (guess who?)

- The mistake a lot of politicians make is forgetting they've been appointed, and thinking they have been anointed.
- Politics is the art of looking for trouble, finding it everywhere, diagnosing it wrongly and applying unsuitable remedies.
- My deepest feeling about politicians is that they are dangerous lunatics to be avoided when possible and carefully humoured; people, who above all, to whom one must never tell the truth.
- He'll double-cross that bridge when he comes to it. He delivers all his statements as though auditioning for the speaking clock. His delivery at the dispatch box has all the bite of a rubber duck.



CONNECTIONS

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.

Our next meeting is on Saturday 16 November at the Meadows Centre, and provided she has recovered OK, Claire Gatenby will be our speaker. The title of her talk will be "Tinnitus: Does how we think, react, sleep, relax make a difference?" Following her talk we will enjoy our popular "Bring & Share" brunch.