

Cambs Tinnitus Support Group

No. 141

NEWSLETTER

June 2018

MEETING

Saturday 16 June

10.00 for 10.30 am

"Prioritising hyperacusis:

Identifying the Top 10 'unanswered' questions that research should target"

Speaker: Dr Kathryn Fackrell

**Research Fellow (Tinnitus and Hyperacusis),
National Research Institute for Health Research,
Nottingham Biomedical Research Centre (NBRC)**

Plus: A Tinnitus Project: by Jess Williams, Audiology research student, Addenbrookes

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.

She is working with patients and partners to improve the knowledge of how to treat and measure tinnitus and hyperacusis.

Jess Williams is a research student working under the guidance of Rachel Knappett at Addenbrookes. Jess will give members a brief outline of a tinnitus project that she is about to start.

Meadows Community Centre

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

Refreshments and Raffle

EDITOR'S CHAT

Tinnitus and hearing problems rarely make daily newspapers or the BBC News, but the case of viola player Mr Goldscheider and his successful claim against his employers, the Royal Opera House (ROH), for acoustic shock, certainly did. Just the thought of sitting in front of a full brass section (>130 dB) during 3 hours of rehearsals for Wagner's *Die Walkyrie*. * As David Stockdale, BTA's CEO, commented: " It is imperative musicians receive the same protection under law as other professions and hope this judgement goes some way towards securing that." [**Must have been as loud as listening to Emerson, Lake & Palmer at Wembley Arena in 1975!* - Ed]

Putting together a newsletter five times a year that our members find of interest is a pleasurable task (most of the time!). However I am always slightly disappointed that I get so few contributions from members; after all, this is your group. Even the odd good joke would help. So how about it?

This is my usual reminder that several of you have not renewed your membership for this year. We don't want to lose you so with either my e-mail or letter is the requisite invoice. If your details have not changed just put your name but please make sure you sign the GDPR section at the bottom. We are always interested as to why you are not renewing; hopefully if it is because you now find that you are able to cope with your tinnitus, so please let me know if this is the case.

Tinnitus Research Initiative (TRI)

The 11th International TRI Annual Conference took place in Regensburg, Germany in March. The Conference was organized by the TRI Foundation in cooperation with the COST-TINNETH Action, funded by the EU within the framework of the COST program, and the German Tinnitus Research Initiative e.V.

One of the presenters was Dr Magdalena Sereda, BTA's Head of Research, based at the Nottingham Biomedical Research Centre at the University of Nottingham. She gave an update on research that she is leading into the use of sound therapy for tinnitus, concentrating mainly on hearing aids and combination hearing aids. This following link will take you to her introduction. (<https://tinyurl.com/y8y3tjjk>)

Does Tinnitus Depend on Time-of-Day?

*An Ecological Momentary Assessment Study with the "TrackYourTinnitus" Application**

Only a few previous studies used ecological momentary assessments to explore the time-of-day-dependence of tinnitus. The present study used data from the mobile application "TrackYourTinnitus" to explore whether tinnitus loudness and tinnitus distress fluctuate within a 24-h interval. Results revealed a time-of-day dependence of tinnitus. In particular, tinnitus was perceived as louder and more distressing during the night and early morning hours (from 12 a.m. to 8 a.m.) than during the upcoming day. Since previous studies suggested that stress (and stress-associated hormones) show a circadian rhythm and this might influence the time-of-day dependence of tinnitus, we evaluated whether the described results change when statistically controlling for subjectively reported stress-levels.



Correcting for subjective stress-levels, however, did not change the result that tinnitus (loudness and distress) was most severe at night and early morning. These results show that time-of-day contributes to the level of both tinnitus loudness and tinnitus distress. Possible implications of our results for the clinical management of tinnitus are that tailoring the timing of therapeutic interventions to the circadian rhythm of individual patients (chronotherapy) might be promising. The final sample consisted of 350 participants.

*TrackYourTinnitus (www.trackyourtinnitus.org) was developed by the Tinnitus Research Initiative (TRI) and the Institute for Databases and Information Systems (DBIS) at the University of Ulm.

JIM'S PIECE

These days it's actually my hearing loss that gives me more problems than my tinnitus, a problem that I know quite a lot of us with tinnitus share. And of course there are some unexpected side-effects like the crooked neck as we try to position our good ear so that we can hear without seeming to get too close to the other person or have our back to other people in the conversation.

But to try and avoid this 'dance' we endeavour to position ourselves at the table to optimise those on our 'good' side - at least those we want to listen to! Although sometimes you have to be a little assertive, I find people don't seem to mind at all.

I always try to make light of it by saying that people shouldn't be on my 'Blind side' as somehow that seems to be more acceptable - humour is always the best antidote. And on that note I will leave you with one of the funniest and most poignant books I've read in a very long time - 'Deaf sentence' by David Lodge. Do read it. You'll soon understand the author is obviously deaf. Relationships are full of misunderstandings but add deafness to the mix and it either makes you laugh or cry. Better to laugh.

Jim Infield
CTSG Chair

Paving the way for new tinnitus treatments

Action on Hearing loss (AoHL) fund applied research projects at institutes and small-medium enterprises across the world through their Translational Research Initiative for Hearing (TRIH).

One such three year project being led by Dr Mark Cunningham, at Newcastle University, ended in February this year. This project could lead to the development of new ways to measure tinnitus, which will help in the development and testing of new drugs to treat it.

Background

Tinnitus can have a devastating effect on people's lives, but despite this high need, there are no pharmaceutical drugs specifically approved to treat tinnitus and few companies are investing in this area. Two of the major challenges for researchers in developing new drugs to treat tinnitus are that:

- There is currently no test for tinnitus that measures a biological change (a so-called objective test). Until now, tinnitus in humans has been measured through questionnaires which are subjective and can therefore give variable results in a clinical trial setting.
- There is no test for tinnitus that can be used in both animal studies in the laboratory and in clinical studies in people. This means that the search for new tinnitus treatments is being slowed down because it is very hard to know if the effects seen in animal studies are relevant to human tinnitus – an essential step in the development of new medicines.

This project aimed to develop an objective measure of tinnitus that can be used in both animals and people. The work was carried out by an academic/industry collaboration between researchers from the

Universities of Newcastle and Leicester and a biotech company, Autifony Therapeutics.

Project aims

This project studied the brain waves produced by regions of the brain involved in hearing. The researchers studied which brain waves were altered in tinnitus, and looked to identify brain wave 'signatures' that could be used as objective tests for tinnitus in both the clinic and laboratory studies. As part of the project the researchers tested the effect of an experimental drug, AUT00063. [Members may remember that a another 2015 study found that AUT00063 was safe, but did not significantly improve tinnitus symptoms when compared to the placebo (dummy) treatment, and that study was therefore stopped prematurely].



Benefits

The hope is that in collaboration, the researchers will identify objective measures of tinnitus that can be used in both animals and people. This would increase confidence in the pharmaceutical industry sector that tinnitus is a viable area for medicine development, encourage increased investment and improve the chances of successful clinical trials to find effective new treatments.

(Amended from AoHL *Soundbite* blog)

Serotonin may worsen tinnitus

Research by scientists at Oregon Health & Science University (OHSU) shows why a common antidepressant medication may worsen the condition of tinnitus.

The study, in the journal *Cell Reports*, focused on the action of serotonin, an important neuromodulator in the brain. Serotonin acts as a neurotransmitter thought to be responsible for maintaining mood balance. Researchers examined brain tissue in mice, specifically the dorsal cochlear nucleus where sensory integration and tinnitus occurs. They discovered that neurons known as fusiform cells within this portion of the brain become hyperactive and hypersensitive to stimuli when exposed to serotonin. "We saw that the activity of those neurons went through the roof," said senior author Laurence Trussell, Ph.D., a professor in the OHSU School of Medicine and who has tinnitus himself.

If the findings bear up to additional research, the study could have implications for a common class of antidepressants known as selective serotonin reuptake inhibitors (SSRIs). SSRIs can alleviate symptoms of

moderate to severe depression and anxiety by increasing the level of serotonin in the brain.

However, the research suggests that SSRIs prescribed to treat anxiety or depression may sometimes worsen patients' tinnitus. "The SSRI may be enhancing the very thing you're trying to fix," said Dr. Trussell. Lead author Dr Zheng-Quan Tang, in Dr.

Trussell's laboratory, noted that a review of the literature indicated that many patients reported an increase in tinnitus soon after they began taking SSRIs.

The OHSU scientists are interested in exploring another area of research focused on a type of ion channel in the membrane of neurons that is activated by serotonin. If the scientists can determine a way to deactivate those channels, they may be able to allow the beneficial effects of antidepressants while limiting the severity of tinnitus.



Amended from AoHL *Soundbite* blog

"Another taste of T'ai Chi"

April presentation by Faradena Afifi

Report by Alan Yeo

T'ai Chi Ch'uan (T'ai chi for short) was originally taught as a martial art (one translation is "supreme ultimate boxing") and longevity exercise. In the early 20th century the health benefits were discovered and it took on a new persona as a preventive medicine or wellness exercise. It originated in China at least 300 years ago and uses a combination of good posture and mindful relaxed awareness. It can be done seated or standing and by anyone with any level of fitness or mobility.

Faradena Afifi (please call me Fara), is a registered Tai Chi Chuan Instructor and was our guide to this discipline on a pleasant sunny day at the Meadows. This was fortunate as Fara made it clear that her session would be minimal talking about her demonstrating and more about us exercising! She explained as a group we would be exploring: stillness, awareness, whole body mindful movement, posture, balance and relaxation using gentle exercises.

Our speaker started with a short relaxation exercise while we were sitting down, principally focussing on contact with the ground while keeping the spine straight, and controlling our breathing.

Feeling somewhat more relaxed, we then headed outside into the sunshine try some basic stretching movements that had some wonderfully descriptive titles; like Wild Goose Flies, Parting the Clouds, Circling a Ball, The Bear, Moving Chanigong (silk reeling) and the marvellous Dragon Plucks the Stars from Sky!

What really impressed me was that, unlike the fairly complex moves which we went straight into with our Taoist T'ai Chi teachers previously, and found quite difficult to replicate, with Fara she then combined some of her basic exercises she had demonstrated into a few more elaborate movements – those which we more typically associate with T'ai Chi.



Fara shows us how to relax

These movements form part of the Beijing 24 step set which is the short version of T'ai Chi Ch'uan that she teaches, and really makes one appreciate how the basic exercises combine to make the more complex moves.

Fara said 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. This improves posture, balance, co-ordination, strength and stamina when practised



Trying to duplicate one of Fara's stretching exercises!

over time. Interestingly, Fara finds these movements, which she practices every day, helps certain of her conditions, including her tinnitus!

Obviously you had to be there to personally experience the above, but you can get a good appreciation of the moves in the Beijing 24 step sequence by going to the link: <https://tinyurl.com/9e987mq> (don't bother with the audio unless you are fluent in Chinese!)

Faradena teaches the Beijing 24 Step, basic Chi Kung, Push Hands and partnerwork. She also can teach non-mainstream classes for example: women only, mental health, learning disabilities, wheelchair users, adapted seated only classes. Her mainstream classes are in St Ives with occasional classes in Huntingdon and Cambridge.

[Her details can be found at <https://tinyurl.com/yamrr8jz>].

CHUCKLES

Tom and Dick are driving along when Dick goes through a red light. 'Careful,' says Tom. 'You'll have an accident.' 'It's alright,' says Dick. At the next red light Dick again speeds straight through without a care in the world. 'That's really dangerous,' says Tom. 'It's OK.' 'My brother does it all the time.' says Tom. The next set of lights are green and Dick unexpectedly puts on the brakes. 'Why are you stopping now?' ask Tom. 'Are you mad?' replies Dick. 'My brother might be coming the other way.'

A Pacemaker as a Treatment of Tinnitus

Researchers at the Maastricht University Medical Centre, in the Netherlands are working on two methods to try and stop tinnitus in patients.

One of these methods uses *Deep Brain Stimulation*. With this technique, a pacemaker is put into the brain, and just like a pacemaker for the heart it also sends electronic signals. These signals should interrupt tinnitus. "At the moment this treatment is tested on animals. With the implant we are now starting to test it with people and hope they will have good results within 2 years." says Lead Researcher Robert Stokroos.

[This short piece was gleaned from a Dutch blog]

2018 AGM SNIPPETS

A pleasant sunny day saw 25 members and guests attend our AGM which preceded the normal meeting.

The CTSG Chair, Jim Infield, gave his usual report on the group's activities over the past 12 months, kicking off with Paul McDermott from Puretone, who explained about the latest developments in tinnitus aids.

June was our big event of the year, celebrating our 30th anniversary with an Information Day at the David Raynor Centre in Great Shelford. David Stockdale, Dr David Baguley and Rachel Knappett were our 3 excellent presenters who spoke to our audience of 70, half of whom were newcomers. At the close, Avril Dring, who had helped organise the group since its inception in 1987, formerly stood down from the committee and in her new role of President cut the anniversary cake!

In September, Dr Derek Hoare from the Nottingham Hearing Biomedical Research Unit gave us an in-depth talk about applying self-help management techniques to tinnitus, and in November Rachel Knappett rounded off the year by facilitating a cracking self-help session. Oh, and the bring & share brunch (inc. minced pies and mulled wine) wasn't bad either!

For our final meeting in February we welcomed back Peter Shearer with his relaxing brand of piano playing.

Our main effort for Tinnitus Week was concentrated at Hinchingbrooke hospital where Sue Peacock was supported by Alan for 2 of the 3 days. Our usual presence at Addenbrookes was a low key affair this year, as our usual patch was unavailable

The CTSG took to the 'cloud' during 2017, with both our Facebook page and website coming online.

Jim also thanked Alan for his efforts with newsletter, particularly the recording of the group's history in the June edition and the September report on the anniversary meeting. At this point, your editor was presented with a 12 bottle box of beer for all his efforts supporting the group [*which is the kind of surprise I like, and very much appreciated!* - Ed].

Jim finished by thanking the committee for their support – everyone willing to stay on for another year – and Pauline Brown also volunteered to come on board. Jim reminded us that we still have a very strong link to the Audiology Dept. at Addenbrookes through Rachel, as Head of Adult Auditory Rehabilitation.

MORE WORDPLAY

- Sarcasm: The gulf between the author of a sarcastic wit and the person who doesn't get it.
- 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.
- Karmageddon: It's like, when everybody is sending off all these bad vibes, right? And then, like, the earth explodes and it's like, a real pain.

CHUCKLES 2

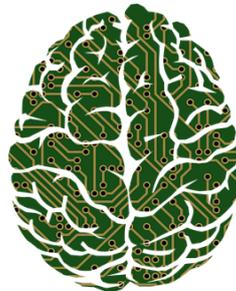
- The Pope is visiting America and decides to take a turn at the wheel of his limousine. The Pope gets in the driving seat, while the driver hops in the back and they shoot off at 80 mph. Not surprisingly, they are soon pulled over by a traffic cop, who radios into the police station. 'We've got a VIP situation here,' says the cop. 'I just pulled over someone who's really, really important.' 'Who is it?' asks the station controller. 'I don't know,' says the cop. 'But his chauffeur is the Pope.'
- An ageing playboy visits his doctor after a lifetime of wine, women and song. 'Well says the doctor, 'The good news is you don't have to give up singing.'

Using virtual reality to improve hearing tests

AoHL have awarded new grants through their Flexi Grant scheme, which are provided to researchers around the world to support a variety of activities that benefit hearing research as well as people with hearing loss or tinnitus. Tracey Pollard, from their Biomedical Research team, explains:-

Standard hearing tests use 'pure tone audiometry', which measures the quietest sound that a person can hear at a range of frequencies (itches) of sound. This gives useful information as to the extent of someone's hearing loss, and can be used to programme hearing aids, but it doesn't fully assess the hearing difficulties that a person is having. In particular, it doesn't measure how well a person can hear speech or other sounds against a noisy background. It also gives no indication of how well someone can hear in more realistic listening, real-world, scenarios.

In this project, the researchers will trial the use of virtual reality (VR) as a way of more fully assessing children's hearing abilities. They will develop a VR game where a child's ability to correctly identify target words against real-world fluctuating background noise can be measured. Wearing a VR headset, children will listen to and



watch a game character say target sentences, which they have to repeat back while ignoring what is happening in the background, including other characters and sources of noise. The researchers believe that this will give a more realistic idea of how well a child can hear in everyday life.

They will also test whether cheaper, commercially-available VR headsets produce similar results to the more expensive, laboratory-standard VR headset they are currently using. This is important for being able to use these tests in the clinic – hospitals and audiology units often have restricted funding, so the uptake of VR hearing testing will be increased if the equipment needed is cheaper.

The funding from this Flexi Grant will allow the researchers to obtain pilot data so that they can go on to apply for more substantial funding to take the work forward.

The Lowestoft Signing Choir by the Editor

Recently on a short break near Norwich, Linda and I took advantage of the Park & Ride to pop into the city centre. While there we reacquainted ourselves with their splendid cathedral; however our timing was not brilliant as that day it was obviously open house for parents and their young children – not good for the old tinnitus levels! We were aware that a choir would be performing, but had no idea it would turn out to be a signing choir, the like of which we had never seen before. The Lowestoft Signing Choir signed to some up-beat anthem style (pop) songs which really caught the mood. After a couple of numbers they invited children from the audience to join in, and they did so, most enthusiastically!



The Lowestoft Signing Choir in Norwich Cathedral

The choir formed in 2003, and consist of a mixed group of people; some deaf, some hard of hearing, some hearing and some with other related hearing difficulties. They have 45 members, consisting of members and friends of The Centre for Deaf People, Lowestoft and students from the Kirkley High School in the town. They are all volunteers and perform at many local events with a large repertoire including popular songs, hymns, war time songs, seasonal songs and carols. Their aim is to raise Deaf Awareness, and promote British Sign Language.

All in all an unexpected but very pleasurable experience, and guess what - I completely forgot about my tinnitus!

100 SUPPORT GROUPS!

Those of you who are BTA members, or have browsed their website recently, will know that the organisation have reached their current target of 100 tinnitus support groups (TSGs) around the country – an amazing achievement. Several new groups have started up in East Anglia, some quite recently. They include Bury St Edmunds, Ipswich, Southend, Kings Lynn, Norfolk & Norwich, Hitchin & Stevenage and Lowestoft. This is all good news for those with tinnitus who are looking for support in the their local area.

You may not know that CTSG actually helped start a TSG in Bury way back in 2005, mainly due to the enthusiasm of one of our then committee members, Elizabeth Oakley, who lived over that way. She was ably supported by Avril Dring and the late Bill Morris, but unfortunately the project never really got of the ground (publicity through social media etc. wasn't like it is t today) and it quietly faded. Let's hope the new group fares better – I'm sure they will.



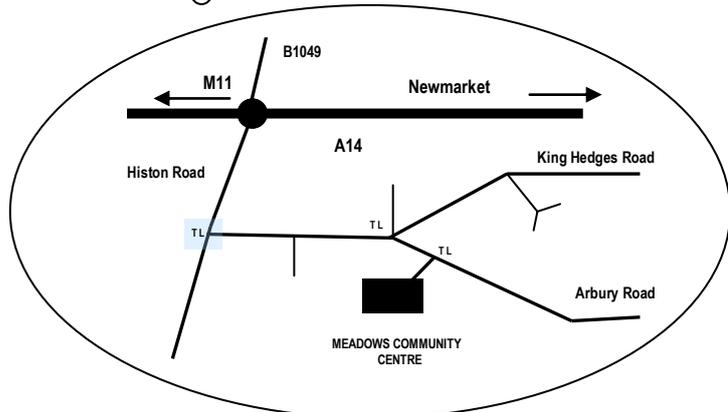
Please remember

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 :-

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**NEVER BEEN BEFORE?
THE MAP BELOW WILL HELP YOU
FIND THE MEADOWS CENTRE**



CONNECTIONS

CTSG is an independent voluntary organisation with a good supporting relationship with Addenbrookes' Audiology Department. We receive no financial support other than from membership subs, donations and sales. This pays for the hire of the meeting facilities and printing and postage of Newsletters. Reports and comments expressed in this newsletter do not necessarily reflect the views of CTSG.

Our next meeting is on Saturday 15 September at the Meadows Community Centre. Elinor Brown, from Growmindful, is our speaker, and her talk is entitled: "Mindfulness-based Stress Reduction"