

Cambs Tinnitus Support Group

No. 162

NEWSLETTER

June 2022

MEETING

Saturday 18 June

at

10.00 for 10.30 am

"Another taste of T'ai Chi"

Speaker: Fara Afifi
Move2Health

Faradena is a Tai Chi Chuan teacher, community musician and massage therapist. She has been a musician her whole life and combines sessions of Tai Chi Chuan and music for adults with complex disabilities as well as teaching mainstream Tai Chi Chuan classes. Her aim is for the session to be a group interactive event; doing some exercises together and then inviting questions. The session will use gentle exercises to explore the following: stillness, awareness and whole body mindful movement,

Meadows Community Centre

1 St Catherine's Road, Cambridge, CB4 3XJ, off
the junction between King's Hedges and Arbury Rds
(Look out for the direction boards to the temporary C/P)

CONTENTS

2. Editors Chat ~ Investigating tinnitus subgroups based on hearing-related difficulties ~ Jim's Piece
3. Hearing loss reversed? ~ Awkward British Problems ~ The international vocabulary of tinnitus
4. Professor David Baguley interviews David Stockdale ~ Chuckles
5. Memories of David Stockdale and the CTSG
6. The Sound of Science - the urgent need for a Tinnitus Biobank

Refreshments and Raffle

EDITOR'S CHAT

I hope that the better weather and the easing of the Covid situation has helped you cope with your tinnitus. Unfortunately our scheduled meeting in April didn't go as planned, due to the illness of Dr James Jackson, our speaker, and I'm sure that impacted on the number of members who attended. However we went ahead with our AGM, any thought of postponing it for yet another year was definitely out of the question! As mentioned in my recent e-mail, happily we have managed to re-schedule James for our vacant September (17th) slot. You may remember we planned for the September slot to be taken by an osteopath practicing cranial osteopathy, as follow up to Mark Smith's excellent talk on somatosensory tinnitus in February. However trying to find such a willing person locally has proved very difficult/impossible, but we won't stop trying.

However, back to our April meeting, the AGM went through smoothly, with Jim, our Chair, Janette, our Treasurer and myself giving our reports. [Remember if you want to see the minutes, and/or a copy of the accounts, then please get in touch]. We are always looking for 'new blood' (a euphemism for new ideas and suggestions!), and we are fortunate that one of our newer members, Pam Bowker, came forward afterwards to be co-opted onto the committee.

Business over, the rest of the meeting went very well, thanks in no small part to John Williams treating us to one of his impromptu meditation/relaxation sessions. It was interesting to see how afterwards everyone started talking in small groups; proof that meditation can promote a relaxed and positive mood and atmosphere [Except for me, who fell asleep as usual! - Ed].

The pandemic has had a major effect on our lives, and it has certainly impacted on our groups activities. The most obvious consequence was the curtailment of face-to-face meetings (F2F) which are one of our main *raison d'être*. Our Zoom meetings bridged part of the gap, and it was heartening to see how many members embraced this format. However I think most people would agree that they are no substitute for the real thing! Some of our members have understandably been reluctant to join in our recent F2F meetings, and we missed you! Hopefully that situation will improve. Our next meeting with Fara will be an ideal opportunity to get back to 'normal', particularly if the weather is reasonable, so we can practice outside as we did before.

Many thanks to those who have renewed their subscription to the group, and we hope many more of you will continue to be part of the CTSG community.

Investigating tinnitus subgroups based on hearing-related difficulties*

Meaningfully grouping individuals with tinnitus who share common characteristics (i.e., subgrouping, phenotyping - observable characteristics that can be measured in the lab.) may help tailor interventions to certain tinnitus subgroups and hence reduce outcome variability.

Purpose

The purpose of this study was to test if the presence of tinnitus subgroups are discernible based on hearing-related comorbidities (the simultaneous presence of two or more diseases or medical conditions in a patient), and to identify predictors of tinnitus severity for each subgroup identified.

Methods:

An exploratory cross-sectional study was used. The study was nested within an online survey distributed worldwide to investigate tinnitus experiences during the COVID-19 pandemic. The main outcome measure was the Tinnitus Handicap Inventory (THI) - Screening Version.

Results:

From the 3400 respondents, 2980 were eligible adults with tinnitus with an average age of 58 years and 49% being female. A three-cluster solution identified

distinct subgroups, namely, those with tinnitus-only (44%), those presenting with tinnitus, hyperacusis, hearing loss and/or misophonia (27%), and those with tinnitus and hearing loss (29%). Those with tinnitus and hyperacusis reported the highest tinnitus severity and those with tinnitus and no hearing loss had the lowest tinnitus severity. Younger age and the presence of mental health problems predicted greater tinnitus severity for all groups.

Conclusion:

Further exploration of these potential subtypes are needed in both further research and clinical practice by initially triaging (determining the priority of need and proper place of treatment) tinnitus patients prior to their clinical appointments based on the presence of hearing-related comorbidities. Unique management pathways and interventions could be tailored for each tinnitus subgroup.

*Among 11 co-authors of this study was Dr Eldré Beukes, Dr Davis Baguley and David Stockdale, BTA CEO

JIM'S PIECE

As I look out of my window right now, the sun is shining, the sky is blue, the trees are green again and some are becoming decorated with the colour of spring blossom, and it makes me feel full of hope. On another day it might be grey, and then it's harder to feel quite so joyful and positive. I guess it's the same with our various aches and pains, not to mention the Tinnitus word! On days when they are more intrusive, maybe because we are tired or stressed, we can try and draw on the hope we felt by recalling the sunny days. Practising meditation can also be a great help, as those who have benefitted from John Williams wonderfully relaxing meditation sessions during our meetings can testify. Let us hope for many sunny days, literally and in our spirits until our next meeting.

With Best wishes

Jim Infield
CTSG Chair

A team of scientists behind Frequency Therapeutics, a MIT spin-out biotechnology company, claim to have developed a new type of regenerative therapy that can reverse hearing loss, without the need of hearing aids or cochlear implants. By programming special kinds of human cells called progenitor cells, a descendent of stem cells in the inner ear, the team discovered a new way to encourage the growth of hair cells inside the cochlea.

The hair cells allow us to hear, but they die off over time or when exposed to excess noise. They usually don't grow back, but allowing the ear to regenerate them could bring back at least some degree of hearing. In our experiments, the team was able to improve trial participant's ability to perceive speech. While that may sound oddly specific, there is a good reason.

In a statement, Frequency co-founder and CEO Chris Loose, said, "Speech perception is the number one goal for improving hearing and the number one need we hear from our own patients." After a single injection, several subjects showed

(From recent article in Sci Tech Daily

statistically significant improvements in speech perception, with some responses lasting almost two years in Frequency's first clinical research.

To date, the company has dosed over 200 people and found clinically significant improvements in speech perception in three different clinical investigations. Another study found no difference in hearing between the treatment group and the placebo group, however,

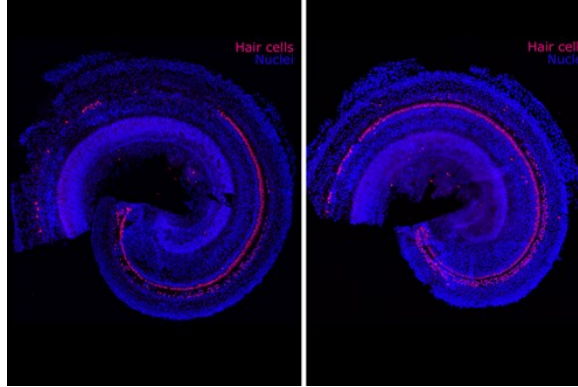
the manufacturer attributes this to possible problems in the trial's design.

The company is recruiting for a 124-person trial from which preliminary results should be available early 2023.

Frequency co-founder Jeff Kamp said, "I wouldn't be surprised to see in 10 to 15 years, because of the resources being put into this space and the incredible science being done, that we can get to the point where reversing hearing loss would be similar to Lasik surgery, where you are in and

out in an hour or two and you can completely restore vision." "I think we will see the same thing happening for hearing loss," he added.

Link to the article is tinyurl.com/4cxywrmn



Images show cellular regeneration (in pink) in a preclinical model of sensorineural hearing loss. Control is on L, Treated on the R

AWKWARD BRITISH PROBLEMS:

- Staring at your phone in silent horror until the unknown number stops ringing.
- Equally, the relief when someone doesn't answer their phone within three rings, and you can hang up.
- "You'll have to excuse the mess" – Translation: I've spent seven hours tidying in preparation for your visit.
- Indicating that you want the last roast potato by trying to force everyone else to take it.
- The overwhelming sorrow of finding a cup of tea you forgot about.
- Saying hello to a friend in the supermarket, then creeping around like a burglar to avoid seeing them again.
- Punishing people who don't say thank you by saying "you're welcome" as quietly as possible.
- Overtaking someone on foot and having to keep up the uncomfortably fast pace until safely over the horizon again.
- "Sorry, is anyone sitting here?" – Translation: Unless this is a person who looks remarkably like a bag, I suggest you move it.
- Not hearing someone for the third time, so just laughing and hoping for the best.

The international vocabulary of tinnitus

(Edited from Frontiers in Neuroscience article)

The overall purpose of this study was to scope out the international vocabulary that is in present use to describe tinnitus. Words or phrases for tinnitus in as many languages as possible were collected and a review of the meanings and connotations was performed. By comparing the survey results between participants that did experience tinnitus themselves and participants who did not, we wanted to shed light on the lived experience of tinnitus, but also indicate discrepancies between those and the understanding and vocabulary of clinicians and researchers.

There has not been an international cross-sectional analysis of the vocabulary used for tinnitus. In this study, with 227 respondents (of which 53.3% experiencing tinnitus themselves), we report such an analysis of 252 words or phrases, from 42 languages and 48 countries. The results indicate that the majority of vocabulary used has a negative connotation (63%), though a small minority are positive (4%) [Really? - Ed]. Many words used for tinnitus in different languages are onomatopoeic - thus mimicking aspects of the percept experienced - or describe the sound (in total 42% of the vocabulary).

The involvement of the ear is implied in some terminology, though other vocabulary expresses the impact. Participants experiencing tinnitus significantly differed on the codes for their proposed words or phrases ($p < 0.001$), with the code "internal suffering or irritation or intrusion" being more prevalent compared to "relate to ear" and "sound is phantom or not real or imagined". This research has implications not only for the vocabulary used for tinnitus in PROM (Patient Reported Outcome Measures) but also, and importantly, for understanding the vocabulary and lived experiences of people with tinnitus by healthcare professionals.

David Stockdale retires from BTA

David Stockdale is stepping away from the British Tinnitus Association (BTA) after 12 years, during which time the organisation has become transformed. Prof David Baguley met with David in the spring sunshine to reflect on past, present and future of the BTA, and tinnitus in general.

Had you heard about tinnitus before you joined the BTA as CEO?

No! it wasn't really anything that I was aware of prior to joining the BTA. Although in my research for the role, I saw the real potential the BTA had to be an advocate for the tinnitus community and to achieve goals far greater than the sum of its parts.

What were your first impressions of the tinnitus clinician and research communities?

Very open and welcoming. There was a real passion there for a strong BTA; to act as a patient advocate, to push for better clinical services and to do this from a place of partnership and collaboration. I have always been humbled by how much support there is for the BTA from all professions. I remember meeting you for the first time in your office in Addenbrooke's along with our colleague and now friend Don McFerran and discussing our hopes for the BTA and what could be achieved in the future. A lot of water has flowed under the bridge (and a few beers!) since then but hopefully the whole community feel proud of their input into making the BTA what it is today.

The BTA has thrived under your leadership. What do you consider to have been your greatest triumphs?



Preparing to run the York 10K to raise funds for BTA

Very kind of you to say. I like to think there have been one or two successes. I see the BTA as having two key remits: supporting people to manage tinnitus well now and pushing for progress towards a cure – or cures – for tinnitus. So, if we look at those, firstly in the support side, I was immensely proud to see us open our 100th tinnitus support group in 2018. We invested in infrastructure to encourage support groups to open in 2012, when there were just over 30 left around the UK. I believed if we put in the resource and support, we could reverse the decline and encourage groups to form and open. We knew that tinnitus could be incredibly isolating and support groups could really help.

On the research side, it has been a much longer journey but the narrative the BTA has put together in why better management of tinnitus and ultimately a cure is needed is something I am proud of, and I am hopeful it will support the advancement of our knowledge of

tinnitus at an accelerated pace.

This started with us looking at the economic cost of tinnitus to the NHS and UK more broadly. We then developed the "cure map" detailing tinnitus research to date, which was published in a paper you and I were co-authors of: 'Why is there no cure for tinnitus?' I believe this is one of the most widely read tinnitus papers of all time. It clearly set out the stall for what was needed and led the BTA to lobby government for more funding to be invested in tinnitus research. There is now a UK Government working group looking at how this can be achieved.

And any notable failures?

Ah! Yes – I think as proud as I am of our impact on research, I am leaving frustrated we couldn't do more and have achieved what we did faster. I always hoped I was an advocate of the patient voice within the



David Stockdale and David Baguley reflecting on an action-packed AAA meeting in the Indianapolis sun in 2017

research community and sought to communicate their desperation for better management and cures. That voice needs to continue to be present and heard by the research community and acted upon. I do hope patients get the hope and progress they so desperately want in the not-too-distant future.

If there's a young otologist or audiologist reading this, and thinking of getting involved with tinnitus work, how would you suggest they begin?

Do it! There is such an opportunity to make a difference both clinically and scientifically – it is an exciting time to be involved in the field.

CHUCKLES

- An elderly gentleman had serious hearing problems for a number of years. He went to the doctor and the doctor was able to have him fitted for a set of hearing aids that allowed the gentleman to hear 100%. The elderly gentleman went back in a month to the doctor and the doctor said, "Your hearing is perfect. Your family must be really pleased that you can hear again." The gentleman replied, "Oh, I haven't told my family yet. I just sit around and listen to the conversations. I've already changed my will three times!"
- Tom takes a short cut through a graveyard at midnight and is disturbed to hear a regular tapping sound. The noise gets louder and Tom stumbles across a man in a suit tapping away at a headstone. Tom looks over his shoulder and sees he's adding an 'e' to the end of the name carved in the stone. 'Bit late for work like that isn't it?' 'Yes,' says the man. 'But it couldn't wait. They've spelt my name wrong.'

David Stockdale and the CTSG

June 2010

'When Avril stepped down as Chairman at our June meeting, it was a milestone in the group's history. She always preferred to be called Co-ordinator, even in the beginning when she was involved in the formation of CTSG way back in 1987, and had been its main driving force ever since. It therefore seemed appropriate that the person who would formally mark the occasion and present Avril with her Peace Lily (and balloon!) should be David Stockdale, recently appointed BTA CEO (pictured right with Avril)'.
 [I'm really pleased that our initial assessment of David was so accurate. He has turned out to be an excellent CEO for the BTA, and under his guidance the organisation has become a real force for advancement in the tinnitus world. He will be sorely missed - Ed]



'Our June meeting* promised to be a rather special occasion because our guest speaker was BTA CEO David Stockdale, and this was to be his first visit to a tinnitus support group since he took up his post in February. It was therefore going to be a learning experience for both of us!'

* "Working for the BTA"

'David then fielded several questions from the audience before ending his talk, and he stayed on afterwards to talk to the committee and members. In fact, to his Immense credit, he was virtually the last one out the door! If he is prepared to listen like this to interested parties and take on board some of their ideas, then this bodes well for the future development of the BTA and its membership. He certainly impressed your reporter, and I suspect quite a few more people in the audience.'

[I'm really pleased that our initial assessment of David was so accurate. He has turned out to be an excellent CEO for the BTA, and under his guidance the organisation has become a real force for advancement in the tinnitus world. He will be sorely missed - Ed]

February 2012



'For our first meeting* of 2012, the group was again pleased to welcome as their speaker BTA CEO, David Stockdale. The group were lucky he was there at all, as he was in the process of moving house that very weekend. The cynical among us might have thought this was actually a good wheeze to get him out of the packing, but I'm sure that wasn't true!

David rounded off his talk with a lively Q & A session, and he was warmly applauded for a thoroughly interesting and informative talk, and for sharing his crystal ball with us. Who knows what will have come to pass on the tinnitus front when he next visits us.'

* "Recent work and future plans for the BTA"

February 2015

David's third visit to us was in early 2015, with a talk entitled: "Tinnitus Research Update". Unfortunately I have lost most of the original CTSG material from 2015, including David's talk and my report. The only material I have are couple of photos of him speaking to us. This is the best one.



June 2017 CTSG's 30th Anniversary!



Although we weren't to know it, this was David's last visit to us.

'David has a special affection for the CTSG as we were the first group he spoke to after joining the BTA. [We didn't know that at in 2010 the CTSG was one of only 30 support groups in the country – Ed] He admits being very nervous at the time, but we must have been kind to him because he has spoken to us several times since, including today!

Mention was made earlier of the use of acronyms, and David described searching for BTA on the web when he joined, only to find his organisation was only third below the British Triathlon Association and the British Toilet Association!

He says they use the acronym less frequently now, and as a result their organisation is now more recognisable!'

THE SOUND OF SILENCE - the urgent need for a Tinnitus Biobank (sourced from the *Quiet* magazine)

During Tinnitus Week 2022, the BTA called for the establishment of a Tinnitus Biobank to deliver a step-change in the race to find tinnitus cures.

What is a biobank?

- A biobank is a collection of biological data which helps to inform, develop and build a picture of a health condition.
- Existing biobanks are of limited use as they have very little data about hearing loss and tinnitus.
- A Tinnitus Biobank would be developed specifically for furthering research into the condition.

What do we want from the Tinnitus Biobank?

The Biobank would have several aims, including:

- finding a biomarker for tinnitus
- finding an objective measure for tinnitus
- Ultimately, we hope that these will help develop a pathway to finding a cure for the condition.

What is a biomarker?

A biomarker is a naturally occurring molecule, gene or characteristic by which a particular process in the body or disease can be identified.

Why do we need an objective measure?

The current questionnaires used to measure tinnitus have limitations. An objective measure of tinnitus would allow future treatments to be more accurately assessed and would ultimately confirm a 'cure'.

And what is a sub type?

A sub type is a special type included in a more general type. So pulsatile tinnitus might be regarded as a sub type of tinnitus, for example. Researchers think there could be more of these.

Is the Tinnitus Biobank going to be expensive?

We believe the Tinnitus Biobank would cost about £4 million to set up, which is 0.53% of the £750 million that tinnitus costs the NHS each year. As we picture it, the Tinnitus Biobank would be the largest single tinnitus research project outside of pharmaceutical research. We are calling on the UK government and research funders to fast-track their support for tinnitus research funding to establish the Biobank.

You can also donate to their Tinnitus Research Appeal online at www.tinnitus.org.uk/donate or over the phone on 0114 2509933.

How can I get involved?

You can sign up to be a potential tinnitus biobank participant or to be kept updated about alternatives biobank plans by visiting our website at www.tinnitus.org.uk/biobank.

If you are interested in taking part in the biobank, you will need to be 18 or over and live in the UK.

Can people who don't have tinnitus take part?

Absolutely! We will be looking for people with and without tinnitus to take part in our Tinnitus Biobank.

Where can I find out more?

From the above website:

- listen to our podcast
- watch our short animation
- download our White Paper.



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](#)

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. Reports and comments expressed in this newsletter do not necessarily reflect the views of CTSG.

Our next meeting is on Saturday 17 September at the Meadows Centre, where our speaker will be Dr James Jackson, Reader in Psychology, from Leeds University. James will be talking about his research involvement with the smartphone app Tinnibot. James was booked to speak to us in April, but unfortunately was unwell.