Cambs Tinnitus Support Group

No. 166 NEWSLETTER April 2023

MEETING

Saturday 15 April

at

10.00 for 10.30 am

"The Upper Cervical Spine and Tinnitus"

Speaker: Elliot Swepson, DC
Chiropractic Tinnitus Practitioner
TOPCHIRO

I'm Elliott Swepson DC, a Chiropractor based in London, specialising in Upper Cervical Specific Chiropractic. In our practice we focus on assessing the biomechanics of the upper cervical spine and its impact on the nervous system and brain function. I work with a variety of patients with different conditions, one of which is Tinnitus. I will be giving a talk on Upper Cervical Specific Chiropractic care and how we can help patients with Tinnitus.
Elliott is registered with the General Chiropractic Council (GCC), a member of the United Chiropractic Association (UCA) and a member of the International Federation of Chiropractors and Organisations (IFCO).

New Meadows Community Centre

1 St Catherine's Road, Cambridge, CB4 3XJ, off
the junction between King's Hedges and Arbury Rds
(I will inform you of carparking arrangements when they are known)

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Refreshments and Raffle

EDITOR'S CHAT

We had hoped that our first meeting in 2023 would be held in the new building, however it was not to be, so we gathered in room 2 for our last meeting in the old building. A heartening number of 32 guests and newcomers turned out, making it the best attended meeting since the lockdown began. Additionally three newcomers joined on the day, which was the icing on the cake! It had been 4 years since our speaker, Nic Wray, had visited us, and it was perfect timing given the rebranding of BTA to Tinnitus UK had only taken place in early January. The process had been going on for nearly 2 years, and Nic was in the thick of it from the start. Turn to pages 3 and 4 for my report. Unfortunately, just before the Q & A session my audio recorder ran out of memory - this has never happened before – and hopefully it will never happen again!

Because of the pandemic, the last time the CTSG took part in Tinnitus Week (or Tinnitus Awareness Week as it was known then) was February 2018, when Sue Peacock organised a 3 day stint at Hinchingbrooke Hospital, and I managed 1 day wedged outside Clinic 10 at Addenbrookes (our normal Food Court site being unavailable). There was no real expectation of organising an event this year, a) because of the uncertainty of the rebranding exercise mentioned earlier, and b) the Addenbrookes venue has to be booked months in advance. Hopefully next year we will be able to put on some form of event.

Most of you will by now will have had a chance to look at the Tinnitus UK website. Within the confines of the newsletter, I've tried to give you a flavour of what they are trying to achieve , and my reaction has been positive. But what do you think? It would be really interesting to get some written feedback from yourselves which I can incorporate into the newsletter. Now is your chance to tell us what you think.

Did you know that listening to crickets can be good for your tinnitus? Me neither. I came across this link recently (https://tinyurl.com/3x8an9ut) which opens to a YouTube page. I must admit it was quite calming, although listening to it for an hour, which is what is recommended, would probably be too long!

Finally, the end of March marks the end of our financial year, which means it's subs time for all but our newest members. You will know if you get a reminder attached to the covering e-mail.

In the last newsletter this symbol was displayed. I wonder how many of you knew what it represented. No prizes if you did, but for the uninitiated, Badger is a new product developed by Satellite Displays to help to improve communication for those with poor hearing.

Badger is a closed captioning smart badge that is used to convert speech to text in real time in more than 50 languages. It helps those with hearing loss follow conversations more easily when the other person is wearing the Badger badge, especially in circumstances where lip reading is impossible if the person speaking is wearing a face mask, such as in healthcare settings.

The wearable badge first captures the speaker's voice and transmits it to a smartphone. Next, the smartphone converts the audio to text and transmits it to the smart badge. The smart badge then displays the text like closed captions. '*The single biggest problem in communication is the illusion that it has taken place."*

For a short demo: https://tinyurl.com/mrby2626

Noisy neighbourhoods – how they can cause tinnitus

In a new study with data from 3.5 million Danes, researchers from the University of Southern Denmark found that the more traffic noise Danish residents are exposed to in their homes, the more they are at risk of developing tinnitus. The researchers identified a vicious cycle: living near busy traffic increases stress levels, disrupts sleep, and, as a result, leads to higher risk of developing tinnitus.

This study is the first time researchers have found a link between residential traffic noise exposure and hearing-related outcomes. And for every 10dB rise in noise in people's homes the risk of developing tinnitus increases by 6%. The study team also believe that noise at night time can be even worse for health, because of its impact on sleep.

To try and tackle sleep disturbance in people who live near busy roads, Germany has lower speed limits in some areas at night. Noise barriers and changing the road surface to one that dampens tyre noise can also help. Other suggestions to reduce the impact of traffic noise include moving beds to the side of the house furthest from the road and installing double or triple glazing.

JIM'S PIECE

I was so inspired by our last meeting, and hope you felt the same. It was one of our best turnouts and affirms that CTSG is working for you. We were very privileged to have Nic Wray, the Communication Manager for Tinnitus UK, speaking to us - such a knowledgeable, committed and positive advocate for the organisation, and she created such a positive vibe in the room, with a lively Q&A.

It's great that we can once again be meeting face to face after all the challenges of the last few years. It's also encouraging that we regularly have new members joining the group. I hope they feel welcomed [*I'm sure they do* – Ed] and the meetings valuable, especially as many may travel quite a distance. Of course it also feels good to see familiar faces too.

I apologise for not being able to attend the next meeting as I am writing this on my travels, Bangladesh again this time !

Best wishes

Jim Infield
CTSG Chair

February meeting

Report by Alan Yeo

On a dry, if chilly morning, we welcomed Nic Wray, Communications Manager of Tinnitus UK, for her second visit to the Meadows Community Centre. Nic has been with the charity for nearly 13 years and is now the longest serving member of staff, and the oldest, and admits that sometimes it definitely feels like it! Her responsibilities are wide (see details in February's newsletter), and recently Nic was heavily involved with Tinnitus Week. The purpose of her talk was to explain why the BTA became Tinnitus UK, hence the title of her talk:

Our speaker Nic Wray

'Facing the Challenges'

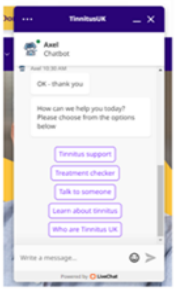
The name change happened on the 9 January this year, although the process had taken almost 2 years; much of the delay due to legal issues involving the Charity Commission and Companies House.

Why did they do it? There were many reasons. When the British Tinnitus Association formed in 1979, under the secretariat of the RNID, it was an association of self-help groups and pockets of volunteers. However, over time, although we were respected for our efforts, the name didn't really explain what we did, and caused confusion by being shortened to BTA (British Toilet Association anyone?), so that search engines couldn't easily find us.

The new name is shorter, snappier and tells everyone what we do ('it says what we are on the tin') and it will increase our visibility to those who need help, and tell them what we can offer. In the UK 1 in 7 have tinnitus, which equates to ~ 7.5 million people, and Nic thinks the charity currently reaches ~ 1.3 million of them. This is a big gap. Possibly some 5 – 6 million people could do with some help and support, even if it's a reassurance that they are not alone, and something can be done. Our aim is for all those other people to be aware of us, and the name change will help this process. Tinnitus UK did a lot of work behind the scenes, asking opinions of people within the CTSG, clinicians and audiologists; and the majority of opinions were positive. We have a vision where no-one is troubled by their tinnitus, and this hasn't changed.

What has changed or new

A lot of effort has gone into increasing the functionality of the website, now with an Events Calendar, Support Group Directory and a Chatbot. Some 760 pages of website content have been refreshed, and the new Chatbot (named Axel after ex-colleague Collette Bunker's dog, and funded by a big lottery) will help guide newcomers around the site. Live Webchat is available during normal working hours, but Chatbot helps answer simple queries at any time, freeing up the team to answer more complex questions during normal working hours.



Tinnitus UK have also changed their social media handles, however despite all our efforts Facebook still has them down as BTA! Another social media feature Instagram has also been sharpened up to try and make it more eye-catching.

Our leaflets are being refreshed (by yours truly!) and our popular Living with Tinnitus booklet has doubled in size (Nic had hoped to have samples to show us, but the Royal Mail had other ideas!). A monthly newsletter called Focus has been launched, and anyone can sign up on the website, or ring up.

Another new feature on the website is the Treatment Checker. Nic explained this is based on treatment sheets which give advice on Safety: (1-regarded as safe, 2-some potential harm, 3-evidence of harm) and Efficacy: (1-evidence it is effective, 2-no or limited evidence it is safe, 3-evidence that it is not effective). These sheets are interactive and downloadable. Some 77 sheets are complete, with some 90 to go! This item is the most visited section on the website, and a useful introduction to Tinnitus UK itself. [For link see https://tinyurl.com/yc3yfspd]

What won't change

Nic emphasised that their values and vision hadn't changed, neither had their mission statement or existing services. Their helpline, webchat, support group network and conferences will continue as before.

Cont. on page 4

Cont. from page 3

Nic's talk was followed by a lively Q & A session. Someone asked if the Tinnitus UK had enough staff to cope with the hoped-for increase in enquiries. Nic explained that when the charity started there were 6 staff, rising to 23 at its peak. They now have 16/17.

Some of the crew at HQ!

The charity is aware of the challenge but has to work within the confines of their charitable income and funding. Tinnitus funding overall is drastically underfunded, and the charity receive no direct government help. They plan to grow, but it is the website and social media etc. that is the key to reaching new people at relatively low cost. They won't go completely digital, but it is the most cost-effective way of reaching more people who need help.

There was a lengthy discussion about how noise exposure is the most common preventable cause of tinnitus and hearing loss, and this was one of the key messages put out during Tinnitus Week. Nic brought a slide showing the noise levels that ordinary items can reach, remembering that a 3dB increase is the equivalent of doubling the noise level.

TINNITUS UK

Decibel level dB	Source of sound	Length of time	Decibel level dB	Source of sound	Length of time
85	Kitchen blender	8 hours	103	MP3 player at full volume	7 min 30 sec
88	Forklift truck	4 hours	106	Motor bike	3 min 45 sec
91	Tube train	2 hours	109	Crying baby	1 min 42 sec
94	Lawnmower	1 hour	112	Live rock band	1 min 6 sec
97	Industrial fire alarm	30 min	115	Ambulance siren	33 sec
100	Bulldozer; hand held drill	15 min	140	Gun shot	instantly

[*Unfortunately, at this point my recorder decided to run out of memory, thus bringing my audio recording to an abrupt halt!* - Ed]

At the end of questions, Nic was given a well deserv - ed round of applause for a thoroughly interesting talk.

WICKED WIT

● At my age I do what Mark Twain did. I get my daily paper, look in the obituaries page and if I'm not in there, carry on as normal. *Patrick Moore* ● Nature, not content with denying him the ability to think, has endowed with the ability to write. *A E Houseman* ● If Kitchener was not a great man, he was at least, a great poster. *Margot Asquith* ● Either that wallpaper goes, or I do. *Oscar Wilde's last words.* ● An archaeologist is the best husband any woman could have; the older she gets, the more interested he is in her. *Agatha Christie* ● I have no interest in sailing round the world. Not that there is any lack of request for me to do so. *Edward Heath*

Ground-breaking tinnitus test paves the way to new treatments

A ground-breaking diagnostic test under development at the Bionics Institute in Melbourne could pave the way to new treatments for Australians with tinnitus.

Lead researcher Dr Mehrnaz Shoushtarian says the fact that there is currently no objective test to diagnose tinnitus or measure its severity means that doctors are often unable to help those affected.

"We have developed a test that can distinguish between mild and severe tinnitus with 87% accuracy using light technology to read brain activity that is analysed using artificial intelligence," she said.

"Our aim is to provide clinicians with a reliable diagnostic test to assess if a treatment is working, and also give researchers the information about brain activity in tinnitus needed to develop new treatments," she concluded.

Pioneering Technology

Bionics Institute CEO Robert Klupacs says the test is an excellent example of bioengineering innovation at its best.

He explained: "Dr Shoushtarian's team uses a technology called functional near-infrared spectroscopy (fNIRS), a non-invasive brain imaging technique that measures blood oxygen changes in the brain."Her team has shown that we can diagnose tinnitus with incredible accuracy in a small clinical study."

"We are now seeking funding to develop a portable version with easy-to-use software that can be trialled for use in clinics in Australia and around the world."

About the technology

The new diagnostic test imaging device shines near infra-red light over the head using light sources set into a cap. The brain's blood oxygen levels effect the amount of light reflected back, which is measured by detectors in the cap. The reflex light is analysed using a special algorithm to provide detailed information on brain activity. The device is portable, non-radioactive, quiet and safe to use with implanted devices such as pacemakers.

The fNIRS cap used to measure blood oxygen changes in the brain

Tinnitus can be defined as the perception of sound in the absence of any external sound stimulus. According to the World Health Organization, approximately 15% of the world's population have tinnitus and this prevalence increases with age.

A population study carried out in the city of São Paulo report that 22% of the population had tinnitus, although It did not appear to affect the daily activities of most patients. However, it can have negative implications for the quality of life in some of the patients, with proven relationships with difficulty in attention, concentration and depression. This group demands more care from health professionals, although all tinnitus should be inquired, regardless of its repercussions.

The study of tinnitus forces the physician to dive into the anatomical and physiological universe of the auditory pathways and their connections in an attempt to understand its origin and the reactions it can cause. The knowledge of the various neural networks involved in the different aspects of the symptom meant tinnitus could no longer be seen only as an auditory phenomenon but could also be considered a sensory, cognitive and emotional disorder. The generation occurs mainly in the peripheral auditory pathways, detection occurs in the subcortical centres, but the perception takes place in the auditory cortex, which makes each patient experience different reactions to the symptom.

The simultaneous presence of two or more medical conditions in a patient may be associated with tinnitus. Among the main ones, the cardiovascular, metabolic, hormonal, neurological, somatosensory causes and diseases stand out. This way, tinnitus may be the initial manifestation of several ear or systemic diseases. But depending on the impact of tinnitus on the affected individual, areas of the limbic system [the part of the brain involved in our behavioural and emotional responses], and the autonomic nervous system [regulates heart rate, blood pressure etc.] that increase patient discomfort, may be activated. The cognitive behavioural process contributes to its severity through negative thoughts, selective attention, and hypervigilance (fight or flight?) Therefore, it is essential to distinguish between tinnitus and the reactions caused by it. For that purpose, questionnaires assessing and quantifying tinnitus and its effects on the patient's life can be used [e.g. Tinnitus Functional Index].

The diagnosis of the factors involved in the origin of tinnitus is the greatest challenge in the management of these patients. Once this difficulty has been overcome, the next stage consists of an art: treatment. Science has been very generous on this point and several tinnitus treatment options are emerging. The art consists of knowing how to choose and use each one of them. Treatment must consider not only the investigation of the causes (etiology), but also the patient's reactions and expectations regarding the condition.

However, regardless of the therapy chosen, counselling is the main component of all of them. Explaining to the patient the reason for the tinnitus often reduces the negative reactions related to it. Subsequently, the treatment of the causes involved in the origin of tinnitus is necessary in an attempt to improve or even eliminate the symptom. Unfortunately, this is not always possible because the cause is unknown or because the patient has marked perception of tinnitus at the cortical level that makes it difficult to improve. However therapeutic actions can focus on creating methods to ignore information related to tinnitus.

Cognitive behavioural therapy aims to identify and change the emotional meaning of tinnitus. Another possible approach is mindfulness, which has been demonstrating benefits on tinnitus, reducing annoyance and facilitating its acceptance by the patient. A third way to improve this situation is acupuncture. Similarly there are two other treatment modalities that act on the central auditory pathways, which are transcranial magnetic stimulation, which modulates neuroplasticity in cortical and thalamic areas, and neuromodulation, whose mechanism of action in tinnitus is attributed to interference on the inputs coming from the central auditory pathways and their associated circuits that reach the cerebral cortex.

Due to the strong association between tinnitus and hearing loss, improving acoustic stimulation to hearing stimulation to overcome the lack of stimulation of the auditory pathways is critical. In this sense, the use of hearing aids and/or sound generator are the first treatment option. In addition, environmental sounds also can help to reduce the perception of tinnitus. Sound therapy is also indicated for patients with tinnitus and normal hearing.

To date, there is no medication with specific indication for the treatment of tinnitus. However, many of them can be useful in controlling associated symptoms such as depression and anxiety or improving the function of the inner ear and their choice must consider the patient's needs. Some options are drugs that improve vascular supply, inner ear metabolism and neuronal function (ginkgo biloba, vitamin D, vitamin B12, zinc), drugs that act on ion channels (Gabapentin and Carbamazepine), drugs that act on neurotransmitters, (clonazepam, selective serotonin reuptake inhibitors, cyclobenzaprine) etc.

The variety of factors that can generate tinnitus and influence the degree of discomfort point to the need for an individualized and generally interdisciplinary approach. Maybe the best approach is counselling and offer sounds. But there are several instruments available to treat tinnitus and improve the negative reactions caused by it. Unfortunately, some are only available in research centres, but the majority are accessible to all patients.

It is up to the conductor to choose which instrument or instruments to use and to conduct the orchestra.

Tinnitus UK award Marie and Jack Shapiro Prize for research into the genetics of tinnitus

Tinnitus UK has announced the award of the Marie and Jack Shapiro Prize to a study that looked at a possible genetic component to tinnitus

The prize was judged by Tinnitus UK's Professional Advisers' Committee, who commented: "The authors of this study have used the records of over 170,000 participants in UK Biobank to identify a gene they newly link to the risk of developing tinnitus. Importantly, the gene was not linked to hearing loss, but seems to have an independent link to tinnitus. Future research on this gene might help to identify mechanisms of tinnitus or develop new treatments."

Professor Frances Williams, King's College London said: "The teams at Twin Research, King's College London and the Ear Institute, University College London are really delighted to be awarded the Shapiro prize by Tinnitus UK for our collaborative work on the genetics of tinnitus."

"Understanding the genetic factors underpinning tinnitus is one of the approaches we can use to identifying the biological pathways of importance, and from this to develop targeted therapies. We are indebted to the many volunteers at UK Biobank who gave so generously of their time and their samples and allowed research on large samples such as this to take place. We are building on this work by recruiting further cohorts and hope to expand understanding of the genetics of tinnitus in the near future."

The work was supported by a PhD studentship from the Royal National Institute for the Deaf and by NIHR funding to support the UCL Biomedical Research Centre.

Deanne Thomas, Chief Executive of Tinnitus UK, said: "We're delighted to award the Marie and Jack Shapiro Prize to this useful study. This project's findings were very interesting and indicate that there are possible genetic risk factors for developing tinnitus. The study shows the potential benefits that a dedicated Tinnitus Biobank could bring, allowing us to understand the condition much better and answer many other questions that, thanks to chronic underinvestment, so far remain unanswered."

The Marie & Jack Shapiro Prize is given each year by Tinnitus UK to the piece of published research, by a UK-based author, 'most likely to result in improved treatment or public awareness of tinnitus', that was published in the last calendar year. The prize is named after the late Jack Shapiro and his wife Marie, who both played an important role in the establishment of the charity and in raising awareness of tinnitus.

CHUCKLES 1

Rodney walks into a bar and says, 'Bartender, give me 2 beers. One for me and one for my best buddy here.' So saying he pulls a 3-inch man from his pocket. 'Wow!' Says the bartender. You mean to say that little guy can drink a whole beer? 'Sure,' says Rodney, so the bartender pours a beer and the little guy drinks it all up. 'What else can he do?' says the bartender. 'Can he walk?' 'Sure,' says Rodney, and flicks a coin to the end of the bar. The little guy runs to the end of the bar, picks up the coin and runs back again. 'That's amazing,' says the bartender. 'What else can you do? Does he talk?' 'Sure,' says Rodney, turning to the little guy. 'Hey, Dad, tell him about the time you were in Africa and you really upset that witch doctor?'

CHUCKLES 2

A chicken runs into the library, goes to the main desk and says, 'Book. bok bok boook.' The librarian hands the chicken a book and it tucks it under its wing and runs out. A while later, the chicken runs back in, throws the book on the desk and says, 'Boook, bok, bok, boook.' Again, the librarian gives it a book and the chicken runs out with it. A few minutes later, the chicken is back, and returns the book saying, 'Boook, bok, bok, boook.' The Librarian gives the chicken in a third book, but this time follows it as it runs out. The chicken runs down the street, through a park and down to the river, where a frog is sitting on the bank. The chicken holds up the book to the frog, saying, 'Boook, bok, bok, boook.' The frog replies, 'Read-it, read-it, read-it…..'

Please remember

This is your newsletter and all comments, letters, contributions or editorial copy relevant to tinnitus or CTSG, or anything you think maybe of interest to our members would be very welcome. Please send to:- Alan Yeo, c/o Newsletter Editor, 4 Claygate Road , Cherry Hinton, Cambridge CB1 9JZ (Tel. 01223 243570 alanyeo70@gmail)

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

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

Our next meeting is on Saturday 17 June at the new Meadows Centre, where our speaker is Dr James Jackson, from the Department of Psychology and Therapeutic Studies at Leeds Trinity University. This talk was scheduled for April of last year, but unfortunately James was unwell and we had to postpone. Hopefully he will be O.K. to speak to us this year.