

Cambs Tinnitus Support Group

No. 145

NEWSLETTER

February 2019

MEETING

Saturday 16 February

10.00 for 10.30 am

“FIVE YEARS later:

What happened after the James Lind Alliance Tinnitus Priority Setting Partnership?"

Speaker: Nic Wray
Quiet Newsletter Editor

Nic has been Communications Manager at the BTA since June 2010. She is responsible for the BTA's communications online and in print as well as being one half of the PR team. In addition to writing a number of the BTA's information leaflets, she also edits the BTA's journal, *Quiet* and co-edits the *Annual Tinnitus Research Review*. She sees providing the tinnitus community with information as a key to helping people live well with tinnitus. A graduate of the University of Sheffield, she is an Accredited PR Practitioner and a member of the Chartered Institute of Public Relations.

Meadows Community Centre

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

CONTENTS

2. Editors Chat ~ Do try this at Home ~ Jim's Piece
3. Single - sided Deafness-an Audiology Update ~ A Report on our November meeting
4. Hearing aids for tinnitus - the HUSH trial ~ Chuckles
5. Listening - a Workout for the Brain ~ Prize-winning Tinnitus Research
6. Reflections on Tinnitus Research ~ Wicked Wit ~ Talking Tinnitus Expo

Refreshments and Raffle

EDITOR'S CHAT

I hope your Xmas break was enjoyable and that Father Christmas was very generous!

The James Lind Alliance (JLA) Tinnitus Priority Setting Partnership (PSP) began in October 2011, bringing patients, carers and clinicians together to identify and prioritise the unanswered questions about tinnitus treatments that they would agree were the most important. The main purpose was to bring the 'minority' voice to drive the research agenda. The priority setting process produced a final top ten clinical research questions, and in February Nic Wray, BTA Communications Manager, is coming along to explain what progress has been made towards answering these questions. Not a meeting to be missed.

February also means Tinnitus Week 2019 (BTA seemed to have dropped Awareness from the title), so the CTSG will have a presence at both Hinchingbrooke (4th & 5th) and Addenbrookes (8th) Hospitals, so if you are in the vicinity during those days, do come along and have a chat. The focus this year is on the problem of people feeling isolated with their tinnitus, and how this can impact their lives. The BTA will be exploring this theme, and hoping to point people in the right direction for the right resources and support. And for the second year running the international tinnitus community will be getting involved to help raise awareness, and as mentioned, your committee will be doing their bit. Enjoy the newsletter!

DO TRY THIS AT HOME

Written by Nic Wray and Catherine Hall (From *Quiet* No. 4 2018)

Meditate regularly

Over time the symptoms of tinnitus can cause stress and anxiety, and incorporating regular meditation or relaxation exercises can help to keep this stress to a minimum. Stress is known to make tinnitus worse and while relaxation techniques or meditation aren't cures, they can provide stress relief which in turn can improve your quality of life.

Try Yoga

Again, stress-busting techniques such as yoga can help you to quieten a racing mind. A constant ringing in the ears can affect concentration and honing in on a particular type of yoga moves can increase your focus and allow relief from intrusive thoughts. Yoga can be done by people of all ages and abilities – search for 'chair yoga' for some simple postures.

Eradicate built-up of ear wax

Tinnitus symptoms are often caused by a build-up of ear wax and if this is the cause of your issue, preventing the buildup of wax can provide natural at-home relief. Use one or two drops of olive oil once or twice a week to prevent wax build-up and keep it moving naturally out of the ear. **Never** insert cotton buds, pens, knitting needles or other objects into the ear to try and remove ear wax.

Make a playlist

Music is known for its soothing properties, and creating

a playlist with relaxing tracks on it can help you to unwind and distract you from the tinnitus.

Download an App

Sound therapy is another option you can try to ease the symptoms of tinnitus. Whale sounds, wind chimes and rainfall are just a few of the sounds that you can use to relax. You can download an app to your phone and use these sounds as and when you need them. We'll be reviewing apps for tinnitus in the next issue of *Quiet* (Issue 1 2019) so look out for suggestions.

Run a bath

Another relaxation technique is to have a long soak in the bath. Add your favourite salts and oils and let your body and mind unwind.

Invest in ear protection

If you have tinnitus, protecting your ears from loud noises is essential. Wear earplugs or noise-cancelling headphones when exposing your ears to loud noises at home, such as drills and hedge trimmers.

Nothing working?

Speak to someone who understands. The BTA have a friendly and experienced Helpline team (**0800 018 0527**) for help and support (Monday to Friday 9am-5pm).

And don't forget your local support group! - Ed

JIM'S PIECE

Do your hearing problems also give you neck ache, or embarrassment, or maybe both? It's curious how one challenge can lead to another. I'm fortunate that my tinnitus is not as difficult to live with as it is for many of you, - it's my hyperacusis and very poor hearing in one ear that are more troublesome. There's no problem when walking or standing next to one person, as shifting round to my 'right side' (or is it the left?), to hear them is easily done. The problem arises when I'm sitting down and trying to have a conversation with a person who's on my 'wrong side'. I have to turn away, thereby losing eye contact, and looking like I'm talking into thin air. Hence the neck ache, and the general feeling of embarrassment at my odd posture! [I know *exactly what you mean* – Ed].

As with many things in life, I think the only solution is to keep a sense of humour!

I'm looking forward to seeing you at what looks like will be a very interesting February meeting, and another chance to support each other on our different journeys.

With best wishes from your chair
Jim Infield

Single-Sided Deafness - Audiology Update

A talk given to the AMNET group by Rachel Knappett last July

Introduction

The Single-Sided Deafness (SSD) population seen at Addenbrooke's hospital includes Vestibular Schwannoma patients, both following treatment and those on the 'watch and wait' protocol, sudden idiopathic hearing loss, Meniere's disease, Middle Ear disease and trauma. Internationally and locally, the current research relevant to SSD populations includes studies looking at Cochlear Implants on the affected ear to managing hearing loss and tinnitus, Quality of Life and Listening Effort. Also of interest to patients with cochlear hearing loss is the REGAIN study, which is investigating whether a new drug can generate functioning hair cells in a damaged cochlea.

In terms of managing SSD there is now a protocol that is followed so all patients are treated appropriately. The four phases of the protocol are:

- Pre-op Counselling
- Assessment (hearing tests are carried out)
- Device fitting with Audiology or the implant team
- Follow up

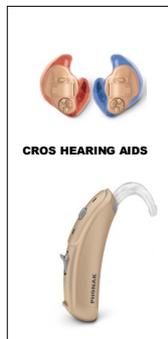
and time is taken to investigate the impact of hearing loss and associated symptoms such as tinnitus.

This will be followed by the appropriate management which may involve CROS/implantable devices, and/or hearing therapy (which involves looking at other strategies that may help), assisted listening devices and onward referral such as Sensory Services, Access to Work, Tinnitus Therapy, Psychology or Local Audiology Service.

NHS CROS technology

CROS* hearing aids are now all wireless, so they are less cumbersome and perhaps more cosmetically acceptable. However, rate of battery consumption is high (batteries lasting just a few days in some cases) and they are very expensive when compared with standard bilateral hearing aid fitting.

[*The CROS aid (actually a microphone/transmitter) takes sound from the ear with poorer hearing and transmits to the aid on the ear with better hearing. The goal of this



device is to give the patient two-sided hearing when true bilateral hearing isn't possible].

Trials are being carried out using 'Resound' hearing aids on patients good ear and a 'Multi-Mic', which is an external microphone that streams to the hearing aid via bluetooth. The mic can be positioned wherever it is needed. For people with tinnitus the aid can be set to provide a choice of sounds such as white noise or 'ocean' which can be set at a low level to 'blend' with the tinnitus, reducing awareness of it. Additional sounds (such as rain/relaxation sounds) are also accessible through Apps on smart phones and these can be streamed via Bluetooth and an additional accessory. The limitation of this is that usually SSD patients experience tinnitus in their affected ear only and the sounds are in the better ear. This can still be helpful in some cases and promotes relaxation. Some patients do have hearing loss in the better ear as well, and in these cases the sounds can be mixed with amplification or provided on a separate programme.

Looking to the future

Having outlined what is available from the service at present, Rachel considered what we might be looking for in the future. This includes the possibility of cochlear implants, although these are only possible if there is an intact auditory nerve. Other surgical solutions will no doubt continue to develop. The Audiology team would like to see other manufacturers develop CROS aid technology and consider tinnitus options. There is a growing need to address the psychological impact of hearing loss and tinnitus – AMNET has previously had a talk regarding this and Rachel feels it would be very useful to have a psychologist working alongside the Audiology team. When considering the technology that is available, factors that may improve this could include: the option for a satellite Mic (CROS system), compatible with the external microphone, advanced processing enabling connection to phone or tablet and finally the ability to stream therapeutic sound for tinnitus.

[My thanks to Rachel and Christine Richards of AMNET - The Acoustic Neuroma and Meningioma Network - for permission to use this article-Ed]

REPORT ON NOVEMBER MEETING

29 members and guests enjoyed an excellent self-help session thanks to the guiding hand of our facilitator, Rachel Knappett. A newcomer with her daughter got things rolling with a query about how she could get to sleep more easily with her tinnitus. Various suggestions were offered, including using a relaxation CD (the one Addenbrookes supplies was praised), listening to music through headphones and playing a DVD quietly. Meditation, deep breathing and counting backwards from 100 were also suggested. Rachel emphasised that getting a good nights sleep is important in helping us manage our tinnitus. The removal of excess ear wax (microsuction is best and should be available on the NHS, but few clinics offer it) and GPs that give poor service to tinnitus patients were among other numerous topics covered. It was heartening that a member who had had tinnitus for some time was able to relate and share her experiences with those of one of our newcomers. After the session everyone enjoyed the food bought for the Bring & Share brunch, and the minced pies and mulled wine were as popular as ever! Roll on November!

(Many thanks to Sue Peacock for the pic-Ed)



CHUCKLES

- Three animals, a hawk, a lion and a skunk, are arguing about which is the most fearsome. The hawk says, it's the most fearsome as he is the fastest. The lion says it's the most fearsome because he is the strongest. The skunk says it's the most fearsome because it's the worst smelling. Just then a bear comes along and swallows them all: hawk, lion and stinker.
- Did you hear about the agnostic dyslexic insomniac? He stayed up all night wondering if there was a dog.....
- A Canadian park ranger is giving some ramblers some warning about bears, 'Brown bears are usually harmless. They avoid contact with humans so we suggest attaching small bells to your rucksacks to give the bears time to get out of your way. However, grizzly bears are extremely dangerous. If you see grizzly bear droppings leave the area immediately.' 'So how do we know if they're grizzly bear droppings?' asks one of the ramblers. 'It's easy,' replies the ranger, 'They're full of small bells.....!'

Apparently Julie Andrews will no longer be endorsing Rimmel Vibrant Shades lipstick, as she claims it breaks too easily and makes her breath smell:
"The super colour fragile lipstick gives me halitosis"

**HEARING AIDS FOR TINNITUS**

(Edited from *Quiet* magazine)

In the UK, NHS audiology departments are the main provider for services for people with tinnitus and hearing loss. Garry Meakin from Nottingham Clinical Trials Unit discusses a new clinical trial for people with tinnitus.

Why do we need a clinical trial?

In the UK the most common management strategy for tinnitus is education and support and some form of sound therapy. Treatment is however variable between clinics. While all clinics tend to provide education and support, the additional management strategies (i.e. provision of devices) depends very much on individual clinical decisions. There is no rigorous research evidence for the benefits of hearing aids beyond education and support for people with tinnitus and hearing loss. There is no standard way to treat patients and the decision to fit hearing aids is left to individual audiologists.

Although hearing aids are prescribed primarily to overcome hearing loss, they may also be effective for tinnitus. Hearing aids can amplify environmental sounds and mask or provide distraction from tinnitus. They can reduce listening effort and improve communication which can reduce the stress and anxiety commonly associated with tinnitus. Other possible mechanisms include preventing changes in the brain related to hearing loss.

High-quality evidence is needed in order to decide whether patients should always be offered hearing aids.

This can be done in a clinical trial that by comparing:

Education and support (the usual treatment)

Education and support with hearing aids

This trial would need to be large and therefore some investigations are needed to find out whether it would be possible to run. This can be checked by running a smaller study, known as a 'feasibility study'. The National Institute for Health Research (NIHR) Nottingham Biomedical Research Centre (NBRC) are working alongside the Nottingham Clinical Trials Unit and the British Tinnitus Association (BTA) to conduct a feasibility study to check:

If clinicians and patients are willing to take part in a trial

what outcome measures are relevant for patients, and

what a large trial should look like.

The study is being funded by the NIHR Research for

Patient Benefit programme.

What are the patient requirements and timelines of the trial?

The trial will recruit adult tinnitus patients with a hearing loss who've been referred to one of five UK audiology clinics for their tinnitus. Recruitment of the required 100 participants is expected to take about a year, hopefully starting in October of 2018.

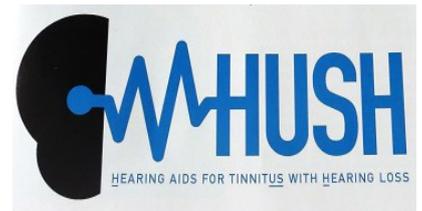
What does taking part involve?

All trial participants will be given standard care, including explanations of tinnitus and its association with hearing loss, available management strategies and counselling depending on patient need and education about lifestyle factors that may affect tinnitus. In addition to standard care, half of the patients who join the trial will be given hearing aids.

Patient involvement in the development of the HUSH trial

The importance of patient-focused research is becoming increasingly recognised throughout the field of clinical research.

Patients are not only enrolling as a participants in trials, but are assisting in all aspects of trial delivery, including and perhaps most importantly, what



outcomes are most important to patients.

This research question was voted as one of the top ten tinnitus priorities by clinicians and patients in a James Lind Alliance [JLA] Tinnitus Priority Setting Partnership. The HUSH trial has been designed and developed alongside the BTA and a patient representative who has had tinnitus for over 20 years. This support has proved invaluable and has helped to ensure that the needs of tinnitus patients are at the heart of the trial plan.

How can I help?

Recruitment will be done by audiologists at the participating audiology clinics, so the BTA or NIHR NBRC are not able to enrol potentially interested people. However, by simply raising the awareness of the you will be making a huge contribution to the success of the HUSH trial.

Listening: a workout for the brain?

(Edited from an Action on Hearing Loss [AoHL] *Soundbite*)

For people with hearing loss, trying to hold a conversation in a noisy environment, such as a busy cafe, can feel exhausting. But why is this? Dr Ian Wiggins, a researcher from the University of Nottingham and AoHL's new Pauline Ashley Fellow, outlines his research in this area and his future plans.

When someone has a hearing loss, the signals that the ears send to the brain become less clear. The brain may have to work harder to make sense of these. Our research aims to understand what goes on in a person's brain as they struggle to understand speech.

Measuring brain activity with infrared light

We measure brain activity using a technique called functional near-infrared spectroscopy (fNIRS). fNIRS works by shining infrared light into the head to measure how much oxygen the brain is using, and can identify what part of the brain is therefore working the hardest. fNIRS opens up exciting new possibilities for studying how the brain copes with hearing loss, because it allows us to see what goes on in a person's brain as they listen through devices like hearing aids or cochlear implants in a natural way.

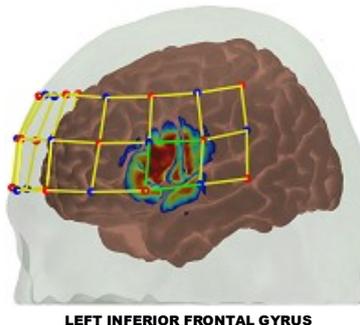
Mimicking hearing loss in hearing volunteers

Firstly we wanted to test whether fNIRS could measure if a person's brain was more active when they listened to speech in difficult conditions. We got young volunteers with no hearing loss to listen to speech that was either clear, or that had been digitally modified to mimic what someone with a hearing loss might hear. The clear speech was very easy to understand, compared to the modified speech, especially at first, and with practice volunteers were able to understand about 85% of the modified speech.

A part of the brain that works harder when listening gets tough

Based on earlier research, we were particularly interested in a part of the brain called the left inferior frontal gyrus (LIFG), located towards the front of the head on the LH side.

We found that the LIFG was more active when people listened to the modified speech (hard to understand) compared to clear speech (easier to understand), suggesting that the LIFG may work harder to help us



uncover the meaning of speech that is difficult to understand.

The critical role of attention

Interestingly, we saw more brain activity in the LIFG only when people paid attention to and tried to understand the modified speech. If they ignored this and listened instead to another background (non-speech) sound, LIFG brain activity did not increase, suggesting that the harder working LIFG reflects the *conscious effort* a person is using to try to understand what they are hearing.

What does it all mean?

Our findings confirm that the LIFG is more active when people pay attention to difficult to understand speech, and we have also shown that this can be measured using fNIRS, a promising new technique compatible with hearing aids and cochlear implants.

However, many questions remain. How exactly does this part of the brain work to help us understand speech in difficult listening situations? How does brain activity in the LIFG relate to the sense that listening is more or less 'effortful'? Will we see the same patterns in people who have a real hearing loss, and do hearing aids or cochlear implants make things better or worse?

What's next?

At the same time as measuring brain activity, Ian will use an eye-tracking camera to record the size of the pupils. Our pupils enlarge when we perform complex mental tasks, so their size can be used as a measure of how much listening 'effort' a person is putting in in order to understand speech. Ian will look at those with hearing aids are affected by realistic levels of background noise, as we all encounter in daily life.

Improving our understanding of these issues is crucial to ensuring that future hearing aids are designed not to just make sounds audible, but rather to make listening as easy as possible on the brain and the person.

PRIZE-WINNING RESEARCH

The Marie & Jack Shapiro Prize is awarded by the BTA annually for the piece of published research 'most likely to result in improved treatment or public awareness of tinnitus'. This year the judges awarded the prize to two teams of clinicians and researchers, chosen from a shortlist of 26. One of these researchers was Dr Eldre Beukes (who came to speak to us in 2016 about the Conquering Tinnitus programme). Psychological treatments such as cognitive behavioral therapy (CBT), are a proven treatment for reducing tinnitus distress, and Eldre and her colleagues (inc. David Baguley and Gerhard Andersson) assessed an internet-based CBT intervention for tinnitus patients. The judges considered the paper an important trial which indicated valuable benefits for tinnitus patients both in improved quality of life and potential savings for the NHS in terms of clinician time.

UNUSUAL TINNITUS 'SOUNDS'

vacuum cleaners
phantom radios
humming fridges
crickets
heavy traffic
blackbirds
singing
Scquelching
marbles
bees
steam trains
escaping air

Reflections on Tinnitus Research

Many of you want to know where tinnitus research stands currently? What are the most exciting developments? Are we getting closer to a cure? Why do some promising treatments take so long to get to the market? In this video link: ([Reflections on Tinnitus Research 2018 | Tinnitus Talk Support Forum](#)), Steve Harrison from Tinnitus Hub (the entity that operates Tinnitus Talk) talks to David Stockdale, CEO of the British Tinnitus Association, and together they reflect on the status quo of tinnitus research*, including picking up (belatedly) on the Tinnitus Research Initiative (TRI) conference held in Germany back in March. Please note the video is ~ 60 mins long. *This was unscripted so it's just a general chat and not intended to cover every single point of every single treatment. It's the things that stood out for them particularly in 2018, and are personal opinions rather than any kind of representative policy.

WICKED WIT OF INSULTS

- I was going to memorize your name and throw my head away • May you be cursed with chronic anxiety about the weather
- I hope you live to be as old as your jokes • You have a ready wit. Let me know when it's ready • Poetry is religion without hope
- You're are as useful as a chocolate teapot • If I've said anything to insult you, I've tried my utmost, believe me
- A good politician is as unthinkable as an honest burglar • Free verse is like free love; it is a contradiction in terms

TALKING TINNITUS EXPO

In September last year the BTA held the UK's first 'Talking Tinnitus' Expo - a unique event designed to bring talks, tasters, exhibitors and support together. The Expo offered those with tinnitus the chance to try out therapies and techniques known to help manage the condition, as well as seek help and support from the BTA and hear talks from tinnitus experts. Over 800 people attending took part in a programme of 12 sessions hosted throughout the day with speakers from both the psychology and medical worlds. Alongside this was a programme of relaxation therapies that visitors could try for themselves.

We have been so pleased with how the event has been received by those who attended. We had people come from all over the UK, as far as Plymouth and Inverness as well as from overseas, such as Ireland

BTA CEO David Stockdale reviews the inaugural Expo

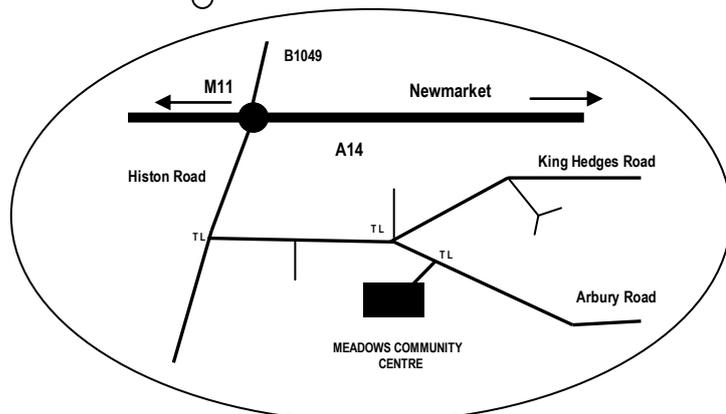
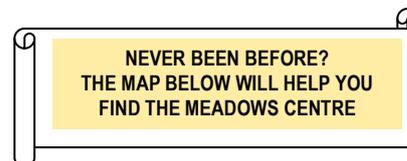
and Sweden. This is a real credit to the BTA team who had worked tirelessly to make this event happen. One of our top priorities is to ensure that people living with tinnitus can gain access to the wealth of information, advice and shared experiences that are out there, and the Expo gave us the opportunity to do just that under one roof.

In an internet age where information is freely available but not necessarily always reliable, we wanted to create a space where advice about managing the condition is guaranteed to be true and trustworthy. It was a great success and we are delighted with how the day went. The overwhelmingly positive response means that this first Tinnitus Expo will not be the last — we hope to see you next year.

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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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 on Saturday 13th April at the Meadows Centre sees Dr Andrew Jackson, Associate Principle Lecturer at Leeds Trinity University, as our speaker. He will explain his latest research topic: the use of the Cortisol Awakening Response as a Biomarker of distress in people with tinnitus.