Cambs Tinnitus Support Group

No. 149 NEWSLETTER November 2019

MEETING

&

Bring & Share Brunch

You are invited to contribute to our popular Bring & Share Brunch, but is not a requirement for attending!

Saturday 16 November

10.00 for 10.30 am

"Tinnitus: Does how we think, react, sleep, and relax make a difference?"

Speaker: Claire Gatenby
Chief Hearing Therapist
Norfolk & Norwich Hospital

Claire spoke to us in 2016, and such was the excellent talk she gave that we have been eagerly awaiting her return. She specialises in working with balance and tinnitus patients, and has a keen interest in how our thinking and behaviour have an impact on our well-being. Claire is a firm believer in trying to change people's thought processes regarding tinnitus and will talk about how tinnitus has an effect on sleep etc. and the importance of relaxation.

Meadows Community Centre

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

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Raffle

EDITOR'S CHAT

In September a paper entitled: "Why is there no cure for tinnitus?" was published in the Frontiers of Neuroscience journal. As David Stockdale, BTA's CEO says in this newsletter, "It's a really important piece of work as it draws together views and opinions from a range of different perspectives on how we can move forward with research and where we've got to so far." To have two luminaries from the tinnitus clinical and research fields, representatives from two charities who actively support tinnitus research and the head of a company actively involved in pharmaceutical trials collaborating in this manner is very encouraging for those of us with the condition. You can access the paper using https://tinyurl.com/y4rlq9rj.

Great news - Claire Gatenby has recovered from her accident and will talk to us in November. Those members who know Claire will not miss the opportunity to hear her again, and new members really should make an effort to come along. And Don McFerran FRCS, one of the contributors to the paper mentioned above, will be our speaker in February - this is also a meeting not to be missed - please put it in your diary.

JIM'S PIECE

We're going for Gold ! The BTA have created a Gold standard for tinnitus support groups to recognise those that give the best support to their local tinnitus community. There are 6 criteria, including following the BTA code of ethics, organising at least one awareness /fundraising event per year and encouraging peer-to-peer interaction.

Your committee believes that the CTSG meets all of the criteria, and in due course will apply for the award.

Assuming we are successful, this can only enhance the standing of the group (via the website and Facebook etc). However, there is always room for improvement, so don't hesitate to let us know if you have any thoughts on how we might improve - we are very open to feedback.

Best wishes
Jim Infield, Chair

The 2019 BTA TINNITUS EXPO

A report by John Williams (Edited by Alan Yeo)

On arrival we were given a "goodies" bag of fliers advertising current commercial products to "help" with tinnitus (or not, as the case may be). Most useful was a generous pad of A4 writing paper!

The main hall was the venue for many stalls and in the side rooms where activities including talks and examples of help including meditation and yoga. I chatted to a member of the Association of Lipspeakers (ALS) who use hearing people to act as professional aids in communication between deaf and hearing people. They were present in each of the 'talks', with some signing, and others simply mouthing the words accurately so that people could lip-read them.

The National Association of Deafened People (NADP) are a small dedicated group helping those of us with tinnitus and a hearing loss (www.nadp.org.uk). I personally wouldn't find them useful but others might, so copies of their glossy newsletter "Network" will be available at our next CTSG meeting.

Audacious are a company specialising in improving sound on your mobile phone. I tried it, and although it might help some, I didn't think the slight improvement warranted the extra expense. *Phonak*, maker of many of the NHS hearing aids, proved helpful. Contrary to what I had been told by one of my audiologists, the wired form of connection (as opposed to WiFi) that I prefer on my CROS aid is still being made (great!)

Stall personnel I chatted to included the Samaritans, Ménière's Society, AoHL and BTA among others - all doing excellent jobs.

I only managed to attend two talks as I was just there for the afternoon. One was an research update that was very involved but interesting; for example I never knew tinnitus could be of an intermittent type (perhaps some of our members have it?). Topics also included looking at ototoxic chemicals, including those used in cancer treatments. The second talk featured a "Healthcare Pathways" display, a kind of guide on tinnitus for patients. This looks very helpful for those recently diagnosed with the condition, and was presented by BTA's Helen Goldsboro.

THE 2019 TINNITUS EXPO

Drs Baguley, McKenna and McFerran are publishing some tinnitus research papers this year. Attempts are being made to find helpful actions, if not a cure, but the latter looks a long way off at the moment. They include: Sound therapy, Neuromodulation, CBT counselling (very promising), Endovascular treatment, Yoga, Acupuncture and holistic methods of care.

I also took in a Yoga/Meditation Taster session run by the group CUBEX (www.cubex.co.uk). The Yoga session was very relaxing and almost identical to the Meditation that I already do. No idea of costs.

Altogether a most enjoyable and informative day. I urge everyone to go next year!

Treatments for hearing loss and tinnitus - what's the future?

(Edited from AoHL *Soundbite)*

Action on Hearing Loss (AoHL) worked with an international group of clinicians to produce an article listing the companies currently developing treatments to protect or restore hearing, or silence tinnitus.

Hearing loss affects almost half a billion people in the world, and is also a risk factor for several other conditions, such as depression and dementia. In spite of this, there are still no treatments available to protect or restore hearing, or silence tinnitus. Worldwide, in the laboratories of universities, hospitals, biotechnology and pharmaceutical companies, scientists are currently developing and testing these future treatments. Hopefully, one day they will complement or even replace hearing aids and cochlear implants, transforming the lives of millions that live with hearing loss and tinnitus.

What treatments for hearing loss and tinnitus should we expect in the future?

In the article, published in the scientific journal Otology & Neurotology, 43 companies around the world were identified, that to date, have worked to develop more than 80 treatments for different types of hearing loss and tinnitus. The list is not exhaustive, so more treatments are likely to exist. Some of these treatments have already failed, but others keep on progressing. Most of the treatments under development aim to prevent hearing loss caused by loud noise or medications that are toxic to the ear, such as aminoglycoside antibiotics or certain chemotherapy drugs, or to treat sudden hearing loss. These preventive treatments are the most advanced (Phase II and Phase III trials) making them the most likely to reach people in the near future. Companies like the US-based Decibel Therapeutics or the French company Sensorion are already testing some of their preventive treatments in people. Preventive treatments also have the potential to prevent or slow age-related hearing loss, a type of hearing loss that is on the increase as the population gets older.

A smaller number of companies are developing treatments to restore hearing. Frequency Therapeutics, a US-based company, and Audion Therapeutics (REGAIN clinical trial) are already testing their regenerative treatments in people, with encouraging results so far. If successful, they will transform the lives of people who have lost their hearing. However, successfully regenerating lost hearing cells is one of the biggest challenges in treating hearing loss. As such, these approaches are not as advanced as the preventive approaches mentioned previously. Companies are also developing techniques to efficiently deliver these treatments to the inner ear. The inner ear is located in the temporal bone at the side of our heads. It is one of the hardest bones in our body, making the inner ear very difficult to access.

MEDICINE PRODUCTION FLOW CHART

Therefore, new ways of delivering the right dose of treatment to the inner ear are needed. Otomagnetics, a US-based company that received two AoHL grants, is currently developing a magnetic system to deliver therapies to the inner ear.

Why is it important to know which treatments are currently being developed?

The process of taking medicines from scientific laboratories to patients is long, and sometimes disheartening for people living with hearing loss and tinnitus on a daily basis. However, it is important for people and clinicians to be prepared for the treatments that will one day change how we manage hearing loss. Some of these treatments will fail along the way, as developing treatments is a very rigorous process, demanding a lot of proof that new treatments are both safe and effective before they are approved to be used in people. However, others will succeed and when they do, they will change the way people live with hearing loss.

[*For a non-exhaustive list of companies that have worked in the development of treatments for hearing loss and tinnitus to date please use the following link:* https://tinyurl.com/yxleoolt *and download the file* - Ed]

CHUCKLES

- A man goes into the pub and admires the stuffed lion’s head mounted above the bar. 'What a great trophy,' said the man to the barman. 'That damn lion killed my wife.' replies the barman. 'Good heavens,' says the man, 'were you on safari? 'No,' replies the barman, 'It fell on her head.'
- Harry heard that most accidents occur within 2 miles of home, so he moved.

Mapping where we are: why is there no cure for tinnitus?

I was really pleased to see our paper 'Why is there no cure for tinnitus?' finally published in *Frontiers in Neuroscience*. It's a really important piece of work as it draws together views and opinions from a range of different perspectives on how we can move forward with research and where we've got to so far.

The charities – ourselves at the British Tinnitus Association (BTA) together with Action on Hearing Loss (AoHL), represent the patient voice in the paper, while Autifony Therapeutics, who have the experience of undertaking a recent major pharmaceutical trial, represent industry. Academics are represented by the University of Nottingham, as well as clinicians, through Professor David Baguley and Mr Don McFerran.

The content of the paper may not be a surprise to many. It is basically the things that I've been talking about for a couple of years now, such as the need for an objective measure of tinnitus and the need to subtype tinnitus. What is new is that we now have the evidence for *why* these are needed and we've been able to produce a much more detailed analysis of where we've got to and where to go next. The paper is also the first peer-reviewed publication of the Tinnitus Cure Map. This again is a project that the BTA has been working on for a number of years. To have it published in a peer-reviewed journal gives the Map credibility and shows that it could be a valuable tool as we really start to map where we are with research and how we look at taking it forward. [*To see an A3 – size version of the map, which in A4 size can be difficult to read,*

What next?

Proud as we are about the paper's publication, this is where the hard work begins! The article sets out our stall - we've said where we think we've got to with tinnitus research and what needs to happen next.

And we're going to 'put our money where our mouth is' as part of our push to achieve our mission to drive and demand a cure for tinnitus. We have recently announced that we are looking to fund more tinnitus research through our Small and Large Grants programmes.

A record amount of funding from the BTA will be made available to catalyse research that addresses our priorities detailed in the paper.

As well as bringing together different perspectives and partners on this paper, we are undertaking other collaborations to improve our understanding and knowledge of tinnitus, as we start to make progress on some of the key areas highlighted in the paper. We hope to be able to announce more news on these projects soon. In addition to committing funding to new projects, we will be supporting research by allocating other resources from within the BTA. Staff will be working directly with researchers contributing time and expertise.

Please do read the paper (https://tinyurl.com/y4rlq9rj) – over 6,000 people have done so far, which is encouraging to see. I'd be really interested to hear what you think about it, and to hear your views on how we take tinnitus research forward.

(Edited from an article on the BTA website by David Stockdale)

I WISH I HAD SAID THAT!

(With thanks to Birmingham & District Tinnitus Group)

- Never let your sense of morals get in the way of doing what's right – *Isaac Asimov*
- Love is like an hour glass, with the heart filling up as the brain empties – *Jules Renard*
- To fall in love is simple, but to fall out of love is really awful – *Bess Myerson*
- Two things are infinite: the universe and human stupidity, and I'm not sure about the universe – *Albert Einstein*
- Do the right thing, it will gratify some people and astonish the rest – Mark Twain
- If everything seems to be going well, you have obviously overlooked something - Anonymous

Cinema sound levels are no joke

With thanks to Emily Broomhead, BTA Campaigns Manager

Deafening cinema sound is ruining films: Hugh Grant

In the Guardian on Sunday, an article appeared which had been set off by a tweet on 5 October from actor, producer Hugh Grant who had been to see the film Joker. In it he simply put: Am I old, or is the cinema MUCH TOO LOUD? Unendurable. Pointless.

The reaction to his post was quite staggering, and we were delighted to be contacted by journalist Vanessa Thorpe to ask for our input for the piece which she was writing as a follow up.

Through *Safe Around Sound* we want to change this situation, and you can help us really easily by completing the short survey we've created at www.surveymonkey.co.uk/r/safearoundsound. You don't have to be someone who goes to the cinema to complete it, we're looking at all social environments at the moment. So please, if you have 4 minutes to spare, your input could make a big difference.

September Report

By Alan Yeo

On a sunny September morning, we welcomed Laura Fulco, from the Ménière's Society, to talk to us about Ménière's and other vestibular diseases, and to tell us about the organisation she helps manage.

The Ménière's Society

Mrs Marie B Nobbs MBE founded the Ménière's Society in 1984 after she met people who had set up a telephone self-help network for Ménière's sufferers in the Netherlands. With support and encouragement from other hard of hearing colleagues, Marie decided to establish a similar support group in the UK. The Meniere's Society acquired charitable status in 1987. Since then the Society has gone from strength to strength. Marie sadly passed away on 13 August 2016.

Although called the Ménière's Society, the charity supports anyone with a vestibular (inner ear) problem, which include: BPPV, Labrynthitus, Vestibular Migraine and Otoxicity to name just a few . The Society have thought of changing their name but so far no one has come up with a better one!

What is Ménière's disease, what are the symptoms and who does it affect?

It is a long term, progressive condition affecting the balance and hearing parts of the inner ear, and symptoms can vary between people and over time. The main problems are unpredictable attacks of vertigo that can last from a few minutes to 24 hours, accompanied by nausea and vomiting. There may also be tinnitus, hearing loss and a feeling of fullness in the affected ear. Periods of remission between attacks can vary from days to months or even years; making it an unpredictable and distressing illness.

As it progresses the vertigo may be less severe; however there may be periods of imbalance, adding to the distress. In the later stages tinnitus is more prominent and fluctuating hearing loss develops. There is permanent damage to the balance organ and significant balance problems are common.

Usually only one ear is affected, however up to 50% of sufferers may develop the condition in both ears. Between 0.1 – 0.2% of the population are affected, depending on the source, affecting both sexes equally. Ménière's can occur at any age and 7-10% of sufferers have a family history of the disease.

What causes Ménière's disease?

The cause of Ménière's disease is unknown, although many factors are thought to be involved in the development of the condition.

These include increased pressure of the fluid in the endolymphatic sac (see image), and other factors damaging the inner ear, including allergies. However, the relationship between these factors and the progression of the disease remains unclear.

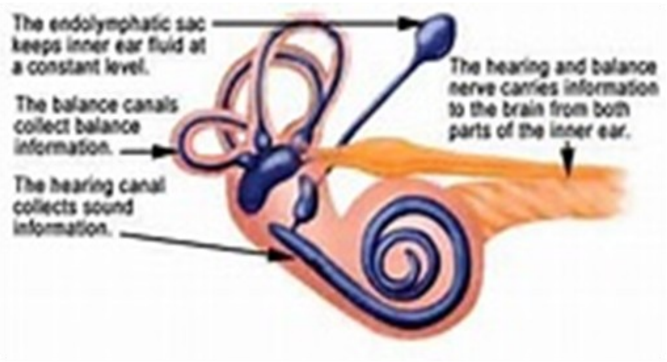

DIAGRAM OF ENDOLYMPHATIC SAC

Diagnosis and cure?

There is no cure for Ménière's disease, and no definitive diagnostic test either. The three main symptoms of vertigo, hearing loss and tinnitus occur in many other illnesses, and these may need to be excluded by tests (e.g. blood tests, MRI scan) before a final diagnosis can be made.

How is Ménière's disease treated?

Treatment of Ménière's disease is aimed at reducing and controlling symptoms. As Ménière's is symptomatic, treatment will vary with the needs of each individual and includes medication and vestibular rehabilitation, diet and lifestyle changes, tinnitus management, hearing aids and counselling. In four out of five people non-surgical measures are sufficient to control the symptoms of Ménière's disease; however, if vertigo remains a problem surgical procedures can help.

How the Society helps

Although only a small organisation with four staff plus volunteers, the Society punches above its weight. Services include a telephone helpline which supports sufferers, their families and carers. The unpredictability of when an attack may occur and its possible severity can be very stressful for an individual, and being able to talk to a friendly, knowledgeable voice can be beneficial. The contact may not yet have been diagnosed, but although the helpers cannot give out medical advice, they can both reassure them and advise them how to find professional help. They give administrative support to almost 30 local peer groups across the UK (inc. one in Cambridge), supply information leaflets and in collaboration with professionals, have commissioned two excellent booklets -"Controlling your Symptoms" (https://tinyurl.com/y4nlnuo8) and "Balance Retraining" (https://tinyurl.com/yyjsojxa) which have proved very popular. They have also helped sponsor several Ménière's-related research projects, and the world's first Balance Disorder Spectrum - an interactive infographic for identifying balance disorders (https://tinyurl.com/y2hh289e).

After a thoroughly interesting and informative talk, Laura then fielded several questions before we thanked her in the traditional way.

The Hidden Disabilities Sunflower Lanyard Scheme*

During Laura Fulco's presentation (See page 5), she mentioned the above scheme of which not many of our members present were aware. It is an initiative designed to act as a discreet sign that somebody has a hidden disability and requires additional assistance while out in public. The scheme was originally developed by designers Tabbers Limited alongside the OCS Group UK, who provide support services to UK airports. Launched in 2016 at Gatwick Airport, more than 10,000 lanyards have been collected to date. The scheme covers a wide range of disabilities, including autism and Asperger's, dementia, mobility issues (arthritis, MS, ME etc.), learning disabilities and visual or hearing impairments. Obviously it could be very useful to anyone with Ménière's disease, and the Society have supplied enquirers with many examples.

LAURA WITH A LANYARD

Now in 2019, it is being successfully introduced to several other major UK airports, supermarkets (inc. Sainsburys and Tesco), railway stations and sports venues and many disabled people are already benefiting from the scheme. The advice is if you're wearing a lanyard, staff can offer you help but won't know what your individual disability and needs are, so just let them know what they can do for you.

[*To find out more use this link*: https://tinyurl.com/y37qgr6g - Ed]

Don't delete this just because it looks weird. Believe it or not, you can read it.

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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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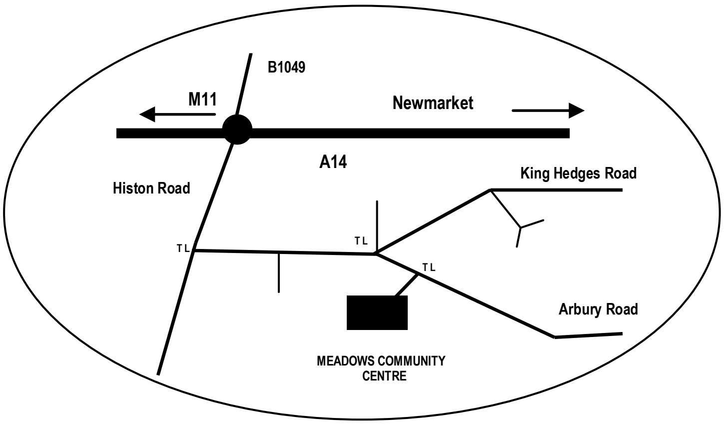
Facebook: **Cambs Tinnitus Support Group**

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



CONNECTIONS

CTSG is an independent voluntary organisation with an excellent supporting relationship with the Audiology Department at Addenbrookes Hospital. It is also a BTA registered tinnitus support group. We receive no financial support other than from membership subs, donations and sales. This pays for the hire of the meeting room, printing and postage of Newsletters, replacement equipment and associated activities.

Our next meeting is on Saturday 15 February at the Meadows Community Centre. Our speaker is Don McFerran, FRCS Consultant at Colchester Hospital, and one of the contributors to the "Why is there no cure for tinnitus?" paper.