

Cambs Tinnitus Support Group

No. 165

NEWSLETTER

February 2023

MEETING

Saturday 18 February

at

10.00 for 10.30 am

"Facing the Challenges"

Speaker: Nic Wray

Communications Manager, Tinnitus UK

"Nic Wray, who has been Communications Manager at the BTA (now Tinnitus UK) for nearly 13 years, researches and writes all about tinnitus, producing many of Tinnitus UK's information resources, including the treatment checker. Nic manages Tinnitus UK's press and media output, edits Quiet, recruits and supports our story tellers, whilst also supporting other teams with their communications. Nic is also studying to become a Chartered PR Practitioner."

Meadows Community Centre

1 St Catherine's Road, Cambridge, CB4 3XJ, off
the junction between King's Hedges and Arbury Rds
(follow signs to temporary car park)

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Refreshments and Raffle

WELCOME TO TINNITUS UK

The New Name and Logo

The new name is **Tinnitus UK** plus the logos and the characteristic 'sound wave' that compliment it.

For over a year, even before Head of Communications, Lucy Straker even joined, the BTA had been working through the process of rebranding, i.e. changing the name, the logo, the look and the feel of the organisation.



Our manifesto

One in eight adults in the UK have tinnitus, yet the condition is often overlooked and dismissed by many. For those most affected, tinnitus can be overwhelming and leave them struggling with day-to-day life.

To everyone living with tinnitus, our message is clear; your struggle is our cause. As a research-led organisation, we empower the global scientific community to help understand tinnitus, discover new ways to treat it, prevent it and ultimately find a cure.

We provide a range of services backed up by the most up-to-date research, created specifically to help people with tinnitus manage their condition and **lead more fulfilling lives**.

We work with medical professionals to ensure you receive the right information and advice. We also build awareness with government bodies and the general public to raise funds and provide much needed support.

We are Tinnitus UK, and we continue to fight for a world where no one suffers from tinnitus.



The Manifesto

Essentially similar to what they have now. Making sure the organisation is there to help people living with tinnitus, to raise awareness of tinnitus and how to manage the condition. Plus support for research, further treatments, management techniques and ultimately a cure as well.

Why the new name etc.

There are several reasons for the changes: Their name will have tinnitus at the front, telling people exactly what they are, rather than BTA, which could mean anything. The change should mean they will reach new audiences, and hopefully this easier recognition will boost their fundraising profile. The reasons for the changes will be summarised in a FAQ on our new website.



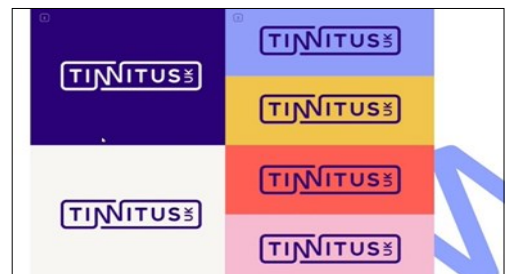
10 January 2023 - target date

Why?

- Increase visibility
- Reach new audiences
- Improve our fundraising ability
- An FAQ will be produced for the launch

The Logo in different colours

The main logo will be either white on blue or blue on white, which are the primary colours. The other colours combinations will be secondary



What will change?

- New website – inc. Chatbot, events calendar etc.
- New (well converted) social media
- New brochures, leaflets, etc.
- New Tinnitus Support Group logo
- New Gold Standard logo
- New Gold Standard certificate

What will change

The main changes are summarised in the box. Principally a new website is being put together, including a Chatbot feature giving people 24 hrs access to information, as well as their normal Helpline. Information will be much easier to access, and there will be an events calendar featuring group activities etc.

What won't change

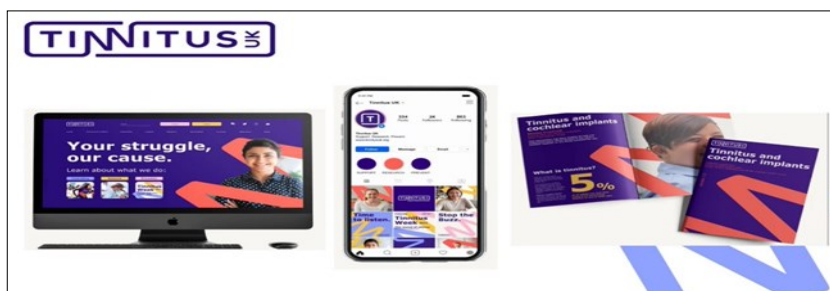
Not changing will be their services, including the helpline, webchat and SMS etc. Support groups will continue, albeit with new branding. The mission statement and values remain, and the staff and volunteers will still be there, as will the same website and e-mail addresses.



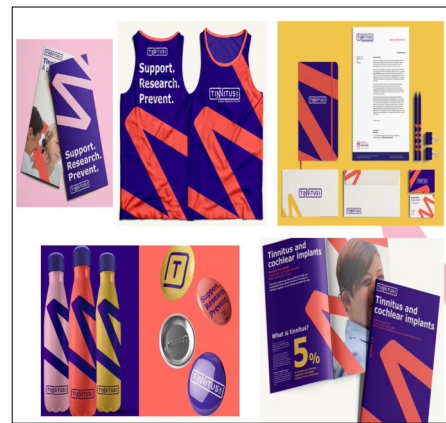
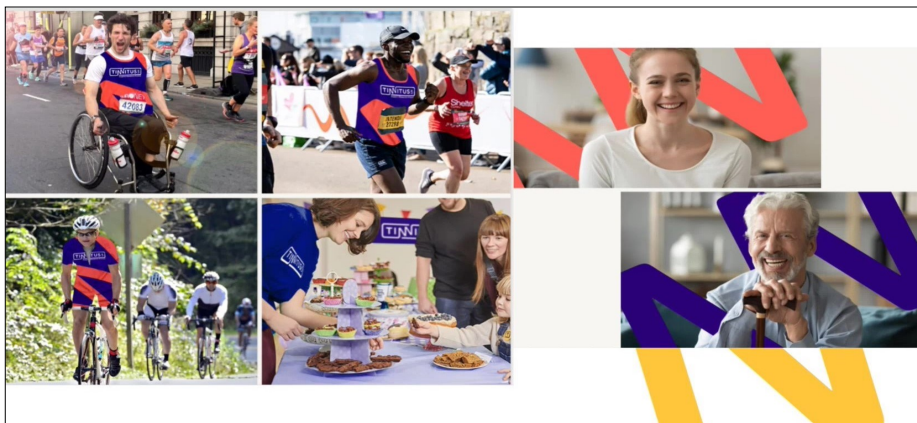
What won't change?

- Our services – helpline, web chat, SMS etc.
- Support groups (albeit with new branding)
- Our staff and volunteers
- Our values and mission
- Our website url and email addresses ie **tinnitus.org.uk**

WHAT THE NEW LOGO AND COLOURS MAY LOOK LIKE



These are some examples of how the social media, literature and merchandise might look, although they are not confirmed as yet. Apparently the water bottle design was a big hit with those who were asked for their opinion.



EDITOR'S CHAT

So finally the deed has been done! On Tuesday 10 January 2023 the BTA changed their name to Tinnitus UK. Obviously a lot more than a name change is involved, and the new logo, manifesto, colours and some ideas of possible future merchandise etc. is illustrated on pages 2 and 3. Personally I was very pleased it happened early in the month, as it has allowed for the newsletter to be re-jigged to include the montage of material that had been prepared earlier in October. My first impression is that the ethos of the organisation has been preserved, and the changes will hopefully make the charity more visible in the tinnitus landscape, and improve their fundraising capabilities. More funds means more focussed tinnitus research, and that's got to be good news for the future of those with the condition.

Whether you think this move is a good thing or not is obviously a personal judgement, but my initial impressions when I first knew about the changes were very positive, and they still are. This rebranding exercise was obviously planned with a lot of thought over a protracted period, and I hope its objectives succeed. It would be interesting to find out what our members think of the move; so please let me know your thoughts for the next newsletter.

Sorry to disappoint, but we will still be in the old building for our February meeting; however we will definitely be in it's new neighbour by the meeting in April. However, don't that put you off from attending on the 19th, when we welcome Nic Wray, Tinnitus UK's Communications Manager, talking about the challenges ahead for the new entity. From her last visit in 3 years ago, we that Nic is an interesting speaker, and the ideal person to explain the thinking behind the rebranding exercise. There will be opportunities to talk to fellow members, and please don't forget the raffle!



You maybe intrigued by the symbol on the left, and what it represents. It symbolizes a new product that will help communication for the hard of hearing. More in the next newsletter!

JIM'S PIECE

New Year greetings to everyone from Rajasthan in India. One of the many delights about this country, apart from the delicious food and all the sights, are the sounds. Let me try and paint you a sonic landscape:

People talk gently at times and loudly at others, when speaking across large distances, which can seem rude to the western ear. On the street, the cry of street vendors, loud and clear. In town, the persistent sound of tooting horns, the tinkling bells of rickshaws, the thud of tractor engines and the general noise and hubbub of the market.

The first sound of the day is the Azan, the timeless Muslim call to prayer just before sunrise, reverberating over the rooftops from many mosques. From Hindu temples, the ringing of bells which accompany the rhythmic prayers. Sometimes music blares out loudly, maybe brash or lyrical but always with a strong rhythm. In the late afternoon, the sound of children playing in the street after school and as the sun sets the buzzing of cicadas (*I think there's nothing worse for someone with tinnitus* - Ed) as day becomes evening. Life continues late into the night, when finally all the busy sounds of life are quiet and a peaceful silence reigns until it all starts again early in the morning.

Best wishes
Jim Infield
CTSG Chair

November meeting

Report by Alan Yeo

Saturday 19th November saw members and newcomers congregate in Room 2 of the Meadows Community Centre, on what will be one of the last meetings in the old building. I had hoped that our February meeting would be in the sparkling new building, but that will now not be until April. Numbers were a little down on our usual count, but this was more than compensated by the attendance of three newcomers, Julie, Frances and Nicholas, who had been in touch with me a few weeks before, and felt sufficiently motivated to come along and see what we were all about! The usual tea/coffee and bics put everyone in a relaxed mood and we kicked off with Rachel introducing herself to our new visitors.

Acting as master of ceremonies in her usual relaxed style, she soon had people talking about their particular problems they have with their tinnitus, and being given sound advice in return. As it can be a little daunting to

talk about themselves, and newcomers are never pressured to speak, however our trio had no problem talking about their particular worries, and also contributed to the various discussions. Topics ranged from problems with sleeping, avoiding excessive noise at work, hyperacusis amongst others.

After about an hour, which seemed to fly by, we got round to the mulled wine and warm mince pies, which every one thoroughly enjoyed. Raffle prizes were chosen by the lucky winners, and it was good to see members taking the time to engage with our newcomers.

Talking to others who have had tinnitus for some time is particularly helpful to those relatively new to the condition, and we

always emphasise this benefit to all who contact us. After a really good session the members made their way home, while the committee members had a discussion about the 2023 programme and other matters.



CHUCKLES

- Did you hear about the family who were evicted from their tree house? Apparently the bank said they hadn't paid their mortgage, but the family said it was just a mix up because they had recently switched branches.
- From free ad newspaper in Bournemouth: "A Bargain to Jump at?"
"Parachute for Sale. Only used once. Never opened, small stain. £199 o.n.o."
- A plague of flying ants cause a music venue in Alice Springs to shut down. The manager rings his boss and says. "Flying ants have stopped the show." The boss replies, "What's your problem, mate? Book 'em for another week."

A smartphone app that supports tinnitus users wins 2022 global innovation award

In the third annual prestigious Hearing Technology Innovator Awards for 2022, Dr. James Jackson, from Leeds Trinity University, along with audiologists from Australian-based Hearing Power, have been recognised for their Tinnibot smartphone app. which supports people with tinnitus. The Innovator Awards recognise the organisations and people who bring new hearing care ideas to life and help drive innovation forward across the industry.

Dr. Jackson is a Reader in Psychology and Programme Lead for MSc Psychology (Conversion) at Leeds Trinity University, and has lived with tinnitus his whole life. He joined forces with Dr Fabrice Bardy and Dr Matthieu Recugnat - the co-founders of Hearing Power - in 2019 to share their research knowledge and experience of tinnitus and hearing loss.



Dr James Jackson

Tinnibot offers immediate relief and long-term effect through a hybrid treatment approach, and represents a prime example of the potential in personalised digital therapeutics. The app facilitates a new opportunity to receive tinnitus support directly to the user's phone whenever it suits their needs, but it also provides the opportunity to meet with Cognitive Behavioural Therapy (CBT) expert through a video chat interface.

The mindfulness aspect of the app, developed by Dr Jackson, teaches people how to change negative thoughts and increase resilience through relaxation and meditation, and the audio files are read out by a post-graduate student from Leeds Trinity University.

Dr Jackson said: "Tinnibot's USP as a tinnitus smartphone app is the chatbot function as it enables people to talk with the software, being more honest than they may be with another human being. The app is also a gateway to different treatments as it provides education, sound therapy, mindfulness and CBT. Users are supported and have an increased understanding of what they are living with and what support is available to them."

"The Tinnibot app is the first of its kind. There is still a journey ahead and we have the ambition and passion to continue collaborating to be able to help others."

"This has been a real pleasure. I would just like to say how much I appreciate the chance to work (unpaid advisor!) with the wonderful Matthieu Recugnat and Fabrice Bardy at Hearing Power as we see Tinnibot go from strength to strength. This award for Hearing Power is well deserved. Well done guys! Am proud to be a little part of it."

(Edited from University article)

Nearly 15% of all people have tinnitus

A study finds that 14.4% of all people in the world experience tinnitus and that 2.3% have severe tinnitus.

A scientific study carried out a systematic review and meta-analysis of previous articles about tinnitus. The review was performed by searching PubMed-MEDLINE and Embase. In the study, the prevalence estimates from 83 articles and incidence estimates from 12 articles were extracted.

The study found that the prevalence of any tinnitus among adults was 14.4%. The prevalence of severe tinnitus was 2.3%. 9.8% experienced chronic tinnitus and 3.4% overall were diagnosed with tinnitus.

The prevalence of tinnitus did not significantly differ by sex, but the prevalence increased with age.

Major global problem

This means that tinnitus affects more than 740 million adults globally and is perceived as a major problem by more than 120 million people, mostly aged 65 years or older.

The study suggests that the global burden of tinnitus is large, similar to migraines and pain.

WICKED WIT

- The only thing to do with good advice is to pass it on. It is never of any use to oneself. - *Oscar Wilde*
- Money won't make you happy..... but everybody wants to find out for themselves. - *Zig Ziglar*
- Never put off till tomorrow what you can do the day after tomorrow. - *Mark Twain*
- When everything comes your way you're in the wrong lane. - *Anonymous*
- Nothing so needs reforming as other people's habits. - *Mark Twain*
- Old age is fifteen years older than I am. - *Oliver Wendell Holmes*
- Get the facts first. You can distort them later. - *Mark Twain*
- Life is one long process of getting tired. - *Samuel Butler*
- Life is so constructed that an event does not, cannot, will not, match the expectation. - *Charlotte Bronte*
- Have the courage to be ignorant of a great number of things, in order to avoid the calamity of being ignorant of everything. - *Sydney Smith*
- I was born with a plastic spoon in my mouth. - *Peter Townsend*

Tinnitus seems linked with sleep – understanding how could bring us closer to finding a cure

There's currently no cure for tinnitus, so finding a way to better manage or treat it could help many millions of people worldwide. One area of research that may help us better understand tinnitus is sleep, and there are many reasons for this.

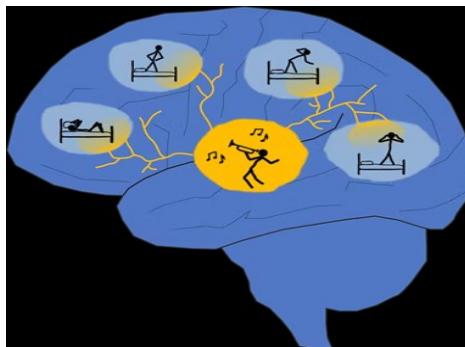
Firstly, tinnitus is a phantom percept; when our brain activity makes us see, hear or smell things that aren't there. Most people only experience phantom perceptions when they're asleep, but for people with tinnitus, they hear their phantom sounds while they're awake.

The second reason is because tinnitus alters brain activity, with certain areas of the brain (such as those involved in hearing) potentially being more active than they should be. When we sleep, activity in these same brain areas also changes. Our recent review has identified a couple of brain mechanisms that underlie both tinnitus and sleep, so a better understanding of these mechanisms – and the way the two are connected – could one day help us find ways of managing and treating tinnitus.

Sleeping and tinnitus

When we fall asleep, our body experiences multiple stages of sleep, and one of the most important stages of sleep is slow-wave sleep (also known as deep sleep), thought to be the most restful stage of sleep. During slow-wave sleep, brain activity moves in distinctive "waves" through the different areas of the brain, activating large areas together (such as those

involved with memory and processing sounds) before moving on to others. It's thought that slow-wave sleep allows the brain's neurons (specialised brain cells which send and receive information) to recover from daily wear and tear, while also helping sleep make us feel rested. It's also thought to be important for our memory.



A cartoon image depicting the affect that local wakefulness can have on the sleeping brain

Not every area of the brain experiences the same amount of slow-wave activity. It's most pronounced in areas we use most while awake, such as those important for motor function and sight. But sometimes certain brain areas can be overactive during slow-wave sleep, occurring in sleep disorders such as sleep walking. A similar thing may happen in people with tinnitus. We think that hyperactive brain regions might stay awake in the otherwise sleeping brain. This would explain

why many people with tinnitus experience disturbed sleep and night terrors more often than people who don't have tinnitus.

Tinnitus patients also spend more time in light sleep because the tinnitus keeps the brain from producing the slow-wave activity needed to have a deep sleep. But even though tinnitus patients have less deep sleep on average than people without tinnitus, our research review suggests that some deep sleep is hardly affected by tinnitus. This may be because the brain activity that happens during the deepest sleep actually suppresses tinnitus.

Cont. from page 5

There are two ways the brain may be able to suppress tinnitus during deep sleep, and the first has to do with the brain's neurons. After a long period of wakefulness the brain neurons are thought to switch into slow-wave activity mode to recover.

The more neurons in this mode together, the stronger the drive is for the rest of the brain to join. We know that the drive for sleep can get strong enough that neurons will eventually go into slow-wave activity mode. And since this especially applies to brain regions overactive during wakefulness, we think that tinnitus might be suppressed as a result of that.

Slow-wave activity has also been shown to interfere with the communication between brain areas. During deepest sleep, when slow-wave activity is strongest, this may keep hyperactive regions from disturbing other brain areas and from interrupting sleep. This would explain why people with tinnitus can still enter deep sleep, and why tinnitus may be suppressed during that time. Sleep is also important for strengthening our memory, by helping to drive changes in connections between neurons in the brain. We believe that changes in brain connectivity during sleep are contributing to what makes tinnitus last for a long time after an initial trigger (such as hearing loss). between neurons in the brain. We believe that changes in brain connectivity

during sleep are contributing to what makes tinnitus last for a long time after an initial trigger (such as hearing loss).

Treating tinnitus

We already know that intensity of tinnitus can change throughout a given day. Investigating how tinnitus changes during sleep could give us a direct handle on what the brain does to cause fluctuations in tinnitus intensity. It also means that we may be able to manipulate sleep to improve the wellbeing of patients – and possibly develop new treatments for tinnitus. For example, sleep disruptions can be reduced, and slow-wave activity can be boosted through sleep restriction paradigms, where patients are told to only go to bed when they're actually tired. Boosting the intensity of sleep could help us better see the effect sleep has on tinnitus. While we suspect that deep sleep is the most likely to affect tinnitus, there are many other stages of sleep that happen (such as rapid eye movement, or REM sleep) – each with unique patterns of brain activity. In future research, both the sleep stage and tinnitus activity in the brain could be tracked at the same time by recording brain activity. This may help to find out more about the link between tinnitus and sleep and understand how tinnitus may be alleviated by natural brain activity.

(Edited from the *Conversation*)

Here are 5 tinnitus treatments NOT to try.....

† The Annamite tribe in eastern India thought that tinnitus was actually the noise made by a small animal that lived in the ear. It was rather a quarrelsome little animal that fought with other tiny creatures that lived in the ear and the head. The resulting snarling and unpleasant noises were, of course, tinnitus. The treatment was to find a snake, kill it, skin it, set light to it and use the smoke to fumigate the affected ear!

† 1597 John Gerard published his Herbal and suggested that you find some leeks: "The same juice, with vinegar, frankincense, and milk, or oil of roses, dropped into the ears, mitigateth (eases) their pain, and it is good for the noise in them."

† 1649 Another herbalist, Nicholas Culpeper, suggested using beetroot: "The juice of the root put in the nostrils, purgeth the head, helpeth the noise in the ears and the toothache."

† 1886 A scientist called Toynbee died attempting to test the hypothesis that tinnitus might be relieved by inhaling vapours of hydrocyanic acid and chloroform.

† 2004 The internet: "The Auricular pill is a specially formulated dietary supplement which leads to tranquillity of brain symptom (?). The selected herbs have been proved to free you from fidget(?) caused by hearing loss and tinnitus. Taking this dietary supplement regularly will allow you to re-experience the beautiful sounds of nature."

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**



REGISTERED
TINNITUS
SUPPORT GROUP

CTSG is an independent voluntary organisation with a good supporting relationship with the Audiology Department at Addenbrookes Hospital. 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 15 April at the new Meadows Centre where our speaker is Christian Causewell from TOPCHIRO in London. The title of his talk will be "The Upper Cervical Spine and Tinnitus".