TINNITUS TALK
PODCAST
EPISODE 2

A WORLD WITHOUT TINNITUS
David Stockdale
(British Tinnitus Association)

00:00 – General introduction to David Stockdale and the BTA

Sean: Thanks everyone for tuning in to Tinnitus Talk. Today we are going to be interviewing with David and we also have Markku and Hazel on the call.

Hazel: Hi there.

Markku: Hi there. I would like to thank David in the beginning for joining us.

David: No problem. It's your time too. I am looking forward to the discussion.

Sean: Alright David, so a lot of people from the Tinnitus Talk Forum know who you are but I think some Podcast listeners may not necessarily understand what your role is and what you do, so why don't you give us a quick rundown as to who you are, what you do at the BTA and what goes on there?

David: My name is David Stockdale. I am the Chief Executive of the British Tinnitus Association (BTA) which, for a charity, doesn't mean I'm in charge. It means my role is to implement the strategy and the strategic direction that's set by our Board of Trustees. So, every charity has a Board of Trustees and, in our case, they are all volunteers, and all have tinnitus and they decide on what the mission and the aims of the BTA are and what our strategy is. It is then very much up to me to manage the staff team and manage our resources to best achieve those goals.

Sean: Well, that is interesting. So, the Trustees of the Board; they are coming up with the mission of what exactly wants to be done and then they tell you to implement that?

David: Yes, pretty much so. Last year we agreed on a new five-year strategy that is very much set and agreed by the Board and then it is up to me to decide operationally what we do to achieve that and then that is signed off on an annual basis by our Board of Trustees as well. It is the Trustees that really drive the organisation and we do that in consultation, of course, with the tinnitus community and with our membership as well, to make sure that what we do is going to achieve their goals and their aims and what they believe the BTA should be doing.

At its heart, the BTA really is a membership organisation and it is very much driven by surveys and feedback that we get from our members, in terms of what we should be doing and what we should be prioritising.

Sean: Just to touch on this because I know everyone will be asking it. Do you actually suffer from tinnitus yourself?

David: I don't. I have tinnitus, but I don't suffer from it. I hear it at night and I hear it when I am stressed but, no, I don't describe myself as a tinnitus sufferer.

Sean: So, you have tinnitus, but it isn't something that is actively bothering you?

David: That is correct. I haven't sought help for it or anything else. I'm not sure if I'd even have noticed it if I didn't have this job but, yes, it's certainly there and present and something I am aware of when it's quiet or when I'm stressed.

Hazel: David, do you remember this coming on at a certain point or is it something that was always there?

David: No, I didn't have it when I started here. I've been at the BTA for eight years now and I certainly didn't have it at that point, but it's something that has emerged over time, so I only notice it when it is quiet. I've got a high-pitched tone and it is probably associated with a degree of hearing loss I would imagine, just based on general prevalence and what is out there.

Markku: So, David, one question I have in mind is that before BTA, before you joined, there probably was an open position. How did you come about it? Did you have some kind of professional idea why you wanted to become an executive?

David: I've always been around the charity sector. I've worked in a number of different charities and organisations at senior level. Firstly, around youth consultation and then around crime prevention, so nothing to do with health at all. But I really wanted to advance my career basically, so I saw the job come up and I did a lot of research and, just looking at where the charity was and how it was structured at the time, I really felt I could make a difference and drive the charity forward.

I felt that I could really support them in terms of what the charity wanted to do to be a bigger player than it was at the time as well, so it was career motivated if you like but, at the same time, I really felt that I could make a difference. Since coming on board I've really enjoyed it. I really do enjoy the charity as it is. I enjoy the role it has. I really do see us as being a hub of the tinnitus community in the UK; you know working very closely with, not only people who have tinnitus, but also with clinicians and those out there, to help people manage it better. Also, the research community as well. I really enjoy those interactions and overall the charity feels positive and the people out there want it to succeed so, yes, I really enjoy working here.

05:10 – David's motivation

“I'd love to pack up the BTA one day and say: We've done it, we've found cures and we don't need the BTA anymore. That's what drives me”.

Sean: What I also find interesting David is how hard we all see you working. You're on the Forum, you're responding to us, you're responding to emails and you're obviously working hard at the organisation. Has this always been your attitude at all your jobs or is this specific charity organisation making you want to work harder to help people? You just seem to work so hard and it's just so surprising to see someone so into their job.

David: Thank you for the feedback. It's really good to hear that you guys value that as well and when I went to the interview... What motivates me is that I want to close the charity down. I want it to not be needed any more. That's always been my aim whatever organisation I've been with because charities are in that unique position that you could achieve your objectives and no longer exist, and I'd love that to be the case with BTA. I'd love to pack it up one day and say actually we've done it, we've found cures and we don't need the BTA anymore and that's what drives me. I'd love to have that on my CV and have that as an achievement as well.

Sean: Yes, that's a really interesting perspective, that your main goal is to get rid of the BTA, but not in a bad sense, in a good sense that it is no longer needed. I never really thought of it like that.

David: Yes, exactly, everyone's the same who works here. You know, we are a growing team, but no-one works for a charity really for huge remuneration or anything else. You look for those other types of rewards. You want to help people. You want to achieve something significant and that's certainly what drives me and my team and, of course, our Trustees are people that are living with tinnitus, so they want that to happen too.

06:56 – How people with tinnitus contribute to tinnitus causes

Sean: Right, well that was actually going to be another one of my questions. How much of the staff, would you say, has tinnitus or has a similar situation to you? Where they have tinnitus but it's not really an impact on their life? But then the Trustees are really the ones who suffer from it, which is why they're so involved?

David: I think that's fair. There are people here who do have tinnitus and a couple struggle with it a little bit but it's one of those things as well. I'm sure you guys find it as well in your roles that actually if you have a role where you are going to work and it says The British Tinnitus Association above the door it can be a real struggle if you do have severe tinnitus to keep that going and keep that focus on your day job where you've just got that constant reminder about tinnitus, so we have had people on the staff team before who have struggled but, for their own welfare, they have moved on a little bit in the end just because, as I say, to turn up to work and have that above the door every day is not the best place to be if you are trying to manage tinnitus effectively as well.

Sean: You know it's interesting. Ever since I started doing a lot of work with Markku and Hazel for the Podcast it's been mentioned to me that if you are constantly thinking and working on stuff regarding tinnitus, aren't you thinking about it more? And from my personal experience it's a better distraction for me. Even though I'm talking and thinking about tinnitus it's like I'm working, and I'm distracted, and it helps me not really tune into it as much. I guess it's a different experience for me but, yes, people give me a similar question of, if you're always thinking about it and talking about it, doesn't it make it more relevant and for me it is a little distraction. I don't know about Markku and Hazel?

Markku: I have exactly the same experience. It distracts me, it helps me actually to work on this stuff but I would say maybe for the majority - I don't have percentages - but I think from the feedback we have got and the fact that it is so hard to get volunteers and they tend to drop when their tinnitus becomes better, they don't want to think about it all the time. So, I would say for the majority of people they don't want to be in a world where something reminds them about their struggle, so we are the minority in that.

Sean: Yes, and in another sense, it also helps me feel like I'm doing something. Instead of just sitting there and not doing anything, at least I am working on it. I am doing something, I'm pushing it. I am trying to make this situation better by raising awareness or doing something like that. It's like a double-edged sword in a sense where I'm working and it's distracting, but also at the same time I feel productive, like I'm helping the situation, so it makes me feel a little better as well.

Hazel: I have the same motivation. It's like when something bad happens to you, you have no control over it but then contributing something to the cause gives you some sense of control back. Turning a negative experience into something positive to some extent.

David: We're fortunate to have people like you out there doing it because it's not just looking at people who contribute to the BTA, but you look at people who are contributing to the tinnitus community globally as well and it's of real value that people like yourselves are doing that and are involved.

Sean: Just to jump back on to our initial chain of questioning to make sure we get everything. Just to jump back to the BTA. Can you describe to us what the main goal of the BTA is or what the current Mission Statement is? I know we touched on it a little bit before.

David: So, our vision is a world where no-one suffers from tinnitus and that is what we want to achieve. So, we think some of that is achievable now. Because we think there are tools and methods out there that enable some people not to suffer. So, there are management techniques that will get people out of that population but, at the same time, we want to find better ways to manage tinnitus as well, so that we can take more people out of that population; people that do suffer from tinnitus. And, ultimately, we want to find a cure as well.

Sean: So, I know you mentioned earlier in the conversation you have a five-year plan. Can you get into that a little bit?

David: Yes, the plan covers five different areas if you like. One is around **'cure'** and we want to be much more proactive, if you like, in leading progress towards a cure and that doesn't mean necessarily doing things directly as the BTA but lobbying others with deeper pockets than the BTA to invest in cure-based research and also encourage existing tinnitus researchers as well to consider what their focus is and if their focus could shift to areas that we think are important and pharmaceutical companies are telling us are important, to really drive forward that investment from them in tinnitus research as well. So, can we encourage people to look for objective measures to sub-type tinnitus as well and really move research into a slightly different area than what it's prioritising at the moment.

We see this as having more than one angle to it. We certainly want to make sure that there is more curative research happening and that also some of the researchers are, hopefully, looking at the field a little bit differently than is the case currently.

Our other area of our strategy is called **'inform'** and we want everyone to know what tinnitus is and what to do about it. So, a lot of that is around using things like **Tinnitus Week**, using social media and our press work to really drive up knowledge about what tinnitus is at a really basic level to make sure that people just understand what the word means, what tinnitus is and what to do about it as well. We still get a lot of people who get in touch with us who say things like, "I never knew what tinnitus was until I got it, until it was diagnosed", so just really trying to raise awareness amongst the general public about what that is.

Thirdly, we are looking to work on **'prevention.'** So, we want to empower people to really help them make effective choices around noise exposure, then understand the risks and understand what they can do to ameliorate those risks as well and what they can do to reduce those risks of getting tinnitus through exposure to loud noise.

Our final one is around **'manage'** we call it, which is about how we provide the best support to the whole tinnitus community. So how we improve the information that is on our website, how we improve our helpline, how we improve all the different services we have out there to help people who live with tinnitus, but also how we make sure the medical community in the UK is giving out the best advice as well so we offer a lot of training courses and work with a lot of the professional associations as well to try and up-skill people who are coming face to face with tinnitus patients as well to make sure that they have the right skills and right knowledge as well to offer the best support possible to people who are living with tinnitus.

15:58 – Tinnitus funding, health economics, and how to move research forward

"We don't have those [objective] measures in place that would enable the research to really jump forward."

Sean: So, it seems like you guys are basically trying to cover all the bases in regard to research, awareness and helping people that currently have it, so it sounds like you guys are pretty much really doing a good job on that front. At first, I thought you guys were focussing mainly on helping people coming to you, but it seems you have a lot broader reach into all different things than just that.

David: Yes, we are a small team and so deciding how we split our time to do that is challenging if you like. We try and have the different grounds covered. In bigger fields, for instance, cancer, you know, those things would be done by about four different charities. You'd have, in the UK, Cancer Research UK who'd do the research, Macmillan who do the support, and you'd diversify far more. But when you are one charity working in the area, or one that has this major mission around tinnitus then you have to spread yourself a little more thinly in what you do and try and make sure you can do everything that you want to. It's tough and we always have the debate of should we just go all in and just look at research or, should we just go all in and just do supporting people to live with it, but we feel it is important that we try and do our best across all those areas.

Sean: This just reminded me of something. Tinnitus even though technically, based on statistics, it's like 10-20% of people have it. Is that right? Do you know if that is correct?

David: Yes, that's the ball park.

Sean: That's the range. That's a huge amount of the population but, for some reason, there's not that much talk about tinnitus and research about it. I just did a very quick Google search and 12% of women, one in eight in the US, get breast cancer. But the amount of research and information about breast cancer is huge compared to something like tinnitus, even though the amount of people it affects is so much greater. I'm not trying to compare one to the other. I'm just trying to show that the amount of understanding and awareness about both of those conditions are vastly different even though tinnitus, technically, is affecting more people.

David: Yes, and you know we do similar comparisons as well. I am working on a paper at the moment that is looking at some of these comparisons. I think we compared it to diabetes and migraine and other things which you could say are comparable in some ways, in terms of population and the impact they have and the number of research papers that are published in those areas, and the funding that goes into those is vastly different.

Sean: I know recently there was a thread on Tinnitus Talk discussing the funding of certain health organisations and where they put their funding into which research fields and there was quite a strange deviation of money going into certain things that affected a very small amount of the population versus other illnesses and issues that affected a much larger percentage of the population. I mean, I don't really understand if there is any politics behind that, but I just find it interesting that illnesses and things that affect a larger group of people are not a main priority versus things that affect a smaller group of people that have the illness.

I'm just thinking out loud here, but I find it interesting about how that is decided and how money is divided up that way.

David: In the UK a lot of it is health economics so, you know, they do look at the costs and the societal costs and the burden of disease, if you like, for different things. That certainly plays a big part. The challenge around tinnitus research at the moment is some of the things we've touched on a little bit already in terms of definition. Do we have a clear definition of tinnitus? Do we need a better definition of tinnitus?

The research at the moment is very heterogeneous. If five people went at the moment to get diagnosed for tinnitus they'd probably all get the same diagnosis of just having subjective tinnitus, but the reality is they may have very different types of tinnitus once we start to sub-type effectively. So, actually, we are a long way behind. Maybe tinnitus isn't one disease or one condition if you like. It may be several different ones, but we haven't started to really look into that and investigate it.

Then you have the problems, like you say, of outcome measures and a range of other issues as well, so tinnitus research is a little bit messy. To go back to your example of breast cancer, my crass understanding is that you've either got it or you haven't. There is an objective way to tell. We don't have those sorts of measures in place for tinnitus at the moment that would enable research to really jump forward. Actually, I was going to say research in MS is an interesting one to look at as well. From my understanding a lot of research into MS, Multiple Sclerosis, didn't really start to move forward until they had that objective measure and a way to measure MS and see if it was progressing or not, and once that was established the research has recently started to kick on.

Sean: Right, and just to touch on what you said. You go to the doctor and obviously you say: “I have ringing in my ears”.

“Oh, that's tinnitus, get out of here, we can't help”.

It is a very complex thing. There's obviously pulsatile, somatic, noise-induced tinnitus, there's head trauma tinnitus, you know, I think you're right. We do have to push to getting those types of diagnoses instead of just “oh, you just have tinnitus.” There are those sub-types that should be looked into because if you have something like TMJ, yes, you have tinnitus, but if you have tinnitus caused by TMJ then that could be alleviated a little bit maybe? But I feel like a lot of times a lot of people, especially who come on the Forum, it's just “I went to the doctor, I told them I had ringing in my ears and they said it was tinnitus and they sent me on my way.” It's definitely a little frustrating.

David: Yes, I mean medically, unless you're looking into some of the objective causes like pulsatile tinnitus, and speaking from a UK perspective, you will have possibly a diagnosis of pulsatile tinnitus, but beyond that, yes, just tinnitus. You know, somatic tinnitus isn't even particularly well-recognised here and that's something that we're thinking of working on next year because there's some better research around that now but beyond that you may get tinnitus and a reason why that tinnitus is there, so caused by head trauma or hearing loss but that's not then necessarily a recognised sub-type and it's certainly nothing that research at the moment is sophisticated enough to look at and say, let's do a trial and let's look at tinnitus only caused by hearing loss or tinnitus with this hearing loss or tinnitus of this severity only or something. Sub-typing is a real challenge for us and something we really need to think about a lot over the next couple of years.

22:20 – BTA's financials

Sean: To just jump back again to the BTA. We're having such a good conversation, we're deviating so much. So just to hop back a little bit.

So how much, if you know, of the BTA's budget comes from patient donations or donations in general? Or is it all donations?

David: No, our donations are about 14% of our income, so about just over **£100,000** last year I think came in patient donations. We also get gifts in wills. So, people leave a legacy to the BTA, and pretty much all of our research funding comes from that. We do get some grants for specific research projects but the general research that we commission and fund comes from legacy income we call it, so gifts in wills and that's our main source of income in the past. So about third of our income is from that, so you could say that's also donations from individuals. And then about a quarter of our income is through Trusts and Foundations. So, we apply for grants to do things like our Helpline and our Information Days have been funded by support grants in the past. And then we have a membership scheme. We sell some goods as well, making up the rest of the income that we receive.

Sean: And so how much of your budget goes to actually research and awareness? Obviously when you have an organisation, a charity has to be split between salaries, has to go to office management, paying the rent in the office and everything so, if you know, what percentage of the total yearly spending goes towards research and raising awareness about tinnitus versus office costs?

David: 19% of our income last year was spent on research but, beyond that, because we are a small team people working across a lot of different areas, we don't particularly split staff time between awareness or time on the Helpline. That's a little harder for us to do. So, for instance, we will have staff who work on **Tinnitus Week** and put time into that when it's running because it gets a bit 'all hands on deck' as I'm sure is the same as Markku will tell you from last year as well for you guys. But then everyone does shifts on the phone Helpline as well and then we have the **Tinnitus Support Groups** that we are looking to support so it's a little bit more confusing beyond that. In terms of our admin and premises costs, that's 4% of our overall income goes on admin, and then we've got fundraising costs as well. There is kind of a mix, and then about 25% of our costs last year went on training. So, events that we run for professionals and our **Conference** and also doing the **Information Days** as well and other days for the general public. It's split across a number of things, but the easiest thing to track is the research. But like I say, if you are looking at how much we spend on awareness versus other things, it's a little harder for us to break out just because we don't time-log everyone's time on those sorts of things at the moment.

Sean: Sorry, what were the initials that you said, 90% or 19% on research?

David: 19 – one nine percent on research.

Sean: Ok, everything you've said, that's very impressive. I know quite a bit about charities in the United States and how they work and there's not a lot of regulation. Once a charity gets some money there's not a lot of "oh, what are you doing with that money?" So, seeing how much of your money is actually going to helping people and funding your goal, it ultimately is quite impressive because I know with a lot of charities in the US that is not really the case. It's quite surprising how much of a giant percentage of that money actually is helping instead of just being recycled back into the organisation.

David: Yes, and we try and be transparent about this, so the numbers I'm quoting are on the back of our **Impact Report** that is available on our website. Our full accounts are available through **The Charities Commission** as well and I think they are posted on Tinnitus Talk anyway so you can see how we do spend the money and how we allocate it and, of course, they are audited as well by an independent audit firm so it's not just us saying it. They are fully audited accounts.

Sean: So, you're saying people on Tinnitus Talk are keeping tabs on you?

David: And rightly so, that's what they're there for.

Sean: Of course.

26:50 – Challenges raising funds for tinnitus (research) causes

Hazel: David, I'm interested in your perspective on fundraising which is related to the financial stuff you were talking about, because I wonder what your experience is with this, but from the experience we've had with trying to raise funds, we've found it exceedingly difficult.

You're very well-aware of course, because the BTA is administering the Danny Boy Fund that we did the fundraiser for or, actually, one of our members, **Ed209**, initiated the fundraiser for. And it raised £5,000 which is not nothing, it's quite a good sum that we can do something really nice with and it's going to curative research – which was always the intention, to raise funds in Danny Boy's name and it should go to research for a cure. But getting that £5,000 took a lot of time and effort and we know that only less than 1% of people who saw the campaign, and went to the **Go Fund Me** page, ended up donating. Considering that most of those people probably have tinnitus themselves, we found that to be very low, and we were just wondering where this comes from? Is it that people have some kind of mistrust with donating to causes in general? We feel like we need more insight into that. I was just wondering what your perspective is?

David: Yes, fundraising for tinnitus is tough. Again, we've talked about the prevalence of tinnitus and last year the BTA's income was **£740,000** and I think the American Tinnitus Association's is pretty comparable to that as well. So, the actual amounts that are getting donated to the major charities is low and there are, of course, other charities working on tinnitus as well. I think online fundraising for tinnitus in particular seems quite tough. You know, a lot of our income doesn't come from online services and tends to come because people have used our Helpline, or we've met people at support groups and things like that as well. It is a tough ask like I say, and we've talked about it before. The percentage of personal donations we get is quite low. Our income through gifts in wills is fantastic and keeps the charity afloat, if you like. It's a real tough environment I think to fundraise money for tinnitus because it's one of those things as well that unless you've got it, it's an even tougher ask when there is so much competition out there, so you do rely on people living with tinnitus to keep the organisations going really and to keep research going as well.

Markku: For Danny Boy's campaign I think the page got something like 60,000 views and again less than 1% donated anything. And recently **Ed209** and **attheedgeofscience,** who are members of Tinnitus Talk, they ran a sponsored ad campaign on Facebook. **Attheedgeofscience,** I think he spent **US$300** advertising the **Professor Rauschecker Research Fundraiser** and the result was zero donations and the target group was **'Tinnitus Sufferers'**. So, it's really hard when the sufferers themselves don't see value in helping fund these causes.

David: I think around research it's a tough discussion to have in a way. There is some validation in that. There are obviously discussions about the value of tinnitus research ongoing on Tinnitus Talk regularly and a lot of people have got a fair point that it's hard at the moment to see where that real direction's coming from and what you would get most 'bang for your buck' for around research, so I understand some of that.

From the Danny Boy thing I think my hope is that we can build some trust by showing that we're running that, by it being a community-led initiative and the fact that we will have a vote on the piece of research to fund will hopefully build some trust and transparency and show that people do have a stake in it. And maybe it's one of those things that we have to sit into for the long term and hope that people see the value in participating in that way, and we build some trust that the money is going to the research that the community believes is right.

Yes, it's a slog, basically. It's a really hard fundraising message, because again we look at what else you can do, and I joke about it a lot because I'll go and do a fundraising pitch to a company. The company has decided they are going to support a hearing charity if you like or something. I'll go do one, people are onside and some of the people in the room are with you and some of them are going to vote and then Hearing Dogs for Deaf People come in with a little puppy and no-one's going to remember what you've just done because there's a cute little Labrador. So, you just look at the messaging and what you're doing and the tools you have, compared to charities working in animal welfare or children's charities, and it's hard to get other people involved beyond the tinnitus community, unfortunately.

Sean: So, David, what you should do is bring in little puppies and talk about how tinnitus affects not only humans but also animals. That will get you some money!

David: It is absolutely that type of thing. It is that tugging at heartstrings thing that works quite well in those environments sometimes. It's hard to really talk about it unless you've got it, I think. I do a lot of Health and Safety talks. It's the same thing; I always start by doing the talk, because I know people are there because they have to be, and I always say no-one cares about tinnitus until you get it, and then you do. And then you just take people through that journey because it's so easy to dismiss unfortunately unless you have lived it, or you have had that real experience of it, and trying to bring people on board with it can be a challenge, who just aren't aware of it or aren't particularly concerned about it.

33:33 – Conveying the tinnitus experience and distinguishing levels of severity

“Tinnitus is easy to dismiss, because many people have experienced it short-term and then they associate that as being the same as what others are experiencing, which it's not at all.”

Sean: I think people are ignorant. They're not being malicious. They just don't necessarily understand the extent of what tinnitus is, and we have had people discuss this all the time on the Forum where they say, “I didn't even know what tinnitus was and once I got it, it was like, Oh my God! Why isn't this more talked about and why don't people understand this?”

We even have some users who had tinnitus but then it went away, but they are sticking around because they know how terrible it is and they take it very seriously now because they know how much people suffer from it. So, I think it's one of those things where you don't really know about it. You don't have any experience of it. “Oh, what is it? Oh, it's just a little ringing, or whatever.” But then when someone gets a full smack in the face with it they’re like “Oh my God, this is no joke.”

David: I think that is the challenge because I think everyone has experienced tinnitus. Everyone has been to a loud environment and left and had the ringing in the ears for a few hours afterwards. So, everyone's had that, and I think that's what makes it so easy to dismiss because everyone's been in that environment, they've had it, it's gone away and whilst it was there for two hours it's not that big a deal. I think that's one of the challenges with tinnitus. It's easy to dismiss because people have been through that experience and had it short term and they just associate that as being the same thing as everyone else's experience, which it's not at all.

Sean: I think it's important that we talked about distinguishing between the different types of tinnitus before, and I think it's important that we distinguish something like that. There is something called fleeting tinnitus people have, but something like that's temporary ringing in the ears; that is very different from chronic tinnitus. When people say tinnitus, it encompasses everything involving ringing in the ears, so when people, like you just said, you are right, it is a temporary thing. People say like "I had that one time, it was just a little ringing, but it went away." They don't understand that it is a completely different thing.

David: Absolutely, I agree.

35:32 – Prevalence and the socio-economic cost of tinnitus

"The fact is that tinnitus costs the UK over 2 billion pounds a year; it's huge."

Sean: Something I wanted to talk about is the importance of the different types of statistics and facts when it comes to tinnitus. So, when you guys are trying to raise awareness of tinnitus, what different statistics and facts are you throwing out there to try and catch people's attention?

David: I think it's the stats. It's that one in ten people have it. I think how common it is surprises people and not only that but how many people have it to a level where it has an impact on quality of life so that 2% of the total population have tinnitus to a level where it's impacting on their day-to-day activity and people are really struggling with it. They are big numbers and they are often the ones that we look at and use a lot. Beyond that, we use a lot of the numbers that we found in the economic study as well; the societal cost of tinnitus. The fact that tinnitus costs the UK over **£2 billion** per year is huge.

Sean: Same in the United States. It's a massive cost.

David: Again, they are big numbers and things that do get people's attention, I think, so they are always useful to know and understand and, then, just the cost of tinnitus to the NHS. The fact that the NHS spends around **£750 million** per year on supporting people to manage tinnitus. There is a huge opportunity there for better ways to manage it and a cure as well to hit those markets, so I think they are the sorts of numbers that are useful to use and useful to put out there. Beyond that, I'm not sure. There are other numbers I use but I always think those are the key ones really. Just how prevalent it is and then just some of the big numbers around costs as well.

37:25 – Educating doctors to be more helpful and compassionate

[Interlude] Markku: Coming up next, we talk to David about how doctors treat their tinnitus patients. Many of us have had a bad experience with a medical professional. It might have been down to a lack of time, lack of understanding or even lack of empathy. You will hear David explain what the BTA is trying to do about that. But, first of all, let me introduce you to the results of a poll that was organised on the Tinnitus Talk Forum.

The question was 'Did you find a doctor who really cared enough to get to the bottom of your tinnitus problem? 74% answered 'No' and I will give you a quote from one of our members.

"I came to the conclusion that nobody cares. None of the doctors I met wanted to help me. Nobody even asked or went through the list of conditions that can cause tinnitus".

Signed by a disillusioned patient.

Alright let's get back to David here.

Sean: Does the BTA try and help reach out to doctors about that compassion that a lot of people talk about when it comes to tinnitus? When people first have tinnitus a lot of doctors seem cold. They don't really seem too empathetic or sympathetic towards their patient. They just say: "This is it, just live with it and deal with it." you know what I'm saying?

David: Yes.

Sean: And that's not something that people with tinnitus when they first get it want to hear. Do you do any work with trying to educate doctors or trying to push the message that you guys have got to be a little more understanding here? This is a very serious thing.

Sean: Yes, we do. So, we have produced practice guidance for family doctors, so GP's in the UK and we have been disseminating that a lot and we're doing some educational material as well working with Action on Hearing Loss, one of the major charities on hearing loss in the UK and developing tools for family doctors again in Northern Ireland. So, yes, we are doing work around that and it is always a key message that we are getting out and we go to the main National Conference for GP's every year as well to again just try and get that message out there that, yes, they need to be doing better by their tinnitus patients.

To be fair most of them are receptive to that message because they willingly admit it's not covered in their mainstream education, so we do a lot of work with them to try and get that compassionate message right; to make sure they are not making someone's condition worse by the information they are giving them as well. So, yes, we do do that a lot with GP's. We need to do it better with ENTs and it's certainly one of our targets next year. Just how do we work better with the ENT community as well to make sure that they are not doing that negative counselling as well.

David: I feel like based on my experience and other people I have seen on the website, that ENTs are some of the biggest culprits when it comes to this. The message of 'learn to live with it.' When people come in very distressed, like a lot of the people on Tinnitus Talk talk about this. They go in very distressed because, obviously, tinnitus can be very distressing, and ENT's will downplay the tinnitus and chalk up the distress to 'anxiety' and it will be like 'Oh you have to get your anxiety in check, you've got to get that in check. Your tinnitus isn't really that bad. It's just your anxiety about it.'

I agree to a certain extent, but if the tinnitus is bad it's causing the anxiety so, initially, the tinnitus is still the big problem, so telling someone just to live with it isn't very comforting which I think a lot of ENTs need to realise and stop using that terminology because I feel it's very damaging psychologically when someone comes to them and they say "oh, just learn to live with it" and essentially just says to the person "there's nothing we can do, you're on your own."

41:08 – Representing severe tinnitus sufferers

Sean: When it comes to representing the spectrum of people who have tinnitus, does the BTA represent every single class? You know: the people who have it but don't really notice it, like yourself, people who have it mildly, moderately, severely, very severely? Do you even distinguish between those people or do you just put everyone into a category of people who have tinnitus and are representing everybody?

David: Yes, I'd like to think the BTA is here to represent the whole tinnitus community and everyone within it. If someone rings our Helpline we don't say: "oh you've only had it for this long" or "well, you don't sound to be struggling too much," and hang up. We're here to help anyone who wants our service basically. We don't discriminate or think that we're not here to represent certain elements. We're here to help everyone and I see our role as here to bring together researchers and clinicians as well and work with them, as well as people living with tinnitus. I would certainly like to think the BTA represents the whole tinnitus community and that we are here for everyone.

Sean: That makes sense to me. I guess it would be hard to distinguish between, oh, for mild sufferers we're going to do this... So, I guess it's good that you are just trying to help everybody out. But do you guys still recognise the different 'classes' of tinnitus?

David: Yes, we do. When you pick up a Helpline caller you are never sure who you are going to get or where someone's at, but I would say the majority of people who use our Helpline or are attending support groups are at that end of people who have moderate to severe tinnitus. Just because if you did have mild tinnitus you're not going to be ringing a tinnitus helpline, so the majority of people that are accessing the services that we have are certainly at the severe end, really.

The other thing I would say about it as well is that a lot of the work we do around supporting the people with severe tinnitus is unseen as well. So, it's lobbying to make sure they are included in research trials and they are at the forefront of people's minds when research trials are designed. It's making sure that, actually, when we are doing training we are really supporting professionals well to make sure they can give the best service to those patients because, again, they are the patients that are going to have repeat appointments in an Audiology Clinic and a Tinnitus Clinic, so we want to make sure that the professionals there and are as best equipped as possible to support those people as well, and those who are really struggling. So, a lot of our work we do is there to support the severe end, if you like, and people who are really struggling with it.

43:57 – Promoting or not promoting upcoming potential treatments

Sean: So, regarding future treatments and the BTA, is there some hesitation when it comes to discussing future treatments and things that could be coming out?

David: Not particularly. We are very careful to not promote anything that doesn't have an evidence base or not be seen to promote something that doesn't has an evidence base. We always wait until research is published before really discussing a new therapy or a new treatment.

For one thing, we don't want to raise false hope or raise awareness of something that, ultimately, might not work and, over the years there have been a lot of different false dawns for tinnitus sadly, so we don't really want to get involved in that type of speculation.

We support a lot of companies. We support a lot of trials behind the scenes, but we don't necessarily discuss it until we see the published research and see high quality published research as well. So, randomised control trial level research is what we look at and what we try and use to evaluate different treatments or management techniques that are out there.

Sean: An issue that a lot of people talk about is they feel that certain tinnitus organisations aren't talking about this and ask: “why aren't you promoting this?” And like you just said, is it because you feel that the science needs to be there. You don't want to be giving people false information and false hope. That's why you're more conservative when it comes to talking about these things because you've seen in the past there's a lot of hype around a product and then the product or the pharmaceutical, the drug or whatever, ultimately fails and then you're standing there and everyone's saying “well, what happened?” and you're like “I don't know.”

David: Yes, there is some of that. So, we do talk sometimes about what research is happening and what's going on, so I guess the big news at the moment is, of course, **Neuromod,** and we've had them at our **Conference** and at our **Expo** but we're not endorsing it and we're not talking about it publicly. We'll very much wait for the research results to be out there. And digest it at that point really.

Sean: So, you're basically saying “hey, this is what's going on and we can't validate any of this but we are just informing everyone that this is potentially coming down the pipeline."

David: Yes, and if people ring our Helpline and ask questions about something like that, we are very open and honest and say there is no evidence it works. There's no evidence it doesn't work either. We are in the same boat as everyone else. We are waiting for that validation to be out there so that people can make an informed choice.

Sean: So, I assume you have seen the Neuromod Q&A that was recently done with Tinnitus Hub. I know officially you can't make a statement for the BTA, but what is your personal feeling on this?

David: I haven't watched the video yet to be fair, sorry about that! But I have had a few conversations with Neuromod and I think personally it's great to see a company doing it the right way.

They did bring something to market [in 2015] and we were in discussion with them at that point. They quickly withdrew it because they saw the importance of getting a robust evidence base for it first. So, really good to see a company doing it the right way to want to get that evidence base out there and I think it will really be exciting to see what the research says. A bit like everyone else, we are waiting for those papers to be out there, so we can fully interrogate them and understand what benefits the product does or doesn't bring.

Sean: You think that it's more of you'll just be expressing those statistics based on those studies? You won't necessarily be saying 'it worked'. It will be like these are the statistics, this is what they're saying?

David: Yes, I think so. Again, it depends what it says. My understanding is that the randomised control trial research is some way off being published. What they will publish soon will be Proof of Concept stuff, which again will be insightful, and we'll be waiting for that RCT and see what that says further down the line as well. But yes, it's certainly exciting and it's great to have a company investing in the space like Neuromod is and actually I think what they are doing is really, hopefully, upping everyone else's game as well in terms of the quality, and the RCT and the length of time that trial is commissioned for is really good to see and really refreshing. Especially in the devices space because that has been really lacking.

Sean: There's also been in the background – we have been keeping up with some pharmaceutical drugs that are coming down the pipeline and one of the big ones that is causing a lot of hype on our end which I'm sure you've heard about, is a company called Frequency Therapeutics. They are looking into a regenerative medicine. I'm sure that based on what we have just been talking about that you guys have been aware of it but like we've also talked about, you guys can't promote it or really put it out there because they're still technically in the safety phase right now or just finished it.

Markku: Yes, some of our members are really vocal about this. They think they want ATA, BTA and other hearing organisations and tinnitus organisations to promote Frequency Therapeutics to bring together tinnitus patients and try to lobby the government to allow fast tracking of the drug. So, what is your opinion of that, David? What would you say to a person who wants that from the BTA?

David: So, we're following some of the regenerative medicine. I spoke a little bit to some of the people who are working on that in the UK. We are just actually looking to commission a paper on it for our magazine, **'Quiet'**, just to look at some of the different work that is happening around this and not just what Frequency Therapeutics is doing but also what some of the other companies are doing around the regenerative medicine space as well and, yes, it's interesting and exciting but it's very early-stage stuff. I can speculate on it but that's all I'm doing. In the same way as anyone else in the Forum is at the moment really and likewise, as I say, we are trying to get a paper together on it, but anyone who writes that is, similarly, just putting across a personal opinion at the moment I think.

Because the research is in its infancy. It needs to move on a little bit I think for us to understand it more. I mean, I don't know what you guys think? You're probably following the discussions on Tinnitus Talk around Frequency Therapeutics closer than I am. I don't know what your impressions of it are in terms of where it's up to and regeneration of the inner is a bit of a 'golden goose' at the moment. I mean, you do that, and you are winning Nobel Prizes. It's a huge goal. There are companies beyond Frequency Therapeutics looking at it as well, so that type of regeneration work is interesting and is useful. Like I say, we can speculate about its impact on tinnitus. It should have an impact if you just think of the mechanism of the ear but it's a way away from having a proven model. There are a lot of different models at the moment.

I know The Hearing Health Foundation were looking at one link to the fact that chickens can regenerate their ears or their inner ears, so there is a model there you can learn from and there is research happening in the UK at the University of Sheffield which is really interesting around it so, again, lots of stuff happening. Very early days and it will be interesting to see where it goes over the next few years.

Sean: Just to give a quick overview. If anyone listening doesn't know what we're talking about. Basically, regenerative medicine is a way to regenerate hair cells in our ears, specifically Frequency Therapeutics are looking at ways to use cells that are in our body that are inhibited from regenerating to form some type of drug that will allow those cells to start regenerating like it does in chickens and reptiles, which all have the ability to regenerate their hearing. In humans we don't have that ability, because those cells are suppressed from regenerating, based on our biology. So, they are trying to stop that from happening so those cells can regenerate in humans. I think that is their ultimate goal. I am by no means an expert on this drug, or this company, but that was my basic understanding of what is going on.

David: Yes, I think that's the basic premise around regeneration of the ear at the moment.

52:43 – Promoting or not promoting currently available treatments

"We don't promote TRT. [....] My personal opinion on TRT is: the world has moved on a little bit."

Hazel: Just to go back to treatments in general, because you say you can't endorse specific treatments until all the data is there, but are there specific treatments that you do actively endorse when people come and ask you for help and, conversely, are there treatments that you would actively discourage people from trying because they might be harmful for instance?

David: What we encourage if someone gets in touch is to speak to their GP, so speak to their family doctor and go through the standard health pathway that's available in the UK and when they get to the Tinnitus Clinic or Audiology then, in partnership with the Audiologist, talk through their different options. Look at what options are available and ideally work in partnership with your Audiologist to see which are most suitable for you and which ones you think are going to work because, at the moment, you look at what is available and what is standard within a healthcare pathway.

There is not strong evidence for anything having a huge impact, so we think it's more important that you decide and look at what you want to do and do that in a collaborative way with a health professional and you will have more of an opportunity and more likelihood that that works than anything else. In terms of stuff that we don't promote we've just started a section on our website called 'Tinnitus And' which just goes through the evidence base and how safe some of the different therapies are so I think we've got four we've done so far and we are looking to add four a month at the moment and just look at the efficacy and the safety for each of the different individual treatments. So, there will be things on there that we do, and don't, end up recommending.

Sean: That's fantastic that you guys are doing that because there is a lot of stuff out there that a lot of the Forum members, and a lot of people, feel is complete BS.

Hazel: Or they're scams, basically.

Sean: Seeing that you guys are taking the step of: Ok, here is a treatment. Here is something that people recommend. Now we are going to look into these studies. We are going to look into whether it is actually efficient or not and we're going to be able to give people advice as to: 'don't do that, there's not enough evidence, or the evidence isn't there or, you should maybe try this, there is some evidence here' because there's a lot of stuff out there and a lot of stuff that people feel is just a scam, unfortunately.

David: That is the type of thing we are looking to develop. It is tough because with a lot of these things people get very animated one way or the other because it has helped them or hasn't. There was a product a while ago, which I won't name and, literally, we'd get letters and emails every day. One saying "Why isn't that on the front page of your website, it's absolutely cured my tinnitus, it's fantastic." The next letter would be: "This has just robbed me of thousands of pounds and how on earth can this be allowed to be available?"

Hazel: I think I know which one you are referring to, David.

David: Well, it might not. Because tinnitus is so heterogeneous though, we don't necessarily know how it's working and it might be that tinnitus is cured at a level for some people and does work at that, but for others it doesn't, but because we just do population level studies where we don't really have that sub-typing then it's hard to say, so we are careful with it and, yes, we are starting to get that list together hopefully, saying what we think is safe or not, and what has an evidence base or not.

Sean: Do you recommend the 'gold standard'? What people talk about as the 'gold standard' for tinnitus treatment is TRT. Is this something that you guys have looked into; that you promote for someone or do you leave that up to someone to go to an Audiologist and then the Audiologist will figure it out?

David: There is a bit of that. We don't promote TRT. It's not really available in the UK. There's only one way to train in it now so you have to go to the US and complete the training course to be able to offer TRT and it's in the format that it is delivered. It's a sort of 18-month programme so you wouldn't really get that on the NHS either. It's nothing we promote. It's not available. My personal opinion on TRT is that the world has moved on a little bit. I don't think it's quite there. I mean, certainly, in terms of counselling approaches and how TRT is delivered, it uses a form of counselling called **'directive counselling'** which a lot of people have moved away from now. It's not particularly seen as something that would be resurrected or used widely in the UK.

Sean: Yes, that seems to be an issue in the United States. The complete opposite. It seems to be the gold standard here. Unfortunately, as we've discussed, the evidence around TRT's effectiveness is a little shoddy, to put it in a nice way.

David: There are challenges with some of the research that's out there. What I would say is that, actually, using some sort of sound therapy and using some sort of counselling approach so you are having some sort of blended approach is very common but, yes, in the UK pure TRT as it's written in the text books is just not something that is really available or delivered.

Sean: Wow, I wish you could bring that over here!

58:30 – Plans for the future

Sean: We are going to try and wrap this up. I know you are a busy man David. So, let's see. is there anything in the future that's coming from the BTA that you want to let us know about? Anything we should be aware of? Any events? Anything we can do to help you guys out or spread the message?

David: We've got our **Strategy Meeting** in January for the next financial year with our Trustees, so yes, a lot of plans that are happening but nothing particularly public. We will be looking to do an **Expo** again next year. So that's certainly something we are planning to do next year. We are trying to find a suitable venue for that at the moment, so we will be running the Expo as we did this year and which Hazel attended. We will be doing that, and we will be looking to be a lot more active in the cure space and hoping to have a paper out and looking at how we develop our work around that as well in the New Year.

We want to do a lot more digital-based work and digital projects as well and just continue improving what we are doing. The digital projects, the new ideas that we've got, they are all dependent upon us being able to bring in the funding to do those. So, a lot of work for our fundraisers to do as well to bring in the cash so we can do some of that.

Sean: Alright David, I think we've covered a lot. I know you probably want to go and eat dinner and get out of here. I think we covered a lot of the stuff we wanted to and there is obviously some stuff we wanted to talk about, but we only have so much time in the day.

I don't know if Markku or Hazel have anything in particular you wanted to touch base on?

Markku: No, I just wanted to thank all of you and, especially, David. This was a very nice evening for me and for all of us and, hopefully, for our listeners also so, thank you all.

Sean: Thank you David, we know you're very busy. We really appreciate it.

David: No, you guys are the volunteers. Thank you for the time you put in and invest as well and happy to do this again sometime if it makes sense.

Hazel: Yes, I'm sure it will. Thank you so much David. I also think we covered a lot of important ground, so I don't have anything else and thank you Jack (Sean) also for hosting this Podcast.

Sean: So, I think that about wraps it up. I just want to thank again David, Hazel and Markku and I hope everyone listening is enjoying it or taking stuff away from it hopefully. That's the main point of all this.

Thank you for listening everyone and see you next time!