

TINNITUS TALK

PODCAST

EPISODE 8



## TRANSFORMING HYPERACUSIS RESEARCH Bryan Pollard

### 00:00 Bryan's background and personal hyperacusis story

**Hazel:** Hey everyone and welcome to the **Tinnitus Talk Podcast**. I am here today with **Bryan Pollard** and I am especially happy to have him on because many of you guys out there have been asking us for quite some time, **'when are you going to do an episode on hyperacusis'?** Obviously, a lot of people with tinnitus also suffer from hyperacusis and vice versa and there is a lot of overlap so it is an important issue to many and many feel it's even more under-recognized and under-researched than tinnitus, so I am happy we get to pay some attention to it today, and welcome to the Podcast, Bryan.

**Bryan:** Thank you.

**Hazel:** So, Bryan, can you tell us a bit about yourself and obviously you are doing a lot of work in the area of hyperacusis, and I think it came about because you, yourself, developed hyperacusis? So, can you just tell us your background story?

**Bryan:** Sure. I am excited to be able to share a lot of information today. My own background started a little over a decade ago from, ironically, a situation where I was trying to make things safer at my house. So, I had a tree growing partially over the house that was unsafe. I was concerned that it might come down on the house during a storm, so I had it cut down. It was quite large, and I was at home from work to watch the procedure because there was, actually, a little bit of risk to part of it hitting the house in the cut-down procedure. So, after staying outside while they were using chainsaws to cut it down, I was quite relieved that it was down safely. I thought the most dangerous part of the work was done and I was just inside eating lunch. I had assumed that they would start cutting up the large chunks of the tree to put on a truck, but that was not the procedure they chose to do. They actually brought in this huge, industrial-sized wood-chipper and began chipping up the entire tree, including the large chunks. It was incredibly loud. I remember thinking, I don't think I've heard anything that loud in my life. I stood at the window watching it a few minutes and then proceeded to eat. And when I left, I walked right by the wood-chipper. Little did I know that there was significant damage that had already occurred, and I had some delay, but several days later I began experiencing a lot of various symptoms including ear pain and, kind of, the normal path for hyperacusis sufferers.

**Hazel:** Wow, so how did things develop from there?

**Bryan:** Like a lot of people I proceeded to the normal Clinical Community, at the ENT. There was quite a bit of normal procedural steps followed for testing hearing damage. There was no detectable damage by the normal auditory examinations and, so, eventually, I got around to several Audiologists. Basically, you know, they were just rolling out the standard things. None of them even mentioned hyperacusis. In fact, hyperacusis didn't come up until I started doing my own internet searches and, eventually, I found that that seemed to describe what I was experiencing much better than anything that had been suggested. Eventually I found someone quite a distance away, about 45 miles away, that did the standard **TRT Treatment for hyperacusis** and I proceeded to go through that process for about a year and half with the standard protocol. Very, very little progress during that time but I actually did continue standard **TRT** for over five years. Throughout the whole time I did not get significant gains but just some modest improvements.

**Hazel:** I'd like to hear more later about your experiences with treatments, various treatments. but what were you, at the time, experiencing in terms of symptoms? Can you describe what it's like for someone how doesn't have it?

**Bryan:** Sure. My symptoms turned out to be fairly typical although at the time I didn't know that because it's a discovery from the mystery of what one is experiencing. Basically, when I was around what used to be normal sounds but, you know, somewhat louder sounds, my ear would start throbbing and, confusingly, it wouldn't always throb right away. In fact, sometimes I would think, 'oh that situation didn't really bother me', but when I would lay down at night my ear would start throbbing and, eventually, I began to correlate the loudness of exposures. In fact, fairly early on I bought a decibel meter because the smart phone apps weren't really available as much at the time and I started denoting the decibel levels of what I was exposing myself to, to try to understand if there was some correlation between the levels of throbbing and pain I would experience and what had occurred. Eventually, I did see some correlation although nowhere close to one to one correlation, but additionally there were symptoms like ear fullness, tinnitus - mine is reactive - so that would also spike in relationship to the noise levels I was around.

## 5:59 Becoming a hyperacusis advocate

**Hazel:** How did you go from being someone struggling with hyperacusis to becoming sort of an advocate in this space? Because you actually do quite a lot for other people with hyperacusis. Can you tell us a bit about your work in that regard?

**Bryan:** Well, my involvement was somewhat natural because I was an engineer at a high-tech oriented company where my role had developed into one of solving technical problems. I had studied a number of innovative problem-solving methodologies, including some that had some significant on-line tools to things like a pattern database. And so I started looking at this problem like I was examining more technical problems at work which was not in a bio-medical field, but what became evident to me was that there was no systematic assessment of the nature of what patients were experiencing in the Research Community and, eventually, after

studying some of the basic papers on hyperacusis at the time which were pretty thin, especially from an in-depth technical perspective, I started emailing Researchers directly and reaching out to them and, amazingly, many of them responded. I actually didn't reach out saying I was a patient. I reached out on the basis of saying I am trying to understand this aspect of your research. After getting a number of responses eventually I got connected to **Dr David Mountain** at Boston University and he is a renowned researcher. Now he's passed but he also had an electrical engineering background, which happened to be my background so living close by I was able to go to his office and while he had never studied the condition directly he knew much in-depth work associated with basic auditory functions and he was fascinated by this condition and what I described to him. He had never heard anything like it, and he became a strong partner and advocate and really gave us the basis to begin the work. Eventually, it became clear if I wanted to significantly influence the research, we needed to form that work into some more formal method for which a non-profit became the obvious choice, to try and get a coalition of forces that could actually start to impact what was being researched.

**Hazel:** So, that became **Hyperacusis Research**? Correct?

**Bryan:** Yes, and that's where there was no debate on the name because you know I looked at the early days of something; if you take Foundations, for example, and at large for various medical conditions, most often they are very large umbrella organisations - meaning they are trying to cover every single dimension of the patient side, the clinical side, the research side and have a really broad basis. Knowing that we were so small and had just a band of volunteers, we intentionally focussed all our work in the early days solely on the research dimension because that is the part we really wanted to directly impact.

**Hazel:** What does the organisation look like today? I think it's still run by volunteers, but have you evolved, expanded over time, in any way?

**Bryan:** Yes, so we did find a couple of avenues that were able to take us into a pattern of being able to multiply what we were doing from a small basis. Yes, it's still all volunteer but the number of volunteers has increased. We do have members focussed on various dimensions of what we attempt to accomplish and we have some very technically-focussed people helping; some very media-focussed people and then some strong leaders on the Board who have experienced a lot of different phenomena in their careers, along with people who also have members of the family who have hyperacusis. And so, what really became our platform of greater influence was our partnership with **The Hearing Health Foundation** which was enabled by a connected Physician in New York City who had hyperacusis and was able to get us direct connections with **The Hearing Health Foundation**. They were started in 1958. One of the largest organisations in the United States focussed on auditory disorders, and that really began to give us a platform to enable the research dollars we were obtaining to go to a much larger audience and that's where, eventually, our partnership for our funding to go to their emerging **Research Grant Programme** has been kind of the foundation of what's grown into something that now has, to some degree, name recognition in the Research Community.

**Hazel:** Yes, we're quite familiar with **The Hearing Health Foundation**. I think they do some great work. We actually published an article in their magazine a few months ago. When I say

'we' I mean **Tinnitus Hub**, the organisation behind this Podcast. We've collected quite a lot of survey data over the years and we published an article about age and tinnitus in one of their magazines so, yes, we have some connections with them ourselves and they seem to be doing a lot of great work.

## 12:02 Various definitions of hyperacusis

**Hazel:** So, I think we should move on and talk a bit about what hyperacusis actually is, and what the different types of hyperacusis are. Do you have a kind of basic definition of hyperacusis that you like to work with?

**Bryan:** Yes, I do. My definition is pretty simple. At the base level I define it this way: **'Hyperacusis is a condition that causes a person to be unable to tolerate everyday noise levels without discomfort or pain'**. That is a fairly limited statement compared to some but one the reasons for trying to keep the definition fairly concise is because there are a lot of variations associated with everything that was just said and, most interesting in the history of the definition of hyperacusis, is how the word '**pain**' has been either in, or mostly out, of that definition. What happened in the early days - the term itself has been around since the 1930's - in the early days of the definition the emphasis on the pain component was fairly big. Somewhere along the way it fell out and the sole emphasis became the issue of loudness and then, one of the things we tried to do is what I initially thought we were the first to emphasise the pain component, until I was doing more in depth research in the last year or so, and I actually uncovered, that what we were actually doing was recovering that emphasis, because it had been there in the early history of the definition.

**Hazel:** I've heard people talk about '**Pain Hyperacusis**' versus '**Loudness Hyperacusis**' where the former means that you literally experience pain with certain sounds and the latter means that sounds are somehow amplified somewhere along the auditory pathway, I suppose. Is there really such a distinction? Are those two different types?

**Bryan:** This is a great discussion and it is one that I have spent quite a bit of time on. One of the core references in the field today stems from the 2014 literature review that **Rich Tyler** led a team to accomplish which we actually helped to sponsor the grant for that literature review. Ultimately, he came to the conclusion of the four basic sub-types:

- Loudness
- Pain
- Annoyance, and
- Fear

My description of that is I think what is helpful about that categorisation is that there is a distinguishing factor between, what I call, two physically based components and two emotionally based components of hyperacusis. Meaning loudness or pain is two very distinct physical symptoms and the annoyance, or fear, has two distinct what could be termed, 'emotional components' associated with the physical symptoms that are felt. So, those are not what I call 'perfect'. Meaning you could probably come up with a few other ways to parse that out, but I think what is super-helpful is really distinguishing whether a patient's main

complaint, or primary complaint, is loudness or pain. Initially, everybody was approaching hyperacusis as of a decade ago, where the primary complaint was loudness and like I referred to earlier, pain was barely in the picture. I think the reason why this is helpful is it allows clinicians to try to delineate what is the primary complaint of the patient. Not assuming that because they talk about sounds seeming louder, that that is the main problem. Now, where these terms may be problematic – and what that Review states even itself – is that these are inter-related and co-mingled amongst the same patient. I don't personally know of a whole lot of people who have only pain hyperacusis and no perception of greater loudness at all. However, I do know quite a number of people who have only loudness concerns associated with their hyperacusis and virtually no pain whatsoever. And so, I think, for the most part, these symptoms do tend to go into a spectrum of variability between patients and what they really help with is the clinician trying to focus on what is the main component of the symptoms that this patient has that we need to address.

**Hazel:** Right, it makes intuitive sense that it is something like a 'spectrum' but is it known whether, in terms of the underlying mechanisms physiologically in the ear and in the brain, whether there are really distinct types of hyperacusis, in that sense?

**Bryan:** I think that the nature of what we know about the distinguishing factors and mechanisms between these various types is still somewhat weak. There is a great model for loudness hyperacusis. It is one that is readily accepted, and I think it explains a lot of factors and that is mostly the **'Central Gain Model'** associated with loudness hyperacusis. It is fairly well-proven that you can, both in animal models and in some human testing, induce scenarios by which there is a louder precept. Therefore, I think there probably is something that is very different associated with a patient who experiences regular pain and it's probably in addition to that core element affecting someone who only has loudness hyperacusis. So, from that sense, my opinion at the moment, with the research we have to date, is that what we are uncovering is, essentially, there are different elements of the auditory system impacted in those who are experiencing hyperacusis. Probably most of those people also have a similar impact as those who only have loudness hyperacusis. They just have these additional elements as well.

### 19:12 How does pain hyperacusis work?

**Hazel:** Ok, that makes sense. So, you said there's a fairly well-established model for how loudness hyperacusis works. Are there any solid working theories on where the pain aspect comes from?

**Bryan:** The pain associated with hyperacusis has several different, possible, plausible theories at this point and we can get into some more depth on each of these paths in some follow-up questions but, broadly speaking, without getting into a lot of detail at the moment, there is the general pathway that's been uncovered with what's termed **'Auditory Nociception'** which has been found to describe what is happening with the type 2 nerve fibres in the inner ear. **Paul Fuchs** and a number of researchers including **Jaime Garcia Añoveros** at **Northwestern** have shown that these type 2 fibres that previously were really unclear of their function overall, are most probably fibres that are only sending pain signals to the brain. Therefore, that was an incredible breakthrough over recent years, compared to all of the history of

Auditory Research where, forever, Researchers had assumed that the cochlea itself, not meaning items surrounding the cochlear but the cochlear itself had no nociceptive fibres like the brain and so as you might know, the brain itself does not feel pain. It sends signals associated with pain, but it does not have the sensory components to actually signal pain. The cochlea was thought to be like that and therefore, for many years my discussions with Researchers on this topic they referred to that as if it were a fact. They said, **'well, the cochlea can't feel pain, so it has to be some sort of associated pain signal'**. Now that this whole pathway of research type 2 nerve fibres has been determined then there is a whole new door that has opened associated within. If that is, in fact, the mechanism for some hyperacusis sufferers what is enabling those fibres to start firing at noise levels different than it would take for them to fire in a person that is healthy. And that is where that pathway of research is currently at.

**Bryan:** The other side of research that also is gaining a lot of momentum is sensory mechanisms associated with inflammatory responses for the middle ear and this is equally gaining steam as a potential key player for some sufferers as a source of pain. There is quite a bit of growing evidence to indicate that, for some people, this may very likely be where the pain mechanism lies.

**Hazel:** Interesting! So, it sounds like there have been several breakthroughs actually in recent years where we now know that different parts of the ear can have pain receptors. So, I guess then the question is why they are more easily triggered for some people than for others? But it makes sense as well when you think about it, because I think anyone experiencing a loud enough sound feels pain in their ear.

**Bryan:** Well that very question itself baffled the researchers for years. This was the first question I brought to **Dr David Mountain**. I said, **'can you explain to me what the threshold of pain is for a healthy person, and why is it happening?'** and he could not. And he admitted the Field didn't know exactly why there was a threshold of pain for healthy people. So, that's been a core basis. In fact, I coined the term **'Noise Induced Pain'** from the term **'Noise Induced Hearing Loss'** to help the entire Field understand this is what we're attempting to uncover.

**Hazel:** Wow, so, sounds like you've really driven research forward in a good direction in that sense.

### 23:57 What is reactive tinnitus?

**Hazel:** So, we'll get back more to research later but just a final question on definitions. You mentioned briefly as well that you experience **'reactive tinnitus'** and we know a lot of people with tinnitus talk about this and also people with tinnitus who have not been diagnosed or don't define themselves as hyperacusis patients but they will, nevertheless, talk about how certain sounds 'trigger' their tinnitus; make their tinnitus louder temporarily. I don't know if this is a formal term or not, but people call it **'reactive tinnitus'**. So, would you consider that to be actually a form of hyperacusis?

**Bryan:** Well, ‘reactive tinnitus’ is an accepted term amongst most of the Research Community. It’s not as strongly accepted by clinicians so there is an interesting, small discrepancy there, but many do accept it although they do give it slightly different titles. Having attended many Research Conferences, I have heard a number of talks that refer to this and I would personally keep it under the tinnitus category, just as a sub-type of tinnitus and I think it is one that likely follows a similar mechanism as those whose hyperacusis gets worse with loud sounds because they frequently go together, not for everyone, but for those who do have hyperacusis and have tinnitus, many find that these cycles of what become elevations in their pain associated with loud noises they were recently around there were also elevations in their tinnitus at the same time. So, I would propose that there are likely similar mechanisms at work in both.

## 26:01 Treatment options for hyperacusis: sound therapy

**Hazel:** Let’s move on to treatment or hyperacusis management. We got a lot of questions about this from our listeners for different types of treatment, and what you would advise, but maybe you can start with sort of a general overview of what’s available today for the average hyperacusis patient?

**Bryan:** As you know, the summary associated with hyperacusis treatments in general in the Clinical Community is weaker than for tinnitus and so I do start the foundational references on what is typically put under the tinnitus umbrella first, and kind of go from there. The core reference in the US for **Clinical Practice Guidelines for Tinnitus** was set in 2014 by **The American Academy of Otolaryngology**, and that was a full reference document that gave the evaluation of every single major therapy and whether it would be considered as a definitive recommendation or something clinicians may recommend or not recommend on the basis of their evaluation of clinical information at the time. And so, it’s interesting there that their ultimate statement about sound therapy was they said clinicians may recommend it. That is something they considered as an option based on Randomized Clinical Trials that most of them have some concerns and they leave it open to having a balance between benefit and harm. And so, with that as my foundation, I do personally think the evidence for hyperacusis for sound therapy has an even greater weakness than stated there, and that is that there is a small amount of true clinical data that is based on the full placebo-controlled clinical trial basis. There is not strong evidence to say that it is a convincing treatment in most hyperacusis cases. What there clearly are, are many more individualised, published studies associated with various clinicians that had a practice for either **Sound Therapy** more generally, or **TRT** specifically and there are many types of case studies that show a lot of evidence in the individual cases that there was great value to a certain patient population.

**Hazel:** Can you clarify what exactly you mean by ‘**Sound Therapy**’? Are we talking about white noise generators for instance?

**Bryan:** That is a great thing to distinguish because sound therapy can be differentiated from full **Tinnitus Retraining Therapy**. Sound therapy itself is largely based off of a continuous type of noise, typically pink or white noise are the main recommendations, but now there are obviously a lot of variations of that with many different types of frequency spectrums applied.

**Hazel:** Ok, and so, this is typically part of **TRT**, so **Tinnitus Retraining Therapy**, but that also encompasses other elements. Now, you mentioned that you have undergone **TRT Treatment** for many years, so where do you stand on it currently on its effectiveness for treating hyperacusis?

**Bryan:** I think this is where sub-categorisation of hyperacusis comes into play and can be very important in setting patients' expectation levels. Again, the full basis of studies associated with this is also not very strong for hyperacusis. There was a study earlier this year by **Martin Pienkowski** that was entitled '**Rationale and Efficacy of Sound Therapies for Tinnitus and Hyperacusis**'. In this paper he concluded that there are too few placebo-controlled trials that help to demonstrate the effectiveness of any sound therapy treatment and he highlighted that, especially for hyperacusis, only a handful of studies, mostly case reports, showed true benefit for hyperacusis, broadly speaking. In more specific discussions with clinicians, as well as our own survey data, I have found that for those who have hyperacusis with pain, there is some evidence to indicate that they get much less benefit from either **Sound Therapy**, broadly, or **TRT** overall, than those who have loudness hyperacusis. So, at the moment, what I am sensing is that for those who do only have loudness hyperacusis, there is likelihood of a positive impact from **Sound Therapy** and the range of benefit is quite big, depending on both severity and, maybe, the protocol types and more the specifics around the individual cases. With pain hyperacusis, earlier this year in talk on treatment for pain hyperacusis, the spokesperson said that we treat pain hyperacusis completely independently now from loudness hyperacusis and it requires a much more tailored approach and, also, we typically don't expect the same outcomes as we do with loudness hyperacusis.

**Hazel:** That sounds like a big step forward, but I can imagine it's not something that's fully ingrained in clinicians generally out there in the world. I don't know how many Audiologists, for example, would really make this distinction?

**Bryan:** Sure, I think it's not popular yet, but I think we are getting some momentum to having more people understand this problem. You know, the history where this was not distinguished very well and currently where we are able to get some different types of understanding. One of the things we've emphasised this year is getting more into the **Clinical Community's** hands about the data of what we're learning with our survey data, as well as just a lot more bringing in the research side and so we've had a publication both in the **Hearing Journal** and in the ENT and Audiology news magazines that are for clinicians. So that is a big aim we have right now is really helping in getting this information into their hands.

**Hazel:** That's really great and I am sure it will help many patients.

### 33:27 Sound exposure, setbacks, and the role of stress

**Hazel:** What's your view... so and from my understanding, a lot of hyperacusis patients are asked to practise some kind of desensitisation where they expose themselves to sounds that are just above their comfort level and the theory is that if you just keep doing that the comfort level will go up. I can imagine it doesn't maybe work like that for everyone. What's your view on that?



**Bryan:** Well this topic brings up another important element that I think has also not been looked up very deeply in a Clinical Community and that is the topic of 'setbacks'. With increased exposure to louder sounds is control of the situation and, specifically, what we've found is that most patients find their most critical element of their progress is to prevent setbacks. So, setback prevention is a high priority that many sufferers have and, what happens is the more you allow yourself to be around situations that are going to have louder sounds is you increase the risk to a major setback. And, for many people, a major setback may take many days, weeks or even months to recover from and therefore they don't see that forward momentum and gain because of the setback. And so, unfortunately, we don't have enough evidence yet to really help guide patients on this journey. Most determine this themselves. They kind of figure out that '**magical threshold**' for themselves and they are able to make progress without lots of setbacks. So I think, unfortunately, this is something that it's going to be a while before we can have a clinical type of recommendation, but at the individual patient level once you know where your limits are for setbacks, I think it's important to prevent those in order to maintain forward progress.

**Hazel:** Wow, I don't know how this is talked about in the hyperacusis community, but in the tinnitus patient community which obviously includes many people with hyperacusis, there is always so much talk about protection and when is protection 'over-protection', and how do you strike that balance between protecting just enough without going crazy and completely isolating yourself and locking yourself in a soundproof room kind of thing. So we see so many debates about this on the **Tinnitus Talk Forum** and it's really tricky and because I can imagine, for some people yes, they do require that level of protection or maybe temporarily require it in situations that would totally be ok for most ordinary people, but then we also see cases of people who become so scared of everyday sounds and so scared of the setbacks that that in itself causes them a lot of damage in a way, in the sense that they really can't lead any semblance of a normal life. So, it's so tricky because it varies so much per individual what is right, and you see people advising each other as if they know what's right for everybody else. So, you get very tense discussions, I don't know if you recognise this?

**Bryan:** Sure, obviously this is huge in our community and one of the things that has been great over the last year or two is getting a lot more evidence-based data to show what is generally happening in larger populations. We did find in a survey this summer that was completed by over 350 people, that setback prevention was more important to them than things associated with just general loud sounds, you know, becoming more tolerable. In other words, they would much rather prioritise not having a setback over being able to tolerate slightly louder sounds. So, the question becomes '**what exactly is happening with a setback, physiologically?**' This is a new aim and emphasis we have with the Researchers to get this studied in animal models because, in fact, we have had what I would say, risky advice, going to patients who are all lumped into one large category and if you, as a clinician, do not really understand what is happening physiologically and yet you advise a patient to a certain level of exposure and they have a huge setback, you don't know what that's done to them. I think, most importantly on the research side, what we want to see happen is we want to see the evidence gained that helps to demonstrate is there a physiological change that is happening along the auditory pathway starting with the middle ear or is this something that is more perception-based? The evidence that I am seeing is starting to give the impression that I think there is a physiological change that is happening, even though we don't fully understand what

that is and, therefore, like any other injury, re-injury becomes a dominant concern. If you have a joint problem that you consistently re-injure, you'll never get the healing. So, I think there is a trade-off that has to be found, and I think it is much further beyond the scope of the psychological round that has been thought. I think it's over-categorised as a psychological concern. Obviously, there are psychological components to the decision, but I think the physiological part is one that we can get a lot more evidence to help patients make better choices while we search for the cure.

**Hazel:** Well, that certainly would make this discussion a whole lot more objective. Do you think it works the same for tinnitus by the way? Because a lot of the discussions, tense discussions that I mentioned, are people with tinnitus whose tinnitus gets worse after being exposed to certain sounds and then other people saying 'well, no, it's not because of the sound exposure, it's because of your emotional reaction or fear that your tinnitus is getting worse', which could also be the case, because we know that stress can trigger tinnitus so it's very hard to make that distinction. But do you think what you were saying applies to tinnitus as well?

**Bryan:** Again, I think it definitely applies in some cases. It's hard to say whether it's a high percentage or a low percentage. I think there's quite a bit of crossover. Stress itself is a very interesting phenomenon and even in research papers which I've seen presented at **ARO, The Association of Research for Otolaryngology**, I've seen differences in perspective about stress factors: whether or not they were causative or a result of the impact. To me this is too easily automatically assumed to be causative and my perception is we need more research to understand when the stress, in fact, may be the additional stress hormonal impact is something that occurs because of the event, and is not a factor in causing it. But that is still debatable. I certainly don't have the science to try to prove it today, but I am trying to get Researchers to think about ways to put more science into this rather than having the baseline assumptions that have always been there.

**Hazel:** Yes, I think that's much needed and totally agree.

## 42:18 Treatment options for hyperacusis: surgery

**Hazel:** So, let's talk a bit more about treatment options. We've covered **TRT** and **Sound Therapy**. Are there any other viable treatment options at the moment? Some people have mentioned some kind of surgery which I don't really know what it's about. Are you aware of any kind of surgery for hyperacusis?

**Bryan:** Sure, I mean there's a physician in Florida that is really promoting this right now and it's gaining some momentum taking the nature of what's been done for **Superior Canal Dehiscence** where there is round and/or oval window reinforcement procedures to stiffen those to kind of dampen all sounds. He's put some information at present that is indicating a lot of positive impact so that's I think, good news, for those who find benefit there. But it isn't helping everybody. I do know of cases that it hasn't helped at all. And there are some concerns in the deeper Research Community associated with the model of what he's pre-supposing it's doing that it could, in fact, do something very different on the basis of what's being learned in the Research Community. So, it's not actually a new procedure it's just new that it's being

done solely on the basis of hyperacusis. We are obviously very interested in keeping a close eye on it but, right now, I don't see enough evidence that it could be a purely recommend. I think every patient has to really understand what is going on with the process and the protocol and the risk and to see if it could be beneficial.

**Hazel:** Yes, that sounds like sound advice. I mean, we've seen on the **Tinnitus Talk Forum** people flock to certain doctors trying experimental procedures and, even if they're legitimate doctors, the evidence isn't there yet. It's experimental and I do fear sometimes that people are so desperate that they don't inform themselves properly of the risks and they could even get a lot worse, so I think that's sound advice.

#### 44:48 What can patients do to get help or help themselves?

**Hazel:** So where can people go to get sort of reliable information on treatment options? How can they find a clinician who is experienced with hyperacusis, for instance?

**Bryan:** So, obviously, we frequently get asked that question, **'where can I get some help locally'?** and it is not always easy, depending on where one is. You know, the good news is there are more Audiologists who do promote a programme associated with tinnitus and hyperacusis and those are obviously places to start, but it does require a little more digging than just making a phone call or just making an appointment at a Clinic. One of the things that's been interesting as I've been out in the Clinical Communities is just talking to those who do have a Practice where they treat hyperacusis is, **'well, how many patients do you see do a week or a month'?** Some literally only see a few a year and there's almost no way around the fact that, you know, for any condition that a clinician is treating a few times a year they are going to be less able to really comprehend everything they need to do for the patient, and that's a challenge. I mean, it's kind of a Catch 22 situation where, you know, they're not gaining the type of experience that may help them to have a little more expertise. So, I think asking some fundamental questions about, you know, how are they trained to treat hyperacusis, where were they trained, what are they doing to keep up with the latest research? Those are all fundamental questions it's important to ask a Clinic if you are looking for help and, knowing that, you can get a starting point to know whether or not they might have something valuable for you. The other thing that's really big in many different medical communities right now is **Individualised Patient Care** and really finding out what they do to take that individualised patient perspective because that's another problem with treatment protocols when a clinician has the standard practice of a **'one size fits all'** approach and they really try to box everybody into that same little group that they were trained on. I think that sometimes is what leads to advice that isn't helpful.

**Hazel:** Yes, that sounds very recognisable and I have heard this from many people, and I think it applies very much to **TRT** as well, which I think is what's called **Directive Counselling** or something? It's very top down. It doesn't really take the patient perspective into account and I totally agree we need to get to a more patient-driven model. What would you say to someone with hyperacusis who has already tried many different things? So, they've already tried **TRT, Sound Therapy, Psychotherapy**: are there still any options available to such people?

## 48:17 Dietary and lifestyle approach

**Bryan:** There are a number of different things for the more rare of a disorder you have the more you have to kind of look at the entire picture of your health and see what might be impacting. We know there has been more research in the Tinnitus Community on the impact of things like what happens associated with certain categories of food, for example. A popular one that is debated is caffeine, the impact of that. I think that everybody that suffers from something that is poorly understood, one of the things every single patient can take control of themselves is to look at their nutritional framework and look to optimise it. We are starting to learn that there are several different reasons to think that there may be some inflammatory responses associated in some types of hyperacusis and therefore whole health approaches associated with anti-inflammatory concepts might be beneficial for some people. So, although that's less defined and it's not the same as a curative treatment approach for many people, it's something that's in every patient's control.

**Hazel:** Ok, so there are still things people can still do to explore either by themselves or with a doctor, by a process of elimination, what works and what doesn't work. Maybe lifestyle changes that may make it more tolerable? Is that what you're referring to?

**Bryan:** Yes, in these types of explorations it's not so much as **'curing'** you know as **'maintaining control'** and trying to mitigate the situation from worsening. You know, oftentimes we learn the science many years after we see an effect and so while there is, you know, if you go to the research associated with the impact of various environmental factors - for example, again at **ARO** this year, we had a whole segment on: **'What is happening in the space to help the ageing population and their disease impact?'** - there was a whole segment of that on the impact to various diseases for inflammatory issues. So we don't know yet how that might play a role in conditions like hyperacusis or tinnitus but it is, at least, a space that we can see the individuals can make a choice and there are individual cases where people do find a significant impacting factor but it's not, you know, at a point where we can have specific recommendations yet.

**Hazel:** Right, so people would have to go at it with some trial and error and maybe try one lifestyle change for a few weeks, see if that makes a difference. If it doesn't then try something else.

**Bryan:** Sure.

## 51:52 Where can patients get reliable information?

**Hazel:** Right, so apart from treatment options, I think I already briefly mentioned the need for people to have access to reliable information. There is a lot of information online. You know, this is really an avenue that is important for many people. You know, finding whether it's peer to peer support online like we offer at the **Tinnitus Talk Support Forum** or, you know, just informational resources. For many people it's probably even their primary source of help but, you know, it's hard to know what's reliable and what's not. Can you give any advice on what resources online are reliable and accurate, or not?

**Bryan:** There are two types of resources that people can utilise, and it really depends on the stage they're at. For example, you have the person first investigating a new condition and you know they're going to Clinical Programme Sites, such as at **The University of California, San Francisco** or they have a **Hyperacusis Patient Management Programme** described online. Those clinically-oriented places can give a good start but, as we were just discussing, one of the things that's important to remember when you go to the mainstream type of sites, they're not going to be comprehending recent research and at the minimum there's a five to ten year gap between what's being learned in Research compared to what's in the Clinical Community. And that's true of many conditions, not just Auditory conditions. That's something we're constantly trying to work on. To try and bridge that gap. But what many quickly learn is that if they want to learn what is going on in the Research Community you can use a tool like **Google Scholar**. You can directly see what's being published and we do try to bring that forward on our site and on our Facebook channel very regularly, what's being learned in the Research Community, and I think that can be really helpful to patients who've already done a lot on their own and they really want to know what's been uncovered that can be helpful. The challenging part about following research is that sometimes you don't directly know the implications of what that really means back to you as a patient on a clinical level so that is where communities can be helpful for attempting to interpret that. Again, we do see that as one of our key aims, to be making that connection in all the directions needed so that what we know in the research can turn around faster to be helpful to patients.

**Hazel:** Right, so maybe this is a good moment to plug your website? Where can people go to find you?

**Bryan:** Sure, we're at **Hyperacusisresearch.org** and that's where we do try to bring the latest news there. We have a daily updated Facebook posting for **Hyperacusis Research** as well that you can follow regularly as well as Twitter and we try to bring all of those latest tidbits there, which does automatically have an initial discussion that happens. As well as we have larger summaries associated with the research conferences that we attend every year and try to summarise into ways that are meaningful to the patient.

## 55:45 Hyperacusis hybrid device clinical trials

**Hazel:** Great. So, let's move deeper into research and spend the last part of this discussion talking about research developments. We've got a lot of questions from listeners asking your opinion on specific research that's going on but maybe a good place to start is to ask you what current avenues of research or specific studies, even, are you most excited about?

**Bryan:** Sure, well there are a number of avenues that are very exciting. One of those is the **Hyperacusis Hybrid Device Clinical Trial** at the **University of South Florida**. This was a project that came about as a result of many years of efforts on the part of numerous individuals. **Dr Craig Formby** from **The University of Alabama** originally, **Dr Edmonds** who's at the **University of South Florida** who is leading the project. We had connected through a number of different avenues. And specifically **Dr Formby** heard the patient stories of those who could not find an avenue of improvement and he brought this idea forward which we quickly supported that's let's develop a device that could help patients who need some type of way to attenuate loud sounds as they try to come over that threshold of being in a quiet environment out into the

louder world. And so, this device specifically has a sound attenuating mechanism to screen out all sounds up to the patient's comfort level and also has a built-in white noise generator. So, I was excited to help initially support that project, to help it over the threshold of getting funded in the Research money required for a Clinical Trial, and then being able to examine the process and protocol being used in the Clinical set-up at the lab there in the **University of South Florida** and have seen that it is a super-rigorous programme and project that they have got set up. Patients are enrolled. It has started and we're excited to see that kicked off the ground.

**Hazel:** Why are you so excited about it? What do you think it could really bring to patients?

**Bryan:** Well, number one, of course the first key aim is to see improvements in the patients that are participating in the trial, that their hyperacusis does improve. But number two, it establishes a new avenue for helping patients who have this dilemma of, what you brought up earlier, about protection levels. Today you pretty much have an on/off switch in control of your hands, right, you put in an earplug, or you don't, you wear an earmuff, or you don't. This device will allow you to hear normal sounds, say, up to the level that you determine of 65 decibels. Therefore, you are not having an earplug in for those lower level sounds. You're hearing that sound normally. Then, at that point it's going to clamp those sounds to mitigate them getting louder to your ear than 65 decibels, so it's truly providing a transitional avenue, technically, in a way that has not been feasible yet. So, it's an incredible way to work around this problem of setbacks. If the project is successful and proves to have that kind of value, this will be a great tool to try to make continued progress and not have setbacks along the way. Because previously you had to make that choice. **'Oh, I have an earplug, or I don't'**. This way you have the benefit of the earplug all the time you need it because the device is there, but you don't have to get all sounds muffled that are below your comfort levels. You hear them normally so it's an incredible breakthrough from that sense because again, if successful, this will be the first time that patients are no longer faced with this dilemma themselves but have the technology help them.

**Hazel:** Great, yes. It sounds like something that would give the patient more of a sense of control, so coming back to that notion of patient-centred treatment.

## 1:00:31 Other exciting new research developments

**Hazel:** But what about the work going on around hearing regeneration? Is that something you're following, and do you think it could provide a plausible treatment avenue maybe for pain hyperacusis?

**Bryan:** Sure, yes, so this is also obviously in the long-term strategy for everything. This is the centre of the future. We happen to have forged our partnership with **The Hearing Health Foundation** the year before they kicked off **The Hearing Restoration Project** in New York City, so I was able to attend that and to see that first-hand the programme rolled-out. And ever since then, obviously, we have followed this work very, very closely in the many different dimensions that it covers, right from sensory hair-cell regeneration, to notch-signalling pathways to many genetic reprogramming techniques that are all part of what it's going to take to have a successful hearing restoration. Most recently, **Charlie Liberman from**

**Massachusetts Eye and Ear** associated with **Harvard** spoke at our annual Benefit Dinner where he described the many new developments that companies like the company he helped form, **Decibel Therapeutics**, are finding in their paths of progress and so this is critical to the future of many different auditory conditions. Now, we don't yet have the evidence to say where, exactly, will be the intercepting point associated with their work and hyperacusis and even more specifically, hyperacusis with pain. We do know that there are possible links and connections but there's quite a bit of evidence needed, you know, to prove those out. So, to use a bad pun, we do have the 'ear' of these researchers, so that when they are investigating, the paths they are investigating they can keep in mind hyperacusis as a component of where that research may lead and, oftentimes I find that by having a condition in mind, that can alter projects and programmes today that can therefore make that connection in the future that is needed, to know exactly how it will apply and when it can offer help.

**Hazel:** Yes, but that brings up also an interesting question that one of our listeners asked. You know, it's kind of related to this whole inter-relation of all these various auditory conditions. And the question was **'if there was a cure for tinnitus, do you think it would cure hyperacusis as well'?**

**Bryan:** I think there is a much better chance that it would cure loudness hyperacusis rather than pain hyperacusis. It's definitely hard to say because of how much more we need to learn about the auditory pathways. I think if you take, for example, the central gain model, which may play a fairly evenly strong role in both tinnitus and loudness hyperacusis. If you are able to impact that mechanism positively, likely people with both conditions would get benefit but I'm not so sure in that case that there would be benefit for those with pain.

**Hazel:** Is there any other interesting research that you'd like to make people aware of?

**Bryan:** Sure, well we're obviously following the work associated with the middle ear conditions that have explored how various components within the middle ear may be playing a role, specifically in pain hyperacusis. What was first coined actually back in the 1980's, **Tonic Tensor Tympani Syndrome** is one of those that we followed. **Damian Ponsot** in France was a key researcher that helped me to be connected to this work and he has done some great summary of this functional basis of what this **Tensor Tympani** is doing. More recently, **Miriam Westcott's** work is one that has helped to dissect the details of the symptoms patients experience that she feels confident is inter-related to mechanisms that probably do play into pain hyperacusis, so that's definitely one that we are following closely. I have a number of key connections to the folks involved here and I do believe this is going to have a really strong impact to a sub-set of the population.

**Hazel:** Yes, that's very exciting and I am learning a lot of new things here as well because since I don't have hyperacusis myself, I've been following the tinnitus research more closely. I want to start wrapping up and I have a final question for you but before I ask it, I just want to check with you whether there's anything at all you still want to cover or comment on?

**Bryan:** So, we do have exciting news on a new avenue of research coming together at the next **Tinnitus Research Initiative**, which is going to be a Conference in **Vancouver in 2020** and it's going to be a topic on **Hyperacusis and Associated Symptoms** so this is going to specifically

dive into some of Miriam's work so she will be part of it. **Miriam Westcott** as well as a number of other key researchers who are coming together to look at the mechanisms of hyperacusis associated with multi-skeletal disorders of the head/neck complex, including the middle ear, the trigeminal nerve and inflammatory responses so we will be able to participate in that. It will be significant for two reasons. The first is that it is the first time at a Forum of this level that these topics will be getting this sort of attention associated especially with these inflammatory and middle ear components so we are excited to get that out into the Research and Clinical world. Secondly, also exciting because **TRI** does not often cover hyperacusis and this will be a really important avenue where as many as 400 participants will get to hear about some of the details behind what's going on in the front for hyperacusis and so we're really excited about that.

**Hazel:** Well I'm excited about attending that Symposium because I plan to be at the **TRI Conference in Vancouver**, hopefully with a few other **Tinnitus Hub** volunteers, and it will be great to meet you there in person as well because we haven't met in person.

**Bryan:** Great.

### 1:08:07 How can we help push research forward?

**Hazel:** So, Bryan, final question, what can people, regular people with hyperacusis who want to see the research move forward and who want to help Researchers get to that cure. What can they do to facilitate that?

**Bryan:** Well, many people ask me: **'How long will it take to find a cure'?** There is obviously no easy way to answer that but, one thing we do know as a general rule of thumb in the medical research community, is the more researchers tackling a problem the faster progress will be made to find a cure. As we know, Researchers need funding and funding comes in multiple ways. A core way is large institutional grants, typically from large Governmental sources, but also non-profit funding. One of the drivers to both of those arenas is media attention and the first thing I always point individuals to is if you have an avenue where you can get media attention on the problem of hyperacusis whether it's your specific case or someone you know with hyperacusis, you can get it in print, you can get in on tv, that is critically important. Because people don't support something they've never heard of very easily and we do live in a very media-savvy age. There are lots of avenues that offer a lot of different ways to get the word out to help more people and the public understand, **'hey this is a phenomenon; this is a condition that needs your support'**. In the US I have specifically been told by our **Government Agencies** that they look critically to **Patient Advocate Organisations** to determine their priorities. They literally said **'hey, if there's a condition that has no Patient Advocacy Group, it's highly unlikely we would fund anything for that problem'**. And so, that's where groups like **Hyperacusis Research** become important because we can be the voice to aggregate your voices together to help that Government Agency see that funding is needed. I am excited that, here in the US, we were able to influence our core Agencies at the **National Institute of Health** to include hyperacusis as one of three core aims for what, originally, was only focussed on hearing loss and then eventually would focus on hearing loss and tinnitus and now hyperacusis is that third bullet to their aim. So that took a lot of work, that took a lot of influence, that took a lot of years. And that helps those grants



that get to those people's tables to be more strongly considered than if they're solely for hyperacusis and so that is key. We used the research dollars that we raised money for to fund what we call 'seed-grants'. Our emerging research grant programme and the partnership with **Hearing Health**. While there are other smaller grants, typically it's the type of grant needed for a Researcher or Investigator to get what's called 'preliminary data' to support that larger grant application and we've seen that multiply here in the US from just three or four years ago the most that was ever happening in a year for funding was about \$1,000,000 a year. Now we're seeing \$3 – 4 million more per year in research grants from the Government for hyperacusis and that's still not large but it's at least growing, and that's the way we look to use the money that we raise is to literally turn it around and multiply it by 100 with these larger sources of funding.

**Hazel:** That's very impressive and you know this whole political lobbying avenue and media avenue, it's things we've recently started looking into at **Tinnitus Hub**. It's really a tangled web to understand how this whole funding aspect works so we've started looking into that and then the media aspect. I would say both tinnitus and hyperacusis are probably difficult conditions to get media attention for. To take the example of tinnitus, people always say: **'we need an ambassador, we need a celebrity who has tinnitus and speaks about it publicly'**. We know of many celebrities who do have tinnitus, but very, very few of them have spoken about it publicly and none have really taken on a real ambassador role, at least not consistently. So, I wonder why that is and it might be the same for hyperacusis, that it's somehow not a condition people like to talk about publicly. It's not considered 'sexy' enough. I don't know! Do you have view on that?

**Bryan:** Well, yes. We've studied this quite in depth because it's even harder to find anyone of name recognition who has hyperacusis and yes, I think you know, the first challenge associated with these conditions is that they are invisible. And any time you are up before the public talking about something unseen there's a degree that you're putting yourself at risk to people thinking this is all in your head and so I think, you know, as I've looked at other parallel conditions, what I've seen is that it's most hard to get that attention for something that can't be seen and, therefore, you know, we have to find ways to make it more clear to people what that impact is. When we did our work associated with you know, what some have seen from our site, a teen girl, **Cindy**, who had significant hyperacusis impact her, we started a journey where her family really wanted to use her condition as a platform to help people understand what this can mean, we saw that there was a lot of compassion once we started getting this story out of a young person's life that was dramatically altered. They just needed to see how that altered life looked and you know that case, that did receive a lot of international media attention. It eventually made it to **People Magazine** and to tv as well and a number of places so it's definitely difficult. You have to be very deliberate. You have to really go after the communication channels in every avenue but it's well, well worth it and that's where you know if hundreds and thousands of us are doing that ourselves, eventually some of our stories will be heard.

**Hazel:** Right, on that note, I think we should wrap up. Bryan thank you so much for your time but, more importantly, for the very important work you are doing that benefits people with hyperacusis around the world.

**Bryan:** Yes, well thank you for hosting me today and for your patience and, also for staying up late. What time is it there?

**Hazel:** Almost midnight! We're facing a considerable time difference but, luckily I'm a night-owl, so that helps.

**Bryan:** Well, I greatly appreciate that, and your time as well.