

TINNITUS TALK

PODCAST

EPISODE 14



VISUAL SNOW AND TINNITUS Phantom Phenomena

Dr. Peter Goadsby: "It's one thing to have a bad problem. It's a whole other thing to have a bad problem that people tell you doesn't exist."

00:00 General introduction

Hazel: It's not often that you meet someone who has been a true game changer as an advocate for people suffering from a chronic condition. But I met two people recently of whom I think it really wouldn't be an exaggeration to say they have been trailblazers for raising awareness and kickstarting research for a relatively unknown condition called visual snow. I really think you need to listen to what they have to say, because not only are there so many similarities between the two conditions – they are eerily similar – but also, I think the tinnitus and visual snow communities could learn a lot from each other.

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01:16 Introducing Sierra Domb and Dr. Peter Goadsby

Hazel: Hey everyone and welcome to the **Tinnitus Talk Podcast**. Today we're going to be talking about visual snow. It's a topic we've been wanting to cover for quite some time because there are quite some interesting similarities with tinnitus and I'm very happy to be joined by two guests today. We have with us **Sierra Domb**. She suffers from visual snow herself and is the founder of the **Visual Snow Initiative**. Welcome, Sierra.

Sierra: Hi Hazel, happy to be here.

Hazel: We also are joined by **Dr. Peter Goadsby**. He is a neurologist and has, for many years now, been researching visual snow. Welcome, Peter.

Peter: Hi, thanks for having us.

Hazel: Let's get started with you Sierra. I think our listeners would be interested to hear a little bit about your personal journey with visual snow and maybe along the way you can also just describe what it is, because it's not that well known. A lot of people won't know that much about it.

Sierra: Right, and I didn't know much about it prior to getting it myself. I have visual snow syndrome and I've since founded a non-profit for it, but the journey to get there was interesting. So, essentially, I was a university student and I noticed that, when I looked at the whiteboard, I could barely see my professor and what was written on the whiteboard one day. All I was seeing was flashing lights, flickering dots and static and it completely obstructed my vision in both eyes and, at that point, I was extremely alarmed because I'd never seen anything like that in my eyes before and in my vision. So this prompted me to go to a doctor, an eye doctor, to see what was wrong with my eyes and what I was seeing but all of the optometry and ophthalmological tests they did yielded normal findings, so essentially something was wrong but they couldn't figure out what it was because all my tests were coming back that my eyes were structurally fine.

Even when I would go home and try to lie down at night, when my eyes were closed I was still seeing the flashing lights, flickering dots and static and at that point they realised that maybe this is a brain issue. It has to do with brain processing and how the brain processes vision so they sent me to neurologists, neuro-ophthalmologists – which is a fancy way of saying 'brain eye doctors'/'brain doctors' – and those tests that they did also yielded normal findings and at that point I was very distraught. I couldn't see clearly enough to drive comfortably, go to school, even I had extreme light sensitivity at this point too. To the point where I couldn't even look at lamps or the sun. It was terrible.

So, my life was being very limited, and I turned to Google. Because at this point the people who were supposed to know what was going on, didn't, and it was there that I learned about visual snow syndrome, from Googling my symptoms. And even though I had seen some of the top optometrists, ophthalmologists, neuro-ophthalmologists and all the doctors in my area and they hadn't known what it was, thousands of other people around the world were going through what I was going through and they knew what it was like and they had heard of this condition. So, thenceforth I decided to do something about this. It concerned me that my doctors had no idea what this was and there was a lack of awareness for visual snow syndrome and it is a brain disorder that affects your eyes, right? So, your eyes are structurally fine, but it has to do with brain processing.

05:13 Symptoms of visual snow

Hazel: So, if you could just describe the array of symptoms that could come with visual snow syndrome?

Sierra: There are many visual symptoms and non-visual symptoms for visual snow syndrome. For the visual symptoms the most hallmark, or common ones, are snow-like dots all over your visual field, small floating objects or flashing lights. Seeing those in both eyes, photophobia, which is the fancy word for sensitivity to light, palinopsia as well, which is continuing to see

an image after it is no longer there. So, something could be in front of you but even after you walk away you are still seeing it, right? You see images within the eye itself and that is referred to as entopic phenomenon, and there's other visual effects like starbursts, halos and double vision. I said 'starbursts' and I wish I was referring to the candy! But it's really, just again, strobe lights in your eyes.

Coincidentally, going over to the non-visual symptoms of visual snow syndrome, the most common one, at least from what we've heard, (Peter can correct me), I would say is tinnitus. So, ringing, humming, buzzing sounds, a lot of people complain of that with visual snow syndrome. Also, depersonalisation which is a fancy word for feeling detached from yourself. I mean people with visual snow literally have a layer between them. Not literally but metaphorically I guess they see a layer between themselves and the world because of the static and this veil of light over their eyes so it can make you feel very detached and this can lead to anxiety or depression.

People also get brain fog and confusion, dizziness, nausea, insomnia, and other sleep-related issues as well as tingling sensations in the legs and arms and as well accompanied by general pain throughout the body. I'm sure Peter has heard of a ton more as well but the one thing as a visual snow patient I would imagine is very frustrating, and I can speak from personal experience as well, is that the name '**Visual Snow Syndrome**' highlights the most salient part of the condition, which is the visual part of it, the visual snow aspect, but there are so many other non-visual, physical symptoms that make life really difficult and I just think that this is important to underscore in all of this. It's not just a simple, 'Oh, I just can't see well' thing, which is not even that simple. It's pretty debilitating and horrible. You don't have clear vision, but you also experience so much other discomfort which is why I think it is important.

Hazel: Thanks for explaining that Sierra. I think that's a useful and valuable addition. Essentially, it's phantom vision just as tinnitus is phantom sound, right?

Sierra: Exactly, they are very comparable and a lot of people who have visual snow actually have tinnitus as well, so we get a lot of questions about that and I'm glad you guys are exploring the overlap because it's very interesting.

Hazel: So, you've had to self-diagnose in the end you said because most doctors don't know what it is?

Sierra: Right, it was to the point where I was printing out information and actually studies that I had seen Peter had done online. Printing them out and taking them to my doctors and they recognised the legitimacy of the problem. They recognised at this point that this was a probable thing that I could have but they didn't know anything about the condition and they didn't know what to do about it and they'd even told me they'd seen people as well who had this but they didn't know where to refer them or how to help. So, it was then that I started a non-profit, the **Visual Snow Initiative**, to fund research and facilitate awareness for **Visual Snow Syndrome** and that's where we are today.

Hazel: Great, well, we'll be talking a lot more about that later on but for now let's move on to Peter.

09:21 Dr Peter Goadsby – How did your interest in Visual Snow Syndrome begin?

Hazel: Peter, I'm interested because, I think there's very few medical researchers who focus on visual snow, so why did you become interested in it?

Peter: I got interested in visual snow because of, I guess, an intersection of three things that were timely. As you mentioned, I'm a neurologist. I specialise particularly in headache disorders and the most common thing I'm sent to see is migraine. About a quarter of migraine patients, it depends upon age but about a quarter, have what's called 'migraine aura'. Typically, 90% is a visual aura, seeing aura. And what they'll see are bright, jagged, sharp-edged lines that start in a little part of the vision. Then they expand, they get bigger, come towards the centre, and then, more or less mysteriously go away. Then the headache starts and will last about an hour or so. And these sparkly, jagged lines are very distinct.

And because I'm interested in aura, over the years I would have been sent a number of people who had this continuous dynamic, tiny dots all over the visual field and they have been sent to me and I have been told they were atypical aura. They were certainly atypical, or it didn't sound like aura to me at all. They came to me from time to time and I would say to them, 'I don't think you've got migraine'. A quite unsatisfactory way of practising just to say I don't think you have what you came to see me about and not offering much else.

I didn't really focus too much on it until I saw two other things happen. I saw a child, about seven, who had the same sort of continuous dots in the field that he would see on a wall and came along with a diagram of it that he'd made on an old computer programme called Paint. And you could see these dots and I thought to myself, 'wow, he's seven' and what he says is exactly what a 50 year old with the same problem would say and it makes you focus on the fact that it has to be a thing because this was more than fifteen years ago, so there was no sense that this seven year old was going around on the internet and I don't even think iPads were around. So that focussed my mind.

And about the same time, in January 2005, I was at a meeting of the **North American Neuro-Ophthalmology Society (NANOS)**. As Sierra was saying, these are neurologists who are also trained in the eye. So, neuro-ophthalmologists. I was asked to talk about migraine aura as I'm a migraine person. And I did the presentation and I thought, well, I'll talk one slide about this visual disturbance thing and see, because I was interested for them to tell me what they think it is, as it was just interesting. I made the presentation and it really was an explosion at question time as almost everything discussed was around this visual disturbance. It was like battle lines at one point. There were clearly people in the audience – and we're talking about hundreds of neuro-ophthalmologists now – people in the audience who thought this was a thing that they'd seen, and they weren't sure what it was; and it varied from that group through to the ones who associated it with hallucinogenic use and I assured them of course that my seven year old child had not been taking LSD to the best of my knowledge, or the best of his parents' knowledge. That seemed like such a ridiculous explanation. Through to the people who just thought that the patients were crazy and it got to a point where one of the neuro-ophthalmologists got up and said, well he didn't think that the patients were crazy as he had this syndrome and he didn't think he was crazy and he certainly didn't take

hallucinogenics. At that sort of point, rather wisely, the Chairman of the session decided that he had had enough.

I walked away from that with quite clearly the impression that this was a thing, that it was not understood at all, that you could have two of the literal experts on the subject sharply divided even on its existence that that would be something that at some point in my career I needed to pick up and do something about. I was struck, there's as an anecdote that the person who wrote the first paper, in 1995, a guy called **Grant Liu** was in the audience and he got up and said he'd written about these cases. He got up and said that he wasn't sure what it was. He didn't really want to write the paper up. His supervisor made him finish it. The referees, the people who looked at it in the journal thought it was nonsense but the editor of the journal, a guy called **Bob Daroff**, a very smart neuro-ophthalmology guy in North America decided it was a thing and it got published. The early history of the medical side of it is, let's say, fraught, to say the very least.

Hazel: Yes, it sounds like that was a very heated event that you attended.

Peter: It was interesting. I had subsequently similar discussions with colleagues, who thought that taking an interest in this was just madness, frankly, that I'd lost my mind.

Hazel: A kind of career suicide if you will. It's funny I was just earlier today doing some research for this Podcast and I came across a website that just reports on medical research basically. It seemed like quite a legitimate website and there was an article there from earlier this year about some visual snow research and the title of the article was, 'Visual Snow is Real', and I just thought that was so telling that in 2020 apparently there is still a need to publish an article with that title.

Peter: Yes, it's an extraordinary thing isn't it. And you can imagine how frustrating it must be for people who have this problem. It's one thing to have a bad problem. It's a whole other thing to have a bad problem that people tell you doesn't exist.

Sierra: Been there....

Peter: You've got the tee-shirt!

Sierra: Pretty much. It's actually insane to think about when you're going through this first-hand, that people are legitimately suffering and just being denied and granted there are different degrees of visual snow like I'm sure with tinnitus it's the same thing right. Like there are varying degrees of how much people can function with their tinnitus or with their condition but for a lot of people it can be very insufferable and to go to a doctor and to be turned away. Can you imagine something like tinnitus that is very much real, people are just denying the legitimacy of it when it's so blatantly there, especially for the people who experience it.

Hazel: Yes, that must be very disconcerting and I think people with tinnitus often feel like they're not taken seriously and it's true to a large extent that they aren't, but at least they're

not being told that, you know, you're making it up, it's all in your head or something like that. For the most part at least, I think it does happen but not that often.

Sierra: They definitely still get marginalised. But I think even with visual snow we are at the point now where people are recognising that it's credible. We're getting there, we're getting there.

16:53 Current status of neurological understanding of visual snow

Hazel: Peter, can you just tell us a bit more about what is the current status of neurological knowledge about visual snow and its origins?

Peter: From an origin perspective comes in two flavours, broadly speaking. People who can't remember when it started, i.e. they seem to have had it indefinitely and people in whom it starts at some point and they can tell you more or less when it happened. That's what we know about the start. It's pretty clear that the problem is a brain problem as opposed to an eye problem so the outside apparatus, the eye, the cornea, the covering of the eye, the lens, the back of the eye called the retina and the nerve, all that seems to function. It's the way the brain is handling the information wherein the problem can be found and the key areas are areas of the brain that are involved, unsurprisingly, in vision and areas of the brain that are involved in how we decide, or how the brain decides what it's going to pay attention to in the space in which it is. All feeling information, all the senses have this system of controlling what they attend to, or what they pay attention to so most of your listeners to this Podcast, so maybe not everybody, most of your listeners will have clothes on, and they won't – well some could be in the bath, that's the wonder of the Podcast – and they won't notice or they won't be feeling their clothes but you know, if they think about it, it's not like their skin is dead or something, the skin is working fine and if they touch their skin they will feel that. So you put clothes on and fundamentally the nervous system has to ignore a lot of things that are going on so that you can focus on the things you want to focus on and if that system of control is not functioning properly in the brain then the brain will have information that is, you might say, surplus to need. And when we put that together we have a reasonable idea that the main focus of that is in a part of the visual system. Most of that information I am saying is coming from brain imaging, what is called '**Functional Brain Imaging**'.

Hazel: It sounds a bit Peter like you're saying that everyone has visual snow to some extent, but most 'normal' brains have some kind of mechanism to filter that signal out before it reaches our conscious experience?

Peter: I wouldn't go so far as to say that. What I'm saying is that visual processing is not normal and it is also pretty clear that there is an area back in the vision part of the brain, the back of the brain, that are not functioning in the same way as people who don't have the problem. I'm choosing my words carefully because the study of visual snow is in its infancy, so to speak. Really, less than a couple of decades and the brain is a complex thing which is almost a dumb thing to say. I hedge around whether everyone has it at some level. I think that's a more complex question. But, certainly the combination of this control system and the particular part of the brain that is not functioning properly, the sum total of that is what patients

recognise as visual snow. I don't think I'd want to go so far as to say that it's part of normality. We have no evidence to say that.

Hazel: Thanks for that clarification then. So, I understand there is very little known for sure but what have you learned so far from those neuro-imaging studies you mentioned?

Peter: We started out by looking at a type of study that uses brain metabolism to compare the brain so the brain uses glucose as its energy and you can label the glucose to do imaging with what you call a ligand, something you can see on a brain scan. And if you compare people who have visual snow with people who don't there is an area that is just in the back of the brain in a part of the vision cortex that is more active, described as being 'hyper-metabolic'. That area is also just a little bit larger. We're talking about a couple of millimetres different. It's a very small difference. That area is overactive. It's a little bit larger and what's important from the imaging point of view is whether you use this metabolic way, this glucose way of doing things, or you take 17 people with visual snow and 17 without it and you compare their brain millimetre by millimetre or you do another technique, a magnetic resonance technique, where you look at the chemicals that are produced by brain activation that are called the metabolites. All of those different imaging mechanisms or modalities all point to the same area, so it is very hard to walk away from that if several things point in the same direction.

Interestingly enough, in a sort of parallel way, one of my colleagues that got interested in visual snow several years ago, **Christoph Schankin**, who is in Switzerland, has done work using a technique called **visual evoked potential**, so basically flashlights in the eyes. And you look at what the brain electrical activity does and there is a change in that brain electrical activity and we think that the area that's involved in that, from other work, would be this same area of vision cortex so it's difficult not to think that there is a particular place in the brain where this mis-activity is going on because there are several ways of being able to measure it.

23:31 Analogies between visual snow and tinnitus

Hazel: Alright, how far can we actually take the analogy between visual snow and tinnitus? We already mentioned that at first glance it seems quite analogous. One is about sound, and one is about vision, but they are both phantom perceptions. Do you know how far that analogy actually goes?

Peter: There are a couple of directions it goes in. If you look at populations, either population based, so there is a web based study that was done on a UK population or large work that we've done using, again, a web based approach of patients throughout the world, then there's a really substantial group of people with visual snow who also have tinnitus, so about 60% if you look at a population and about 75% if you're looking at patients who you've approached to talk about visual snow. So, the first thing to say is there is a very, very substantial overlap in the symptomatology.

Then the other thing to think about is if you think about what we say when we talk about visual snow, it is a continuous, low-level, non-formed signal which has some variation but it's fundamentally there all the time. I've avoided using some words and the words I have used

deliberately, if I then said I was talking about tinnitus you wouldn't be entirely surprised but if I said I was talking about visual snow then it is what it is.

And the way it behaves it's a remarkably similar phenomenon, I think. Tinnitus of course in auditory, somewhere in the auditory system and, of course, visual snow in the visual system. The other thing that is worthwhile saying and I think it is unquestionably true that there is potential to learn about either from both.

Hazel: One would think so and I think tinnitus research is a little bit further progressed than visual snow research so I wonder if anyone has tried to sort of leverage that knowledge from tinnitus, even though there is still a lot unknown about tinnitus as well?

Peter: When you say 'leverage knowledge' I think that certainly I've read around the topic. I don't think that anyone has come up with a unified approach to the problem that's, how can I say, led to incredible therapeutic breakthroughs. That's not a criticism. I mean, with visual snow we've got nowhere either. These are difficult problems. I think you're right. Leveraging the two together has some utility. How we do it however is a different question.

Hazel: So, Sierra, to continue a bit on the topic of tinnitus, Peter just mentioned about two thirds of people who have visual snow also suffer from tinnitus. Have you experienced it yourself or do you come across a lot of people who do?

Sierra: Yes, we actually do. One thing that we do with the Initiative is we'll commonly reach out to the community and ask that they share their stories or share their symptoms because we're in the interest of helping people of course, but as well as data gathering that way we can give it to the researchers and hopefully this information benefits them in a way that they can come up with solutions. So, we hear a lot from people trying to find correlations between conditions they also have with visual snow. Like they'll say, for example, 'I have visual snow, but I also have 'x''. Therefore, you might want to explore the idea that 'x' and visual snow are connected and the most common one, as Peter mentioned the high percentile earlier, is tinnitus, to be frank. And so, I definitely think that the two manifest differently but the process seems similar. Just one manifests obviously in auditory means and the other one in vision, as you guys were saying.

27:44 Sub-typing for visual snow

Hazel: Peter, I am not sure if you are aware in tinnitus research in the last few years there has been a lot of focus on sub-typing, with some researchers claiming that, you know, tinnitus is not one condition but actually various different conditions and it depends, for instance, on what caused the tinnitus. If it was caused by hearing damage or by, for instance, a neck injury. Is there a similar stream of thought with visual snow that actually we might be talking about different types of the same condition?

Peter: It wouldn't surprise me if there were different ways to get to the final common pathway. I'm struck by the similarity of, broadly speaking, and I mean standing back looking at it, by the similarity of what people say when they have visual snow, no matter what part of the world they come from that say it. So, I think that there must be some common underlying

mechanism. Perhaps you get there from different places, but I think that the underlying biology is going to share more in common than not.

Sierra: May I chime in?

Hazel: Sure.

Sierra: We've been trying to pinpoint a specific cause for visual snow, and this is both interesting and difficult to deal with, but it seems that some people feel like they've had this their whole life, right? And they have. They've maybe been born with it or they've had it for as long as they can remember. And then you also hear from people who have gotten this, like me. I didn't always have visual snow and, from my perspective, obviously I'm not a doctor – legal disclaimer – but, from what I've heard, speaking to people who have visual snow it sounds like it's something you can maybe be born with or have from a young age and, also, acquire. And people will attribute the cause of their visual snow to so many different things and I would imagine that with tinnitus it's similar.

Hazel: Absolutely!

Sierra: You're looking for that one thing that everybody has in common and you can say 'that's the thing that caused this and how do we undo it to fix our tinnitus or fix our visual snow'? but the reality is that people all over the world, different races, sexes, walks of life, ages; they all have different stories. And so, for some people they woke up from surgery with visual snow. For other people they were under a lot of stress, so they remember getting it after an anxiety attack and some people just got it one day and they had no rhyme or reason for it. But, typically, I do find that there's some sort of stress or trauma, whether it's physical or emotional, that has occurred within the patients and from my personal suspicion I think that that maybe has some sort of credence in all of this but that's something again that's more left to researchers and doctors but that's just something I wanted to share. I'm not exactly sure of the process that goes but I feel that stress, whether it be emotional or physical there is some kind of trigger that the body has to endure.

31:03 Will it get better or worse?

Hazel: We've received questions from a couple of dozen of our members when we told them that we were going to do a podcast on visual snow and so a lot of our **Tinnitus Talk** members, well, not a lot, a lot but some suffer from visual snow themselves and, actually, the most commonly asked question, which I imagine both of you guys must hear a lot, is: 'will it get better or will it get worse?' and that's also the same thing when people first get tinnitus and they always want to know and I know that with tinnitus we can't really answer the question because there are no good, longitudinal studies, right, where a large group of people was followed over a longer period of time so we don't really know, we can't really answer that question. But what do you say when patients ask you will it get better or worse?

Peter: Very often sometimes I'll hark back to something I did at the very start when I was at that meeting of the North American Neuro-ophthalmologists. Since they seemed to be engaged, I asked them if they'd ever seen anyone go blind with it and the answer was no. So,

you put together almost every neuro-ophthalmologist in the entire United States and ask them if it had ever progressed that severely and not a single person in the room put up their hand to say they had ever seen that or heard of that. So, I start from that point, that the natural history can evolve but probably has an asymptotic; it approaches a severity that probably never climbs over a point if I can say it that way.

The other evidence I would adduce to that is that when you look in the population work now that got done, the average age of the person in the UK population with visual snow is 50. The average age of the people that we saw who were interested in research is 30. It probably stabilises and doesn't change. My impression is that if it was there from birth that it is unlikely to go away, frankly. And if it came on, then I remain optimistic that it could turn off because it could turn on. All that said, what you said about tinnitus could easily apply to visual snow. We don't have any longitudinal data. What we have is what comes to us and what we've done. It's what we call cross section, looking at a population when you do the study. One problem physicians have, and it's true of all conditions like this that we deal with, is that you are captive as to who comes to see you or who is interested. It's unusual for people to contact a physician and say, 'I was cured, and this is how I got cured'. That is a very unusual thing. Having said this on a podcast I'm sure I'll get a slew of emails in the following weeks that will tell me how people got cured and I am frankly interested to hear that happen because I think that is a rare event.

Hazel: Sierra, have your symptoms changed a lot over time or are they quite stable?

Sierra: So, along those lines, I was somebody young who got visual snow and a lot of young people do, despite what studies say, I understand. But for me when I got my visual snow my primary concern was that it was degenerative and that I would potentially be going blind and that was a huge blow to what I had planned in my life. I'm very much a productive person and a go-getter and I think even if you're not, everybody has big dreams and I wanted to be around to see them, literally and figuratively. So, I didn't know what was going on and when I went to doctors they couldn't really tell me anything about what was going on because they didn't know about visual snow, but they also couldn't tell me that they didn't know for certain that I wouldn't go blind, so this was a fear I lived with for a long time.

Years actually, of uncertainty, before speaking to Peter and learning more about this condition and talking to experts and I find that my condition personally, and I think I can speak for other people, we have sort of a baseline. We have our version of what 'normal' is and maybe it could be that way for tinnitus as well. Like people have their usual tinnitus and then there will be times maybe when you're under stress or you're paying more attention to it or for no rhyme or reason it just gets worse. We'll call that a flare up. And then there will be flare ups. And then you might think, 'Oh my God, this is so much worse than normal, am I going to be this way forever?' and what we find is that it tends to stabilise and go back to baseline – your normal. And there might even be times where it's the opposite, where it's less severe than normal and you wonder, 'oh, is it getting better, and what did I do differently that made my visual snow or tinnitus less noticeable or less severe?' or whatnot and there is a fine line between the mental, emotional games you have to play with this and asking yourself, 'is it actually better? Am I having a better day today therefore I notice it less? Is it actually worse physically or is it more just emotionally I can handle it better or worse today?'. You know it's

a total physically and mentally taxing condition to deal with sometimes which I don't think people understand.

Yes, the short of it is that it can get worse and it can get better sometimes but you find that you stay within the normal and obviously the goal long-term is to get to the point where we have enough research or that we can develop solutions to make a permanent change, hopefully. But I will say, as daunting of a task as that is, you certainly aren't going to get any closer to reaching your goal by doing nothing so that's why you need to at least try.

37:28 Are there triggers for visual snow?

Hazel: Yes, absolutely. Peter, is anything known at all about the different triggers, things that could influence visual snow, make it better or worse. Things like, I don't know, diet, lifestyle, you know, medication. Any of those things?

Peter: That's a very considerably frustrating area. I think Sierra just described it very well. Because the condition has underlying variability the pursuit of what caused the variability in individuals can send them really almost crazy with frustration. So, a very straightforward answer to your question is 'no'. I don't know of anything in particular that will improve it. I can tell you a way of making things worse. That I can tell you. Recreational drugs, particularly the hallucinogenic sort of drugs. That's a spectacularly good way. When we looked at seven hundred odd people, seven hundred odd reports of things that made things better and things that made things worse, that we collected, overwhelmingly the number one thing that made things worse was recreational drugs. I don't want to sound like some sort of bad person who wants to ruin Christmas, but hallucinogenic drugs are a spectacularly useful way of making things worse if you want to do that.

One of the most frustrating things for no effect, vitamins, nutraceuticals, things like that almost invariably have 90% no effect. The same as other things but let me say this, something like anti-depressants most likely to have no useful effect at all and in about maybe 15% will make things worse because this is not about mood. It's not a phenomenon of depression. You know, you don't have to be a rocket scientist to advise people to have a healthy lifestyle because it's good for them and if they're young, and they have a healthy lifestyle, they'll live longer and hopefully they'll see a cure or a treatment or cure for the problem so it will encourage them to do that. But putting that aside, no. It's worth saying that light, sunlight can be quite uncomfortable. Light sensitivity can be a problem and the symptomatology can be quite troublesome in that way but from the point of view of the actual natural history of the condition, short of recreational drugs there are few ways that you can make things worse for yourself.

Sierra: To add on to what Peter is saying, conversely, I would say, as someone who has visual snow, even though it is a little discouraging when they tell you, 'oh well, there's nothing we can pinpoint that is going to help you specifically, no magic pill, no supplement'. To be honest, because it took me a long time to get diagnosed I was kind of put through this wild goose chase of experimentation of, well let's try this supplement, let's try this diet, let's try avoiding this, doing that and it was so stressful. Then to find out that those things had no impact, but also when you're trying to figure out why you have visual snow you might attribute it – I know

people do this a lot – attribute it to multiple things in your life, like ‘oh perhaps it was’ it might sound ridiculous, but ‘perhaps it was that energy drink I was taking’ or ‘perhaps it was that I was doing x or y’ and then you feel like you then have to limit your life because you live in fear that maybe the things that you’ve done up to this point in your life could be what caused it so to a degree it can be reassuring knowing, hey, yes, it’s good to live a healthy lifestyle but maybe you don’t have to avoid legumes because your doctor said that might cure your visual snow any more. You can just eat them. That’s a very petty example, but you understand what I mean. There is at least a degree of freedom there.

Peter: Sometime physicians can be scared of saying to someone what they don’t know and can’t do because there is this kind of mentality that physicians should be able to do. You know, I find people are sometimes a bit angry with me when I say it but if you are just honest with people in your life and if you say that there is nothing you can do at the moment, at least it’s honest. I think putting people through a range of jiggery-pokery to get nowhere. It just doesn’t help anybody. It’s ok to say, ‘I don’t know’. I think it’s not ok to make up some sort of fairy tale.

Sierra: Agreed, thank you.

Hazel: And I think it does happen often also with tinnitus.

Peter: Well, that’s a problem, where there’s a lack of knowledge, people make speculation. I mean, we’ve been doing it since pre-history. You know, there was an explanation for why the sun came across the sky. It was Apollo dragging it across. That’s a pretty good explanation and it worked for a few hundred years but then people understood it wasn’t a thing. I prefer to skip the Greek mythology and Roman mythology explanation and try and get stuck into collecting what are called ‘real data’ as far as I can, to get this on a serious footing. And I’m sure tinnitus people think the same sort of way. It’s essential if you can get to the biology, the more you understand something, the more chance you have to be able to rationally create a therapy.

Hazel: Absolutely, yes. We have to understand the basic mechanisms and doctors will tell patients, don’t go looking online for answers because there is a lot of misinformation, but unfortunately misinformation is also sometimes spread by doctors themselves.

Peter: Well there is good information online and bad information online just as there are physicians who are excellent and ones who are a little bit, you know, who could do with reading a little bit more.

Hazel: Exactly.

Peter: If a person comes to me who has read everything online, I don’t really mind, great. We can discuss what they’ve read. One of the things I like about working with the **Visual Snow Initiative** is the high-quality information. I can send all patients there and I know that they will read reasonable things and I know they won’t be taken advantage of, and so on. I’m sure that in tinnitus you have the same sort of thing. The important thing is the partnership between researchers and interested patient groups. So that people know what is going on.

It's frustrating to have a problem that's not understood. It's worse to have a problem that's not even recognised properly.

44:34 Visual Snow Initiative's "Visual Imagery Project"

Hazel: Absolutely. I know that the **Visual Snow Initiative** recently launched its own kind of treatment. I think it's called the **Visual Imagery Project**. Is that correct?

Sierra: Yes.

Hazel: Yes, so can you tell us a little bit about what that is, how it works and what data you have been able to gather so far on whether it works, or for whom.

Sierra: So, the **Visual Imagery Project** is self-explanatory. Secondary to what our Global Research Team is doing which Peter's a part of that. We wanted to give people potential relief in the meantime and by exposing people to certain visual imagery, hence the name, we have found some patients experience relief. So, we wanted to give people an opportunity to see if they too could find relief and research of substantial value cures takes time. I mean, you can look at what's going on now with Covid19 and we have the entire world trying to work on something and it's still presenting difficulties, right? So, imagine for visual snow, little old us, working on it, but essentially while that type of research, research of that magnitude, we're talking cures, takes time. We wanted to offer people something in the meantime that could give them relief, ideally it would be great if it did, but while it might not fix the problem entirely, it can lessen symptoms.

So that's the type of solution we're trying to offer people right now, through the **Visual Imagery Project**, and we have another one launching soon as well. We've consulted two different doctors who've been collaborating using visual imagery as well. Different kinds, and then from the data that we gather we try to enhance it or make it better based on the feedback that different that people give us, and we provide that information to researchers and then they can explore potential correlations or important things.

Hazel: That's really impressive and great that you guys are trialling this. I imagine you are viewing this as a kind of trial to just get that real-life feedback and see what works and what doesn't?

Sierra: I mean, worse comes to worse, your visual snow stays the same but, at the same time, best case scenario you get some relief in the meantime, and that would be great for people. But we are also gathering data so even if it doesn't help you, you are helping the cause and giving that information to us that we can then use for research and that will lead people potentially in the right direction, which is very helpful. So, you're doing a good thing for yourself and for visual snow awareness and research as a whole.

Hazel: Hopefully, if people are listening and they are interested to take part, I imagine they can just go to your website, right? To find more about this.

Sierra: Yes, exactly, they can just go to www.visualsnowinitiative.org and all the information is there. We have pop-ups on our site with the latest information and if you want to learn more about visual snow syndrome, what's going on, you can just log on. We also have a diagnostic criteria. That's one thing that if you have visual snow or suspect you do, and your doctor doesn't know about it you can just print out our diagnostic criteria that is available on our website and provide it to your doctor and that is how you can get a diagnosis if there's not a formal doctor in your area. But we also do have a resource now, a directory of doctors so if there is a doctor in your area you just go on our website and find the closest one and we are adding on.

Hazel: Yes, that's very useful. I've reviewed your website. It's full of very useful resources, great information, very well-produced informational videos, and things like that so I would definitely encourage people to take a look there.

Sierra: Well, thank you. Likewise, you guys have done an amazing job as well, so please, check them out.

Hazel: Thanks. Appreciated (*laughing). What do you know, Peter, about— what would be the science behind this—or are there any theories behind this—how looking at certain images could potentially disrupt the visual snow signal?

Peter: I think the idea would be to get the brain to track to a different signal. The brain can only do a limited amount of things. You only have a certain amount of visual bandwidth, you might say. So the concept is to engage the vision system in a way that would allow it to disengage, you might say, the visual areas that are involved in visual snow—if I've for understood what's going on correctly.

Hazel: All right, yeah, so theoretically that could work, but I guess there's just not much known about what exactly what kind of visual input that would require.

Peter: Well, that's precisely correct. The problem is if you wait for the perfect solution, then you might wait a long time. As Sierra said, research doesn't happen overnight, but every morning people wake with their problem, so trying to do—trying to, you might say, manipulate the visual system to improve things, it doesn't have any downside to it. And if you could work out what type of manipulation was useful, you could back translate that into how that works. I think having a number of irons in the fire, as they say, a number of ways to try and advance this problem is a really smart way of doing it.

50:30 Other treatments for visual snow

Hazel: Yeah. Can you talk a bit more about treatments in general, Peter, are you aware of other researchers, maybe companies — I don't know — who are actually trying to develop treatments?

Peter: I don't know of any companies taking a vague interest in the subject, frankly.

Hazel: (*Laughing) I'm not surprised somehow.

Peter: Well, yeah, you say that, but population estimates will tell you — if the current estimates are anything correct, then you're looking at maybe 2% of the population with some form of the problem — with the syndrome and maybe 3-3.5% (I'm talking about the UK, where it's been done on a population basis). Even if 2% was correct, that's a staggering number of people, and you don't have to have a big proportion of 2% of the population if you had a therapy to have a way forward, so I think part of the problem is that industry simply hasn't gotten on their dial, number one.

Number two, of course, is that industry are great at scaling up. So look at the COVID areas. You've got the academic people working out how to make a vaccine, but once they've worked that out, it's the large companies that can take enough vaccine for 5 people and turn it into 5 million, because they can do scale up that I think it'll be hard to get industry involved in the problem if they don't know what to scale up. If we knew what to scale up, I think they'd be all over it because there'd be a substantial opportunity, so no industry at the moment.

Hazel: Yeah, but someone else would have to make a breakthrough first and then industry would pick it up.

Peter: Oh, yeah. Well, that's the way it works. Fundamentally academic researchers work things out and industry takes the step of turning that into something large-scale and that seems to work reasonably efficiently. Don't take that as a political statement, just as an observation.

52:45 Most exciting current research in visual snow

Hazel: So on that note what do you think are currently the most exciting strands of research in visual snow. Has there been anything resembling some kind of breakthrough or new insights?

Peter: I have to say, given that someone told me 15 years ago the problem didn't exist, I have to say, I think the fact that you can start to point to which parts of the brain are likely to be involved is quite a lot of progress from, you know, where nothing is supposed to happen. It's a bit like asking — if you have a city and you need to repair a dysfunctional streetlight — if you don't even know which city to go to, you're never going to repair the light. But if someone gives you a map and tells you the GPS coordinates of the light, then you go to sporting chance of going there and working out what's going on.

I'd like to characterize brain imaging as taking us from vaguely wandering around the city to knowing which street to get to. That's a very big start. I think the next big thing will be to understand the nature of the disturbance in that part of the brain. Is it too active? is it too excited? Or is it not turned off enough — is it not inhibited enough? That's a kind of fork in the road. Do you dampen excitement, or do you increase inhibition — do you turn things down? That kind of fork will tell us where to head next. For me that's the most interesting thing because it tells me — it's like the next level of iteration to know where to go if you want to then start to look at what the other therapeutic options are.

54:32 Do we really need an objective measure to make progress?

Hazel: I think in tinnitus what's often cited as a major obstacle to big pharma companies and such investing in it is the lack of an objective measure for tinnitus. There's no objective test—a blood test or whatever—that you can do to objectively demonstrate that someone has tinnitus and how severe it is, so you have to rely on questionnaires and things like that. Is that similar with visual snow?

Peter: If you ask me whether it's similar that there's no measurement of it, then the answer is yes. I have to say — I might get into trouble for saying this — but that sounds to me like a bit of a flat earth policy, flat earth thinking. Just because you can't do a blood test, the fact that you have to rely on what someone says, I don't necessarily take that as a disadvantage. When I see someone who's got a problem and they tell me it's a bad problem, at first pause will be just to believe it. It's the simplest thing to do. Most people don't come to see you because they're crazy and they've got nothing better to do. They come to see you because they're bothered.

I think that if you want a measurement to do it, I understand why people say that they think that makes it easier, but I'm not sure that it does. I'll give you an example. We don't really have any way to measure pain objectively. Now I can say I've got bad pain. What does that mean? It means absolutely nothing. I can say it's really severe. It's my characterization of it. If you get a treatment that stops it, you can measure it anyway you like. If it's gone, it's gone. It's like that's a theme. That concept has not stopped us developing treatments for pain problems. If you need to measure something at some level with these sensory things, that probably means you haven't quite caught on to what it is. If you could turn this thing off, people would just tell you it was turned off. You know, dialing it down a little bit seems to be setting the sights a little bit too low.

I can see why people say what you just said, but I do think if we really understood what we wanted to do, and we could turn it off, what would you need to measure because, you know, 0 is 0? I'm less enamored of this need for the biomarker thing. I mean, I live in the headache world where I don't have a biomarker, but I can tell you, if someone's headache goes away, it's gone. Full stop, new paragraph, it's just gone. And no one argues if gone is good or not because gone is obviously good. And you don't need an expensive blood test if something's gone. I know that's a slightly heretical view of the world, but there you go.

Hazel: No, I think a lot of tinnitus patients are right now applauding (*laughing) what you're saying, and the visual snow people for sure as well.

57:30 The evolution of visual snow research

Hazel: Sierra, can you talk a bit about what the research worlds looked like when you first got involved in this and what you guys at the **Visual Snow Initiative** have tried to do to stimulate research?

Sierra: Oh, my goodness! Wow! You're taking me back to a dark era.

Peter: I was going to say, that's like the depths of dark age, isn't it? That's like what they call antediluvian.¹

Sierra: Exactly (*laughing), yeah, the fact that we had to, as patients, argue that this was legitimate with doctors is extremely troubling. Regarding the blood tests, I think it is a lovely sentiment to just — and it's also convenient — a convenient lovely sentiment to think: Oh, a simple blood test or a simple black or white answer is going to reveal if I have something or not, but I find that in life things are often a gray area and the reality is as well, right? We wouldn't even have come across these blood tests or done any of these exams in the first place if people didn't speak out about their symptoms to begin with. So why is it that those people who first spoke out, right, that was given validity? And then they created tests to look into these conditions, but for people with visual snow, here we are crying, and it's like, all right, well, you know, there's nothing we can do, and it's like no, we need to develop these solutions. We need to develop ways, and even if there isn't a positive or negative test for visual snow, you need to work with patients, right? We rely on communication and feedback to even develop tests in the first place, but regardless I guess we'll backtrack then right to what you were saying. I just wanted to add on that feedback's important.

You were asking about how research was looking a few years ago?

Hazel: Yes, and what you guys have tried to do to stimulate research.

Sierra: When I first got visual snow, it was not only difficult to deal—and I'm sure a lot of people can relate to this with any condition, right? But mostly visual snow and tinnitus. It's one thing to be dealing with the condition itself—the visual symptoms, the non-visual symptoms, auditory, non-auditory symptoms—it's one thing to be dealing with all that and not feel good. So, it's one thing to not feel good, and it's another thing to be marginalized; it's another thing to be told “you feeling good doesn't matter because there's nothing we can do. You feeling good doesn't mean anything to us because we don't understand why you don't feel good.”

You know when you're growing up, you're told: okay, you have a wound? You put a Band-Aid on it. You're sick? You go to the doctor. So, what do you do when you're sick but the people who are supposed to help you don't even know what's going on, right? And that prompted me to not just accept that because I was told by doctors we know something's going on but we don't know what to do. Go home and try to live your life. You need to accept this. And I didn't accept that, and that didn't cut it for me, so I started looking for people who were willing to work with me here and willing to help and that's how I came across Peter. It was actually because Peter was someone who was doing research, and that's how I came across **Schankin**. It's how I came across **Victoria Pelak**, coming across **Joanne Fielding**, **Owen White**, **Yasser Khan**, all the people that we now work with as part of our global research team which has been adding more and more people to it, right?

¹ *antediluvian* – of or belonging to the time before the biblical flood

But those were the originals, and they were kind of the major players and the *only* players who were doing anything, and so from there I realized there was a lot of misinformation and I'm sure with tinnitus, too, people have their own conspiracy theories about what helps and how it started, and the genesis, and where research needs to go, and it was all very confusing for me. I had no idea who to trust or who to look to, but I knew that these experts were invested in research and wanted to help and so that's why the **Visual Snow Initiative** wasn't a non-profit to begin with. We were just a group of people organizing a conference to present the body of current and valid research about visual snow.

So, from there we hosted a conference in San Francisco, a couple years ago, a few years back, where we had a panel of experts and we presented the current body of research. So that was our first attempt to bring sort of current research but dispelling the truths and non-truths about visual snow to the masses. And then from there, we got so many questions and so much interest after the event, and people were asking when we'd organize another one and so on that we decided to start a non-profit to fund research directly. And prior to that, yes, people had done **GoFundMe's** for them personally, but I founded this nonprofit on behalf of everyone. And everyone who has visual snow should benefit from the awareness we're trying to raise and the money we're trying to raise for research, as well.

So we've reached out as far as strategy; we've reached out to the medical community, the scientific community and even beyond that just trying to rely on the power of celebrity, but I find that the power really lies within the people. As someone with visual snow, speaking out is the best thing that you can do in terms of raising awareness and for funding research. Years ago, I didn't know where to put my money to fund research and I didn't even know if that was possible, if there was a place to put it, and who was doing it. Now we know that we have a global research team who are approaching this from every way, looking at every strategy, and the money goes directly to research. It's really simple so we've simplified the process as well as gotten research back up and running in a cohesive way all over the world.

Hazel: I think it's very, very impressive, Sierra, what you guys have achieved and also raised quite a bit of money for research if I recall—also very impressive.

Sierra: thank you; you're very kind. Thank you.

1:03:54 Fundraising and awareness raising challenges

Hazel: We've found it very difficult to fundraise for tinnitus even though so many people suffer from it. Somehow it's not a cause that many people seem to want to give to, so yeah, if you have any tips to share (*laughing)...

Sierra: Certainly, we can talk about it, of course. The reality is and this sounds very pessimistic, but I want to be honest and just speak my piece here. I really think that this is a matter of “until it happens to you.” Until it happens to someone you know or someone you love, it's not on your radar. And I'll be very honest, I didn't care about what visual snow syndrome was before I got it, and I didn't know what it even was. And then even when I had it, I still didn't even fully understand it, right? But it's our responsibility to look out for each other especially

now that we're a community and we can collaborate with other people like how we're collaborating right now. We come from a very similar place in our mission and also our condition, and I'm proud of how far we've come and I'd like to think that humanity has some level of compassion and I asked that people put themselves in somebody-who's-going-through-this's shoes, and you know what? It might not be your son; it might not be your daughter, but it's someone else's son; it's someone else's daughter, and it could easily happen to you. The thing with visual snow and even with tinnitus that's just lovely is that they don't discriminate. They affect people of all walks of life and the reality is even though it hasn't happened to you yet it could very easily happen to you or someone you know, so it is relevant. I think, for anyone who has a sense of ethics, morals and civic responsibility, it's something that they should look at. There are so many conditions that are under-represented and marginalize because the general interest maybe isn't there, but it should be. But it's not our job to wait around sitting on our asses, excuse me, for people to start caring about us. You have to show them why they should care. And the biggest issue with visual snow that I found is with fundraising. It wasn't really about: Oh, here's this condition that you know about that's very debilitating and people can't see clearly, right? Help us! No, they had no idea what it was, so we had to simultaneously educate and then fundraise, which was a challenge.

Hazel: Yeah. Yeah, but I very much relate to your call-to-action that it doesn't help to just sit around and complain that no one takes you seriously, as horrible as that is, but we all have to unite and do something about it. I think visual snow and tinnitus face very similar problems when it comes to public perception. They're both conditions obviously you can't see; you can't tell that anything's wrong with the person.

Sierra: Invisible illness! There we go! Yeah!

Hazel: Yeah and it's just very hard to imagine if you don't suffer from it. And then with tinnitus there's also the issue that a lot of people suffer from it but they have a very mild variance, so very often, when you say, when you try to explain how much you're suffering from your tinnitus, the person will say, "Oh, but my uncle has that and he's totally fine with it; it doesn't bother him at all."—that kind of thing.

Sierra: Right and good for your uncle! But at the same time that doesn't delegitimize what you're going through. I've had people, and granted they mean well, but I've had people tell me when I explained visual snow to them, they're like, "I have that too!" And it's very probable they could, right? A lot of people do. I've come across people that have had it in my real life and that was really powerful, but they'll say they have it and be like, "Yeah, you know, those little squiggly lines you see. They go away. What are you talking about? You're talking about floaters." Floaters! Very different! Yes, that has to do with a fortuitous gel in your eye and all this other stuff — very, very different stuff, but you know people are trying to relate and I think that that's perfectly fine, right?

But it's our job to educate people on the varying degrees of severity. But just because research and these areas are daunting, doesn't mean it shouldn't be attempted. Nothing truly good and impactful can come easily, and I think it's frustrating for people who are going through this. It's an ongoing process. The solutions haven't been created yet. It's frustrating for them to sit by, but I always tell people: finding a solution for problems like visual snow and tinnitus in an idyllic sense — like a cure — it's going to take a significant amount of time, and that's

something that I don't want to hear as a visual snow patient but it's the reality, and I need to accept that, and in the meantime that doesn't mean that other things can't be done and we can't find ways to manage symptoms. And I'd encourage people if they're dissatisfied ever with their current situation, they can easily go out and advocate for awareness and fund their research and reach out to doctors. It's not like we have to sit by as well, you know?

1:09:20 What visual snow research needs

Hazel: Absolutely. Yeah. Peter, we've talked about, you know, how far research has come in a relatively short amount of time but also still a long way to go. What do you think is really needed at this point to give a big impulse to visual snow research? Is it just funding, for instance, or is it large amounts of data? What's really needed?

Peter: I think to make great headway in anything, it's very simply a resource question. It's worthwhile saying that when the **Visual Snow Initiative** came along, we'd really gotten to a point where we would have needed to stop what we were doing because there was just no money about to do it, so the fact that it's continued is a tribute to what's being—itself is a tribute—I think all the people involved in visual snow research would say this—a tribute to what **Visual Snow Initiative** is doing. The next level will be to leverage work that can be done into standard funding mechanisms, which is code for saying the various government foundations. In the US obviously the **NIH**, **European Research Council** and I guess Finland has a government body.

You need to be able to leverage into that to make the kind of quantum leap, you might say, because the conditions of its time, in the sense that we have to take things to explore, if we had started doing this 20 years ago, 25 years ago, the brain interrogation, brain imaging techniques, weren't really what they are today. So it's timely; techniques will only get better. And with reasonable support, progress will be made, so I think it's more to do with, it is to do with just a quantum that you can put into something. That will lead to be a—If we had a huge data array at the moment, we'd be stuck to pursue that from research perspectives.

Hazel: To analyze all of it.

Peter: Yeah, yeah, exactly. I do think it's about resource. Sierra's mentioned just about everyone in the world who's really doing any work with visual snow, the fact that she can say it without drawing breath is a bit...

Sierra: Concerning!

Peter: Well, it's a bit depressing at some level.

Sierra: Yeah, but it's better than no one.

Peter: I agree it's better than no one, but you could divide the number of people who probably got the problem by 100 and I could find you many, many less common conditions where you have to stop and draw breath to list all the people who are involved in it, so there's a great disproportion between what's thrown at the problem and the size of the problem, I suspect.

Hazel: Yeah, it is quite puzzling, isn't it, and again, quite similar to tinnitus. I know there's a lot more people doing tinnitus research, but there have been studies done comparing tinnitus against conditions that have a similar socio-economic burden, so I think diabetes and depression—things that fall in sort of in the same bucket—if you simply look at the socio-economic burden of the disease, but those conditions or diseases received you know dozens of times—it's not just two or three times more funding but it's like 20 or 40 or 50 times more funding.

Peter: Yeah, and of course, the problem is you don't want to be advocating to spend less on diabetes. No one in their right mind wants to do that. The problem is how one cuts the pie, so to speak. It's a very difficult thing. Of course, what Sierra said is very important. Advocacy's important. The people who take these sort of decisions, governments and so forth, they need to hear from people on the on the ground, so to speak, who have the problem, that they're not satisfied and they want something done. The advocacy in that way is a very, very great partner to advancing a clinical problem.

1:14:00 What patients can do

Hazel: Yeah, I think that's an important point. And Sierra, that's also one of the questions that came from one of our **Tinnitus Talk** members. What can patients do to help raise awareness of this condition. Now, I know you already talked a bit about it, but do you have specific advice if people want to help raise awareness?

Sierra: Right, that is a great question and we would appreciate any interest in raising awareness. The great thing about this is that raising awareness can be entirely free. While from a hopeful perspective and as the founder of a nonprofit, I obviously would encourage people to donate if they want to facilitate visual snow research. I understand that financially that might not be feasible for everyone and that's okay, right? That doesn't mean that you still can't have an impact. I would say that because social media is an international means of communicating, feel free to speak out online. I would encourage people to do that as many already have. We have visual snow communities where people can share their symptoms and communicate with each other, which is great, but what about the people who don't know about this yet?

And there are a ton of support groups out there and organizations that work with rare diseases. They work with invisible chronic illnesses, and I think that sharing news about visual snow with them could potentially make waves.

Also just publicly talking to your friends and family even within your small community. I understand in the larger picture maybe that that might not have as great of an impact but even something so simple as getting people talking and having more people understand and saying, "Hey, I have a friend who has that" and whatnot. But in terms of medical awareness please share your symptoms with your doctor and you can go to our website and print out the diagnostic criteria that we have and they can diagnose you. I think education within the medical community is very important for visual snow and Peter can attest to that, of course. Personally, it was it spoke volumes to me. I went to see an optometrist recently and that was

purely just for my eyeglasses, and they asked about my previous medical history, and every now and then I'll tell them about visual snow if they're curious, but the optometrist already knew what it was and I was really surprised and he says, "Yeah," and he goes, "I've seen people that come to me and talk about that and I have to refer them elsewhere, but you know, if my patients never said anything to me I wouldn't have even looked into it, and I went home and started Googling their symptoms because I wanted to help." And even something so simple as that, right? So speaking out his very important online and in the real world, as well.

Peter: Speaking as an observer, and I would agree entirely that education is important. An Israeli ophthalmologist contacted me to say he had seen a case of visual snow and read what we'd written and presented to the annual meeting and was struck by—this is the first case that has been presented at the meeting—everyone was struck by how many had heard—how little bit of experience—but no one had really heard of it before. All education is good. Also, I think that in terms of advocacy, governments and external people to a problem take great advantage of what I call "divide and conquer" in the sense that if there's perceived argument with in a community, it usually means externally no progress is made. If you're unhappy about one particular aspect of whatever's being said in the visual snow world, it will be better to discuss that internally but have a pretty joined up message outside because if you have 5 messages when you speak to anyone in authority, they'll tell you to go back, they'll listen to them all, say they're all valid, and then tell you to work out which one's the most valid. It's a classical way of doing nothing.

Sierra: You mean like a cohesive...

Peter: Yeah, yeah, exactly. If you only go with one message, then you going to have to address the thing you say. So, you know, it's hard because this is a new condition and people get frustrated with the directions of traffic and so forth, but I really encourage people who wanted to advocate, work out very few messages and at least to the outside world have a joined-up approach, because it makes it harder for people to squirm away from what you want.

1:17:32 Finding a cure versus learning to live with it

Hazel: I think that's excellent advice, Peter. I recognize immediately what you're saying and probably maybe, Sierra, you can tell me if it's the same in the visual snow community, but I think in the tinnitus patient community there's different camps, if you will. Maybe two main ones, you know, the ones that are saying "tinnitus is a debilitating condition and we need a cure. Full stop." And the ones that are saying, "Oh, we just have to learn to live with it so just spend your time and energy on that rather than hoping for the cure that will never come," or something like that. Is that similar in the visual snow community?

Sierra: Yeah. Most definitely. It's very similar.

Hazel: Right, so I think that resonates with me what Peter just said because there isn't in that sense, that one clear, common message.

Sierra: Right and we try to act as, we meaning the **Visual Snow Initiative**, we try to act as a liaison, right, from the people who have this to the medical community and the scientific community, ultimately leading to research. But the reality is there are tons of groups, as you said. There are support groups, communities, pages where you can express yourself, your personal feelings, as well as share theories about visual snow and get support. And they're all great and they offer different things. I totally see the power in unity, even if we're different entities, I would like to think we all have one common goal. There's is no agenda that we all have that isn't positive and in some way trying to help people. But it would be good if when we are approaching people and trying to pitch our concept, if you will — pitching why visual snow's important, why it needs funding, why it needs research — if we have everything in order. And I do think it's tricky though like wouldn't you say like with a condition like this it's not just physical for a lot of people it's very emotional so they have a lot of passion sometimes when they speak, but I've had to myself learn how to tone down the emotion and be pragmatic and when I speak, use my words wisely to reach people, you know?

Peter: Yeah, I'm not talking about censorship. I'll say that. All I'm saying is that I think it's a recognized thing in advocacy that less messages get more action.

Sierra: Yeah, if it's cohesive, for sure! And a consensus. There's power in numbers.

Peter: Yeah, exactly.

Sierra: The reality is it sounds easy to marginalize the conditions we have. It sounds easy to just sideline them because oh, well there are not many people who have them. Well, as Peter said earlier, yeah 2% might sound like nothing but it's quite a lot in the scheme of that. But the thing is we hear from people all the time daily, thousands of emails! So you can tell me this condition is rare. You can tell me visual snow syndrome is a rare condition; it's uncommon, not enough people experience it that it warrants awareness and you know getting publicized, but when you're receiving thousands of emails every single day from children, from young people, from middle-aged people, from elderly people, regardless, all walks of life, all over the world, sharing the same stories, and while the majority—while the minority of them, yes, many of them are comfortable—the majority of them, from what we've experienced at least, they are not comfortable and they are not happy, so how can you tell me when you're—if you took those thousands of people and put them in a room with you—how can you tell me that that their words and their feelings—that what they go through doesn't matter? You can't.

Hazel: I think this is why you're such a good advocate, Sierra.

Sierra: Oh, shucks! Thank you! Likewise. Thanks. I don't know about that, but thanks. Yeah.

Hazel: I think we should probably wrap up, but are there any topics that you guys had wanted to cover that we haven't touched on?

Peter: No, I think we touched on most of the things that I had in my notes in front of me.

Hazel: All right, then I just want to thank you both so much for your time and all the efforts you've made that the audience might not know but we had to do multiple attempts before we could get a good recording, and so yeah, we just really value your time and commit and also, of course, your time and commitment to the cause in general. So thank you.

Peter: Well, thank you for taking an interest. It's a pleasure.

Sierra: Yeah, thank you so much for the opportunity to come on, Hazel. You guys are doing amazing work as well. We're very impressed and glad to be collaborating with likeminded, genuine people.

Hazel: Thanks.