



## Sounding Board

### Newsletter of the New Zealand Tinnitus and Hyperacusis Network summer 2015/16

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#### From the Editor

There are lots of facts about tinnitus and information about how to manage the problem that so many of us have. That is important and helpful.

But tinnitus happens to real people. People like you and me in so many different situations. Reading other people's stories helps us realise that we are not alone in the battles we do with our 'screaming ears'. The stories personalise the whole thing.

I've had contact with several people over the last little while for whom tinnitus seriously affects their ability to enjoy life. I like to think that the conversations I have had with those people have helped them a little further along the road, especially to have hope that the ongoing research will eventually be fruitful.

This issue contains one person's story about their struggle with tinnitus, and more information about research that is occurring in different places around the world.

I would love it if you would share your tinnitus story with us so we could publish it in a future issue. Others will gain strength and encouragement from your story. Email me at [cksrbedford@clear.net.nz](mailto:cksrbedford@clear.net.nz) to discuss your contribution with me.

I wish everyone a very happy and hopeful New Year.

Chris Bedford, Editor

#### From the Director's Desk



As tinnitus research continues to push forward and technology advances new theories and treatments arise. One recent development I've been involved in is the development of TinnitusTunes ([www.tinnitustunes.com](http://www.tinnitustunes.com)). Although at an early phase of development this treatment website is a portal for researchers to make their treatment concepts widely available.

At the end of last year I was very pleased to get a research grant from the American Tinnitus Association, and in February will be hosting ATA's CEO Melanie West, letting her know what's going on in tinnitus research in NZ. Great to have the support of such a leading tinnitus organisation.

**Brain week** is fast approaching

<http://brainweek.co.nz/>

With Brain day 12 March. Come and hear & see the latest about the brain

If in **Dunedin** or nearby:

<http://brainweek.co.nz/events/brain-day-dunedin-2016/>

If you are in Auckland or visiting 9am-3pm :

<http://brainweek.co.nz/events/brain-day-auckland-2016-your-amazing-brain-an-interactive-expo/>

Talks

<https://www.fmhs.auckland.ac.nz/en/faculty/cbr/news-and-events/events/brain-week-2016---brain-day.html>

**Location:** UoA Tamaki Campus (261 Morrin Rd)

**Tinnitus will be there!** Tinnitus lab visits at 9 and 12.

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## One Man's Story ...

**Peter McCardle is Station Officer for the Christchurch Fire District of the NZ Fire Service. He writes of his experiences with tinnitus.**



In hindsight I am not surprised that I have tinnitus. I am a long serving career firefighter and part time musician. Before health and safety came to the workplace scant regard was given to hearing protection, the world of a firefighter is a noisy one they work with equipment that is mostly driven by engines from fire engines, compressors ,portable pumps, generators, rescue equipment, and even helicopters. Instructors have to be heard and hearing protection is not always an option. The fireground presents its own hearing hazards from operating equipment to explosions, even false alarms can be a hearing hazard, shopping malls and commercial buildings have fire-alarms designed to drive out their occupants while firefighters wander around inside checking there is no fire before alarms can be turned off.

As a musician I played with bands around noisy venues for about fifteen years, then one morning three days before my birthday in 2008 I woke up and I had tinnitus. I was devastated, I nearly cancelled a trip to Europe, I saw my doctor had all the tests even a M.R.I. I kept hoping they would find something that they could fix but it was not to be.

I manage my tinnitus largely by ignoring it which works pretty well, I don't hear it too much outdoors and I find that when I am busy I don't hear it. I am fortunate in one aspect, that is I do not hear it when I sleep which I am grateful for. I have made one small change to my life as I am now also noise sensitive I always carry with me a couple of earplugs.

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## Understanding the Facts about Tinnitus

Do you (or a loved one) experience a ringing in your ears that no one else can hear? If so, you are not alone. You have tinnitus, an audiological and

neurological condition experienced by more than half a million New Zealanders.

Tinnitus is the perception of sound when no actual external noise is present. While it is commonly referred to as “ringing in the ears,” tinnitus can manifest many different perceptions of sound, including buzzing, hissing, whistling, swooshing, and clicking. In some rare cases, tinnitus patients report hearing music. Tinnitus can be both an acute (temporary) condition or a chronic (ongoing) health malady.

Thousands of Kiwis experience tinnitus, often to a debilitating degree, making it one of the most common health conditions in the country. The U.S. Centre for Disease Control estimates that nearly 15% of the general public — over 675,000 New Zealanders — experience some form of tinnitus. About half that number struggle with burdensome chronic tinnitus, while several thousand have extreme and debilitating cases.

Tinnitus is not a disease in-and-of-itself, but rather a symptom of an underlying health issue. While tinnitus is a symptom of a wide range of conditions, it is most frequently the result of some level of hearing loss. In general, there are two types of tinnitus: **Subjective Tinnitus:** Head or ear noises that are perceivable only to the specific patient. Subjective tinnitus is usually traceable to auditory and neurological reactions to hearing loss, but can also be caused by an array of other catalysts. More than 99% of all tinnitus reported tinnitus cases are of the subjective variety.

**Objective Tinnitus:** Head or ear noises that are audible to other people, as well as the patient. These sounds are usually produced by internal functions in the body's circulatory (blood flow) and somatic (musculo-skeletal movement) systems. Objective tinnitus is very rare, representing less than 1% of total tinnitus cases.

There is currently no scientifically-validated cure for most types of tinnitus. There are, however, treatment options that can ease the perceived burden of tinnitus, allowing patients to live more comfortable, productive lives. The

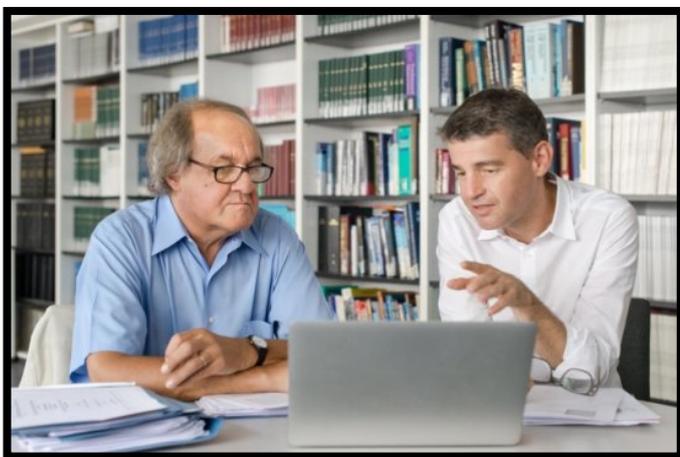
American Tinnitus Association, the British Tinnitus Association, the Tinnitus Research Initiative and our own Audiology Section of The Centre for Brain Research at Auckland University are just a few of the groups actively involved in the ongoing search for a definitive tinnitus cure. The word *tinnitus* is of Latin origin, meaning "to ring or tinkle."

### **Ringling in the ears and chronic pain enter by the same gate**

*Neuroscientists locate gatekeeping system for 'phantom' sensations*

Science Daily - September 23, 2015

Source: Technical University of Munich (TUM)



*(l-r) Co-authors Markus Ploner of the Technical University of Munich (TUM) and Josef Rauschecker of Georgetown University Medical Center are shown.*

*Credit: A. Heddergott / TUM*

Tinnitus and chronic pain have more in common than their ability to afflict millions with the very real experience of "phantom" sensations. Scientists noted similarities between the two disorders more than thirty years ago. Now advances in brain imaging and associated techniques have enabled researchers to begin homing in on their structural and functional bases, revealing what appears to be a central gatekeeping system implicated in both chronic pain and tinnitus. Collaborators at the Technical University of Munich (TUM) and Georgetown University Medical Center integrate the latest findings into a disease model of both disorders in the journal *Trends in Cognitive Sciences*.

Tinnitus sufferers hear sounds that aren't there, usually described as a ringing or buzzing "in the

ears" even though such perceptions clearly arise in the brain. Hearing loss is often associated with tinnitus but does not adequately account for it. Furthermore, not everyone with damaged cochlear nerves or cortical auditory circuits experiences tinnitus. One hypothesis suggests that the decisive factor is whether or not a higher-level cognitive system responsible for "tuning out" negative sensory signals is working normally. This view of tinnitus was hailed as a paradigm shift by people in the field when it was first proposed, in 2010, by Prof. Josef Rauschecker, Director of the Laboratory for Integrative Neuroscience and Cognition at Georgetown University and a Hans Fischer Senior Fellow of the TUM Institute for Advanced Study. Mounting evidence has strengthened the case, as improved techniques allow higher-resolution studies of changes in the brain.

### **Converging lines of inquiry**

Close collaboration between Rauschecker's lab and PainLabMunich, led by TUM Prof. Markus Ploner, has extended this research into the common ground that tinnitus shares with chronic pain. And that common ground now has an address in the brain. Structural and functional changes in the same brain circuit -- including the ventromedial prefrontal cortex and the nucleus accumbens -- can open the gateway to both tinnitus and pain that persists long past any acute cause.

The list of techniques that have contributed to this study is long and perhaps a bit esoteric-sounding, including functional magnetic resonance imaging, voxel-based morphometry, arterial spin labeling, positron emission tomography, and diffusion tensor imaging, as well as electroencephalography and magnetoencephalography. Results from these diverse approaches -- which essentially measure structural characteristics such as gray matter volume and functional properties such as network function -- have been correlated with and interpreted in the light of neurochemical studies.

### **New insights and cautious hope**

In their new paper Rauschecker and Ploner, together with postdoctoral researchers Audrey Maudoux (Georgetown) and Elisabeth May (TUM), present copious evidence that similar structures and functional systems are involved in tinnitus and chronic pain and probably play a central role in both. Significant loss of gray matter and

compromised circuit function are observed in the suspected regions, with considerable overlap between neurological changes in tinnitus and chronic pain sufferers.

All of these areas are also important for evaluating and modulating emotional experiences, Rauschecker says. "These areas act as a central gatekeeping system for perceptual sensations, which determines the affective value of sensory stimuli -- whether produced externally or internally -- and modulates information flow in the brain. Tinnitus and chronic pain occur when this system is compromised."

The researchers propose that this newly identified gatekeeping system determines the relevance and affective value of sensory stimuli and controls information flow along pathways associated with the so-called executive functions. The process, they say, is controlled by two major neurotransmitters, dopamine and serotonin. Damage to this system, they argue, affects the perception of sensory signals in such a way that either tinnitus or chronic pain can develop and carry on in a self-perpetuating loop.

They stress that there are still a number of open questions, particularly in relation to potential clinical interventions. Yet they see reason to be cautiously optimistic. Better understanding could lead to standardized assessment of individuals' risk to develop chronic tinnitus and chronic pain. This in turn might open the way for preventive action and early treatment, including for example cognitive-behavioral therapy, physiotherapy, and pharmacotherapy.

"However," Markus Ploner adds, "better understanding might allow not only for early treatment, but also for more targeted and individual treatment with existing as well as novel strategies, such as dopaminergic therapy." Ploner is a consultant neurologist at TUM as well as Heisenberg Tenure Track Assistant Professor of Human Pain Research.

This research has been supported by grants to J.R. from the U.S. National Institutes of Health (RC1-DC010720), the American Tinnitus Association, the Skirball Foundation, the Tinnitus Research Initiative, and the Tinnitus Research Consortium; to A.M. by the Belgian American Educational Foundation (BAEF); and by the German

Research Foundation, DFG (PL 321/10-1, PL 321/11-1).

**Source:** The **Technical University of Munich (TUM)**.

**Journal Reference:** Josef P. Rauschecker, Elisabeth S. May, Audrey Maudoux, and Markus Ploner. **Frontostriatal Gating of Tinnitus and Chronic Pain.** *Trends in Cognitive Sciences*, 2015; DOI: [10.1016/j.tics.2015.08.002](https://doi.org/10.1016/j.tics.2015.08.002)

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### **TINNET as the Next Step in Tinnitus Research: Towards Evidence – based medicine**

Audiology World News: Tuesday, 10 June 2014

The Tinnitus Research Initiative (TRI) has come a long way to bring tinnitus research from several scientific fields together. The European funded TINNET, 'Better Understanding the Heterogeneity of Tinnitus to Improve and Develop New Treatments', can be regarded as the next step. It aims at coordination and standardization in tinnitus research and the enlargement of an already existing database with results from clinical trials. This should lead to a statistically relevant basis for tinnitus research. It promises the opportunity of standardized processes to enable tailor-made assessment for individual patients.

"At the start of the TRI in 2006 as a private initiative, there was only little tinnitus research compared to the number of people suffering from it. This research was isolated and results remained within the separated domains of ENT, audiology, psychology, psychiatry, and etcetera", Dr. Berthold Langguth, (pictured) head of the tinnitus center of Regensburg University concludes. TRI had the vision to bring disciplines together and to share results and insights.



"Back then", Langguth remembers, "the general assumption and conclusion were: 'Tinnitus cannot be cured, so learn to live with it'. The people involved in TRI, however, shared the belief that tinnitus should be treatable in principle – for instance with brain stimulation– although this treatment nor any other treatment was not proven yet. Their motto was

and still is: 'Together for a cure'." Since then, a lot has been achieved. For many patients, the suffering from tinnitus has been reduced.

### **Evidence base**

"But tinnitus still is a very heterogeneous illness. It is difficult to treat", says Langguth, "treatment is for a large part still mainly pioneering, the domain of pilot studies." As yet, there are no clearly evidence based treatment methods except cognitive behavioral therapy (CBT) – which comes in several forms. Langguth: "But this doesn't affect the tinnitus percept itself, CBT has the goal to facilitate coping with it. While this provides important relief in many cases, it is not yet the solution for every patient suffering from tinnitus. Apart from that, there are many, many approaches with different rationales. Hearing loss compensation, optionally combined with forms of auditory stimulation, is widely accepted, but large controlled studies demonstrating the efficacy of these approaches are needed. Various innovative forms of individualized auditory stimulation offer sounds or music in frequency areas in the neighborhood of the tinnitus frequency. These forms of individualized auditory stimulation can interact with the neuronal mechanisms that generate tinnitus and have shown promising results in pilot studies." But there is still a lot unclear, Langguth emphasizes: "How large are the clinical effects? Which variant works best with which type(s) of patients? What can we expect from pharmacological treatment or magnetic and electric brain stimulation? Before these newly developed treatments can be implemented in clinical routine, a conclusive statistical basis from large studies would be needed."

### **New knowledge**

The TINNET initiative was initiated to change this. It has now been approved by the European Cooperation in Science and Technology (COST) Committee of Senior Officials, thus ensuring European funding. "With that, we get the opportunity to lift tinnitus research to the next level. We still largely depend on the outcomes of isolated trials with a couple of dozens of heterogeneous patients, which causes results to partly depend on group configuration. When data from similar trials from dozens of centers or more can henceforth be introduced in the database, this opens a lot of opportunities." Once detailed data

from many persons is gathered, it will allow us to derive new knowledge, says Langguth: "We could understand in more detail what forms of tinnitus do exist and what the differences between the various forms are. The goal would be to create a data-based expert system, which would provide guidance of which treatment has the best chances for success in a given patient: So hopefully in some years, we can ask the database what would be the recommendation for a 56 years old male, who suffers from a tonal tinnitus since a noise trauma two years ago, and the database would tell us, that a combination of drug X and auditory stimulation Y is the most promising first-line treatment for this individual."

*Dr. Berthold Langguth spoke about the TINNET initiative during the 8th TRI international Conference from 10-13 March, 2014, in Auckland, COST invites tinnitus researchers from as many European countries as possible to participate in the project.*

### **Recording Tinnitus Activity**

Nic Wray, British Tinnitus Association



Researchers reporting in the journal *Current Biology* have taken advantage of a rare opportunity to record directly from the brain of a person with tinnitus in order to find the brain networks responsible. The

observations reveal just how different tinnitus is from normal representations of sounds in the brain.

"Perhaps the most remarkable finding was that activity directly linked to tinnitus was very extensive, and spanned a large proportion of the part of the brain we measured from," says Dr Will Sedley of Newcastle University. "In contrast, the brain responses to a sound we played that mimicked the subject's tinnitus were localised to just a tiny area."

In the new study, Sedley and the University of Iowa's Phillip Gander contrasted brain activity during periods when tinnitus was relatively stronger and weaker, the study was only possible because the 50-year old man they studied required invasive electrode monitoring for

epilepsy. He also happened to have a typical pattern of tinnitus, including ringing in both ears, in association with hearing loss.

*"It is such a rarity that a person requiring invasive monitoring for epilepsy also has tinnitus that we aim to study every such person if they are willing," Gander says.*

The researchers found the expected tinnitus-linked brain activity, but they report that the unusual activity extended far beyond circumscribed auditory cortical regions to encompass almost all of the auditory cortex, along with other parts of the brain. The discovery adds to the understanding of tinnitus and helps to explain why treatment has proven to be such a challenge, the researchers say.



*"We now know that tinnitus is represented very differently in the brain to normal sounds, even ones that sound the same, and therefore these cannot necessarily be used as the basis for understanding tinnitus or targeting treatment," Sedley says.*

The sheer amount of the brain across which the tinnitus network is present suggests that tinnitus may not simply 'fill in' the 'gap' left by hearing damage, but also actively infiltrates beyond this into wider brain systems," Gander adds.

These new insight may help to inform treatments such as neurofeedback, where patients learn to control their "brainwaves", or electronic brain stimulation, according to the researchers. A better understanding of the brain patterns associated with tinnitus may also help point toward new pharmacological approaches to treatment, "which have so far generally been disappointing."

The full paper can be accessed at [http://www.cell.com/current-biology/abstract/S0960-9822\(15\)00278-X](http://www.cell.com/current-biology/abstract/S0960-9822(15)00278-X)

Reprinted with permission from the British Tinnitus Association's magazine, *Quiet*, Summer 2015

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## Want to Talk with Someone who Understands What it's Like??

Sometimes it's good just to be able to chat with someone who knows from personal experience what it's like to have tinnitus.

If that's you, then feel free to give Chris Bedford a call, 07 863 5260, or email [cksrbedford@clear.net.nz](mailto:cksrbedford@clear.net.nz). Chris isn't a counsellor, but he's happy to listen to your story, and maybe point you in the direction of some help you hadn't considered. After all, Chris *does* know what it's like to live with 10,000 cicadas in his head! ☺

## Want to Learn More about Tinnitus?

Check out the following:



<http://www.ata.org> . Lots of interesting and useful information with links to other sites as well.



The British Tinnitus Association have a great website. Check it out at <http://www.tinnitus.org.uk> Once you're at their website, click on *Tinnitus Research* for access to up-to-date and readable information about latest areas of tinnitus research.



[www.tinnitusresearch.org](http://www.tinnitusresearch.org)

Tinnitus Research Initiative is an international non-profit foundation dedicated to the development of effective treatments for all types of tinnitus so that relief can be obtained by everyone who suffers from it.



<http://tinnitus.org.au/>

The Tinnitus Association of Victoria (TAV) is a voluntary, non-profit organization that has been helping people with tinnitus for over 20 years.



An online clinic website.

[www.tinnitustunes.com](http://www.tinnitustunes.com)