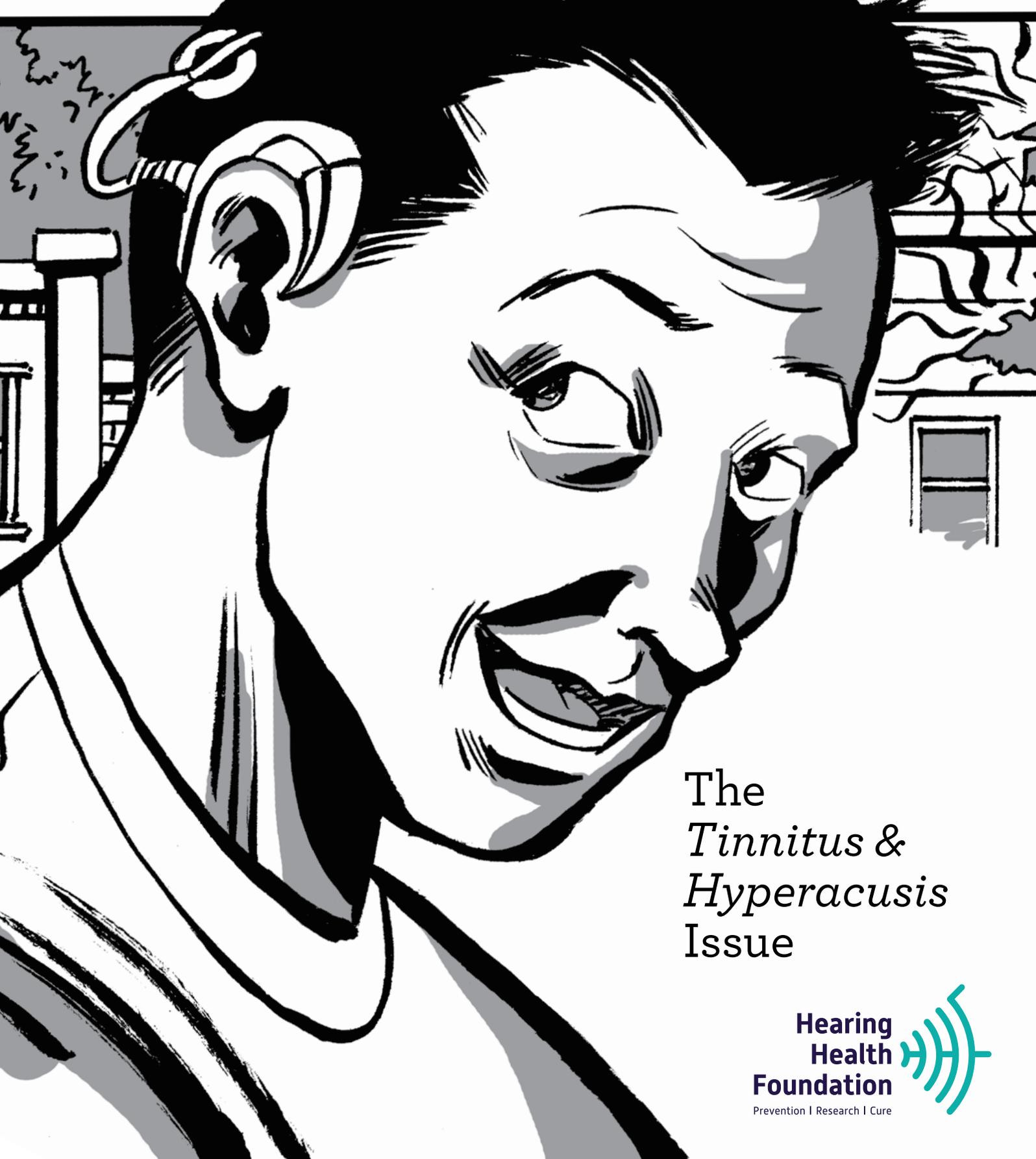


Hearing Health

Spring 2021 • A Publication of Hearing Health Foundation • hhf.org



The
*Tinnitus &
Hyperacusis*
Issue

Hearing
Health
Foundation

Prevention | Research | Cure



What Works for Me

Seeking help for my chronic tinnitus, I turned myself into a human guinea pig. Here's what I learned. *By Col. John T. Dillard (U.S. Army, Ret.)*

I joined the U.S. Army at age 22 and retired from service 26 years later, in 2001. That was two decades ago, but the hearing loss and tinnitus that resulted from my service have stayed with me, making me part of the two million Americans with debilitating tinnitus, and the 20 million with chronic tinnitus.

This has led me to channel my energy into Hearing Health Foundation's Board of Directors, where I have been the chair since 2019, as well as the U.S. Department of Defense's Congressionally Directed Medical Research Programs, where I've completed a third year as a consumer reviewer for their Peer

Review Medical Research Program.

Tinnitus has no cure, but there are many suggested ways to manage it. Most folks who know me understand my extreme caution against what I consider "snake oil" tinnitus treatments, the ones not scientifically backed. So as I've searched for relief over the years, I have acted as my own guinea pig to try to mitigate the symptoms, and I have always followed the science. Believe me when I say I've researched and/or tried everything.

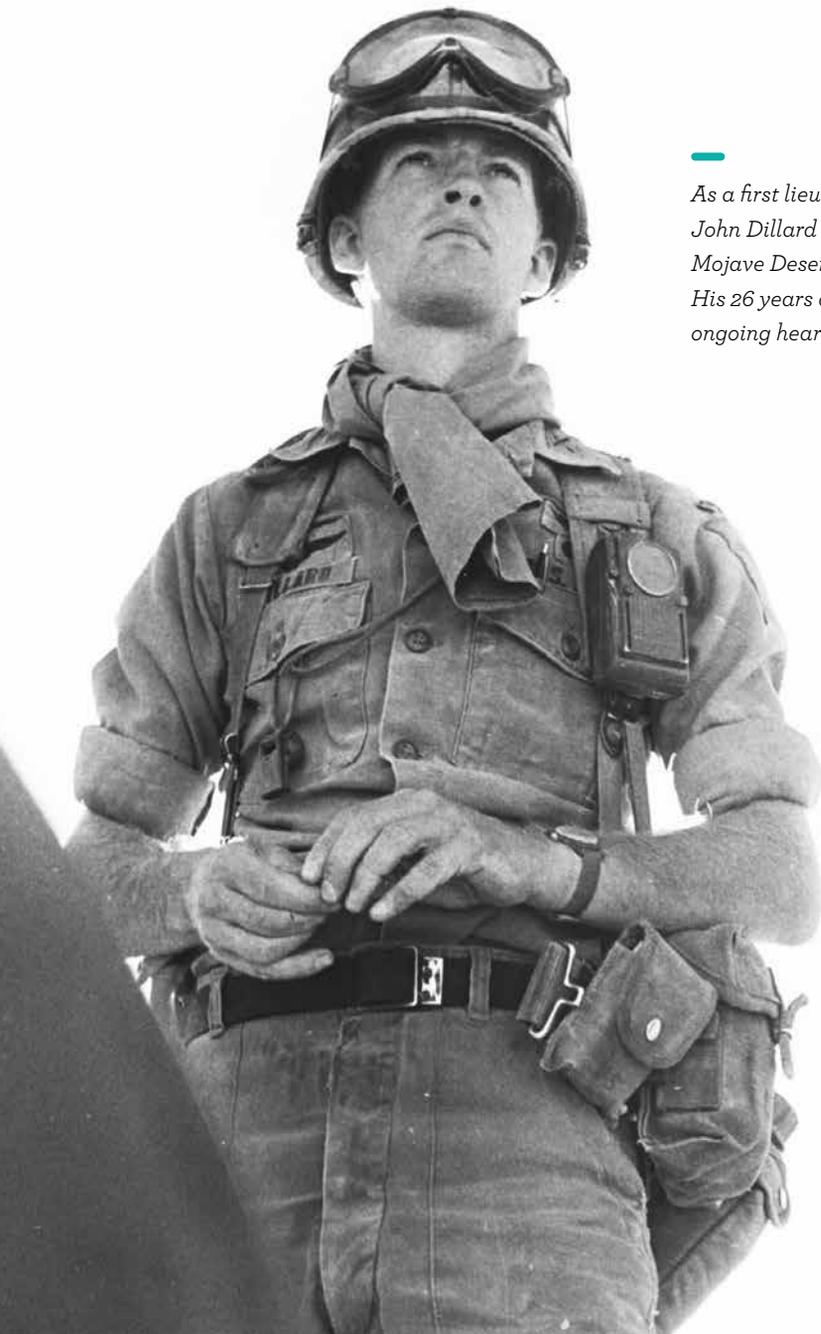
Money Spent

I began my quest by looking for a natural cure. There are several supplements that purport to treat tinnitus. One that is heavily promoted can even be found on drugstore shelves, citing flavonoid antioxidants as an active ingredient. Others contain ginkgo biloba, a supplement with lots of claims. But for relieving tinnitus, these supplements are not sufficiently scientifically backed, no matter what is claimed.

One of the next things I tried was a heavily marketed device that costs several thousand dollars, requiring the patient to listen to baroque music, with a proprietary tinnitus masker supposedly buried within, for some two to four hours daily for 18 to 24 months. Almost all peer-reviewed studies of this product were sponsored by the inventor of what was essentially an expensive MP3 player.

While there was at least one Cleveland Clinic study reporting that the device's promotion of habituation resulted in a bit of improvement in some tinnitus patients, the study noted that it also showed no significant efficacy over regular

As a first lieutenant in 1977, John Dillard trained in the Mojave Desert in California. His 26 years of service led to ongoing hearing conditions.



music. And so, no improvement for me. I had encouraged the Regional Veterans Administration in California to sponsor the product for a trial as I began mine. They did, and had the same results.

Next even more hard-earned dollars were spent on transcranial magnetic stimulation (TMS), a noninvasive (but very unpleasant) electrical stimulation of the brain used to treat depression using an apparatus cleared by the Food and Drug Administration (FDA). There were several peer-reviewed journal articles finding at least a temporary inhibition of tinnitus in some users. Again, the numbers were barely significant statistically, and the best results were only transient.

A doctor in Santa Monica, California, happily administered this to me for a mere \$10,000 using his TMS device for treating patients with depression. As I sat with other patients in the waiting room before my next round of what felt like a thousand slaps on the cheek, I felt as depressed as they were. The FDA clears such devices rather easily, as the manufacturer only has to prove safety, not efficacy. This could have been the beginning of a new application of this technology, but after 16 or so “treatments,” I had to quit the protocol early once strange (additional) acoustic hallucinations started occurring in my head!

Moving on to less expensive and even less proven therapies, I gave acupuncture a try. There are at least several papers floating around that praise its efficacy for tinnitus. But for me, a couple of treatments were all that were necessary to discontinue feeling like a pincushion.

I had the same experiences with direct brain stimulation, cognitive behavioral therapy, a chiropractor specializing in craniosacral manipulation, and mindfulness and meditation recordings.

I was mindful only of the 70-plus decibels of noise I heard inside my head. I found it hard to focus on relaxation when that much hyperactive neuronal activity was taking place in my cranium.

Sound Therapies

A doctor in New York City said he could silence the sound using “noise cancellation” principles, essentially tinnitus pitch-matching (which in itself is a fool’s errand, my tinnitus presenting as a band of frequencies, rather than a single note). I spent another several thousand dollars having his staff make a CD of my tinnitus pitched 180 degrees “out of phase.” To a physicist it sounded plausible, but not to anyone understanding the neuroscience behind tinnitus.

I also tried a \$500 sound therapy treatment from a nice lady who sent me hopeful emails from Australia—it was essentially modified violin (high frequency) music, but there was no progress for me from it either.

Then came a research paper about “notched music” as another potential sound cure that aims to tonotopically remap the brain’s auditory cortex via “notching out” the offending tinnitus frequency from the patient’s favorite tunes, using music editing software. It supposedly takes about a year of listening, two hours daily, according to a peer-reviewed journal article I found.

I obtained the needed software and created a suite of over 200 of my favorite digital recordings. After a year of faithful listening, there was also no progress.

Speaking of so-called sound cures, I participated in two separate trials of University of California Irvine’s research of sounds to induce “residual inhibition.” But I lost faith after the product was getting marketed and sold through certified audiologists before any peer-reviewed

research was published.

No wonder some folks have little faith in the medical industry! Yet I still believe that the truth prevails in the lab and marketplace. So, these various supposed treatments die on their own as crowd-sourced reviews eventually surface in chat rooms and review websites.

Off-Label

Based on my pharmacological research on off-label treatments, I also tried gabapentin, diazepam, nortriptyline, and a host of other drugs, none of which have yet been approved for use with tinnitus.

The science is more accurately reported using blinded and more systemic clinical experiments on these medications. So there’s nothing—so far—on the market in the

Tinnitus has no cure, but there are many suggested ways to manage it. Most folks who know me understand my extreme caution against what I consider “snake oil” tinnitus treatments, the ones not scientifically backed. I have always followed the science, and believe me when I say I’ve researched every potential treatment.

way of drugs that can treat tinnitus. The experiments are ongoing with promising new ideas to either dampen the hyperactivity that causes the perception of noise when there is none, or to interrupt the affected circuitry, or even to regrow the cochlear sensory hair cells damaged by noise exposure—all of which can lead to tinnitus and a related condition, hyperacusis (sound sensitivity).

On the more positive front, while cognitive behavioral therapy—or other techniques to change the way you emotionally react to tinnitus—was not a good fit for me, I know that counseling helps many folks. We do indeed get to choose somewhat how we are going to react emotionally to all things. There’s a bit of “mind over matter” in coping with the aggravating tinnitus. It’s applying psychology to what is definitely *not* a psychological problem.

Also helpful is finding support in a community going through the same experience. Misery does love company.

That said, many will say that after a bit of commiseration with other folks, so that you know you’re not alone in your suffering, you come to realize *you really just have a condition* that you must cope with, and you must go on enjoying life as best you can. It doesn’t take much effort to find someone suffering with something far worse.

The Gold Standard

So what *has* worked for me?

Tinnitus Retraining Therapy (TRT) has been recognized as the gold standard for tinnitus treatments. It was the great otolaryngologist Pawel Jastreboff, Ph.D., Sc.D., a professor at Emory University School of Medicine, who developed the treatment, and when he introduced it in 1990, it included independently reviewed, published research. His 2015 paper, on the occasion of TRT’s 25th

anniversary, notes that the protocol has been shown to be effective for 80 percent of patients, according to the majority of 100-plus studies published since TRT began.

For me TRT was many months of using ear-level sound generators, with and without hearing aids. Strangely, the sound generators feed the brain with a broadband white noise that streams just below the level of one’s individually set tinnitus via “minimum masking levels,” which can be estimated with your audiologist.

Standard-of-care protocols for TRT call for concurrent counseling sessions to reassure the patient that everything is relative, including their tinnitus in loud or quiet environments, and that not emotionally reacting to tinnitus is the first difficult step to “habituation.”

Habituation means getting so used to the tinnitus that you may even fail to perceive it some of the time—first by habituating to the reaction so it is no longer negative and disruptive, and then by habituating to the perception of the tinnitus itself.

My research on the subject allowed me to forego that element of TRT, and the white noise generator seems—for me and several others—to load our brains with acoustic sensations, somehow, that result in a kind of residual inhibition of the perception of tinnitus.

Isn’t that strange? One woman said to me, “Wait—if I am understanding correctly, you want me to amplify my hearing of normal sounds with hearing aids, and also hear my tinnitus underneath that, and

then add a layer of white noise, too?” She thought that sounded crazy.

But for me, that purchase decision (yes, another few thousand dollars) was one I made in about 30 seconds!

Nonocclusive, over-the-ear, comfortable sound amplification restores some of my moderate hearing loss to almost typical hearing across the frequency ranges. And a soothing white noise sound tells me I am actually treating my tired brain to a new trick: *how to habituate to perception*, as Jastreboff aptly put it in his writings.

As a result, every third day or so I experience a quiet day. I have no perception of tinnitus other than a strange movement of it away from the ears and into the “back” of my head. What is incredibly helpful to me is that the brain seems to adjust to the tinnitus sound—sometimes for even a couple of days in a row—because the tinnitus sensation *is not there*.

This is key. It means the brain can habituate so the tinnitus is

I’ve never encountered anyone who used Tinnitus Retraining Therapy and did not benefit from it to some degree. While not a panacea, the treatment has been shown to be effective no matter the cause of the tinnitus, which often is not known, and improvements can be seen in one month. The therapy has also been shown to be useful for treating hyperacusis (sound sensitivity) and misophonia (negative reactions to specific sounds).

My Advice

Thanks to Tinnitus Retraining Therapy, tinnitus is no longer a big part of my life. I've moved on, despite the fact that I can hear my tinnitus most days, even in noisy environments. My advice to new folks I encounter who suddenly have an onset of bothersome tinnitus is:

- » Go to an audiologist.
- » Get hearing aids if recommended.
- » If getting hearing aids, add a tinnitus masker function (or if not, get sound generators).
- » If needed, use sound enrichment (such as white noise) when you take them off.
- » Hang in there for 12 to 18 months.

Soon you'll be able to conquer your tinnitus via "habituation of reaction," followed then by "habituation of perception" (perception of the noise). —*J.T.D.*

no longer perceived. There is now ample research data on this, not just anecdotal accounts, to make it the new standard of care for the Veterans Administration within their Progressive Tinnitus Management program for our hearing damaged veterans. (PTM is essentially a staged, progressive introduction to TRT.)

I've never encountered anyone who used TRT and did not benefit from it to some degree. The first step is, always, to be evaluated by a qualified audiologist, hopefully one who knows a bit about tinnitus and options for treating it as well as hearing loss.

While not a panacea, TRT has, according to Jastreboff's 2015 paper, been shown to be effective no matter the cause of the tinnitus, which is notable because often the cause is not known. And since its introduction decades ago, the better implementation of the therapy has shortened the average time for improvement from one year to just one month.

Moreover, it has been shown to be useful in treating both hyperacusis and misophonia (negative reactions to specific sounds).

A Neurological Disorder

We know now that tinnitus is more of a brain problem that typically starts from damage to the ear in the form of noise-induced hearing loss. We need to help the brain heal itself and correct what is actually an auditory "hallucination" of hyperactive neuronal activity. It's a very resilient, maladaptive feedback loop that works much like learned pain. But while we cannot yet heal the brain, we can take steps like using hearing aids, almost all of which are now equipped with tinnitus noise maskers to help the individual adapt and cope better than ever before.

I am still quite hopeful that various pharmacological approaches now being tested may help tamp down this hyperactivity. And it is hoped that when hearing loss is cured through the regeneration of the aged or damaged sensory hair cells in the cochlea, this breakthrough will also help with tinnitus.

That's why, as I remain with TRT, I am committed to Hearing Health Foundation and how it is looking for ways to prevent and cure hearing loss and tinnitus

through truly groundbreaking, gene-level research by a wonderful consortium of top researchers, while seeding the hearing and balance fields with young scientists coming up the research ladder through career-galvanizing grants. —



Col. John T. Dillard (U.S. Army, Ret.) is the chair of Hearing Health Foundation's Board of Directors.

He wrote about his experience in the military and how it affected his hearing in the Fall 2017 Hearing Health cover story at hhf.org/magazine. For references, see hhf.org/spring2021-references.

Share your story: Tell us your tinnitus journey at editor@hhf.org.

Support our research:
hhf.org/donate.