Tinnitus Today

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Taking Control of Tinnitus

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Preparing for the Future

Tom Lobl, Ph.D., Past Chair, ATA Board of Directors

In the Summer 2013 issue of *Tinnitus Today*, I introduced myself and issued a Call to Action for my future term as Chair of the ATA Board of Directors. It is worth noting some accomplishments related to that Call as a way to look forward.

ATA continues to be the premier organization focused on tinnitus. ATA was an early adopter of “crowd source” funding (before it became a buzzword) to sponsor seed grants, student grants, and primary innovative research in tinnitus. We have funded several innovative grants during my term as Chair – research that we would not have been able to fund without the loyal support of our members.

We continue to provide vetted and accurate information about tinnitus through our website, in *Tinnitus Today* and through a variety of informational brochures. ATA also maintains a registry of tinnitus professionals in different regions of the U.S., and works with over 50 volunteer-led support groups who offer people with tinnitus an opportunity to connect with one another. I appreciate your support, both financially and informational, that has enabled me to lead the organization forward during my term.

During the past two years ATA has recognized that the future will present increased opportunities and challenges. To grasp the future we have initiated several new projects. As you may have noticed, we have a new, clean-looking modern website at ATA.org which has many new features and capabilities. Our new website includes a new Members section which provides an exclusive opportunity for ATA members to access and manage their online member benefits. You can read more about the Members section and learn how to access it on page 7. Over time you will see new content and features that take advantage of these new website capabilities.

*Tinnitus Today* has been given a new and refreshed look and style. Surveys were conducted to get a better understanding of what you as members wanted to hear about. Results drove us to modify our advertising guidelines in order to bring you more information about new and existing tinnitus products. We believe these changes to the magazine represent more of what you want from *Tinnitus Today*. Please continue to give us feedback so that we can continue to improve and make its contents even more interesting and useful to you. You can do so anytime by contacting the editor at editor@ata.org.

We have established new categories of membership for professionals and corporate sponsors to broaden our member base and have greater connection with the scientific and medical professionals who conduct research on tinnitus and who work with the patient community. We hope this closer interaction with these stakeholders will help us in our mission to help people take control of and manage their tinnitus, while the research community continues its pursuit of a cure.

As my term ends, I must say it has been an exciting and interesting period. We are now undertaking a comprehensive review of our mission and strategic plans. We welcome your input and suggestions into this process to be sure that your interests are best served by the organization as we move forward into the future. From where I sit, it is clear to me that the breakthroughs in medicine and understanding of hearing, neural pathways, molecular sciences and chemistry will lead to much progress in the near future. With your help and support you will continue to enable ATA to contribute to that progress.

In closing, I would like to reissue my Call to Action. You are invited to become more active members in ATA and volunteer for tinnitus-related activities in your community. Inform people in your area about tinnitus and the importance of protecting their hearing and their children’s hearing. Tell people about ATA and how their donations can be a catalyst to the day tinnitus is no longer a significant medical issue. Advocate for tinnitus in Washington, D.C., to help accelerate the understanding and treatment of tinnitus. Finally, tell us how we are doing and how we can be a better organization to better serve your needs. Thank you for allowing me to lead you these past two years – I look forward to volunteering with you all to help create a quieter future.

I would like to reissue my Call to Action. You are invited to become more active members in ATA and volunteer for tinnitus-related activities in your community.
Dental Work and Tinnitus

I read an article from 2013 about dental work and tinnitus. It discussed the theory of metal caps on teeth and electrical sensation. I've had bad hearing all my life, since I have scared ear drums from viral pneumonia. In regards to my mouth, I have a metal bridge on my lower right side. On my upper left side three of my molars all had root canals done over time. I also have a four piece bridge covering several teeth in the bottom lower front of my mouth. Soon after this was done, I could feel a sensation slowly growing in my head over a three month period. Then, all of a sudden I woke up one morning with a buzzing sensation in my head mostly on my left side. After about a year the gum around one of the teeth at the end of the bridge became very sensitive to touch. The dentist could not determine a cause since everything looked good on the x-rays and other tests. Finally, a dental surgeon said that the tooth in question needed to be removed and the bridge was partially cut off (part remains on two of the teeth). Once this was done the gum around the original problem tooth calmed down and I had an implant placed. In regards to the tinnitus — when I bite down I can increase the noise in my left ear. The left side of my face hurts and it radiates into my upper left teeth only. I have also had moments when all of a sudden my tinnitus stops for a second as if someone had flicked off a switch. What's going on here?

Anthony Facchini

Thank you Anthony for your question and for sharing your tinnitus experience. Tinnitus related to dental work or that can be modulated by jaw movement (or other facial movement) is more common than you might think. In the Summer 2013 issue of Tinnitus Today, Susan Shore, Ph.D., and her team at the Kresge Hearing Research Institute at the University of Michigan, addressed this from their expert scientific perspective. In that article, the team explains “Tinnitus is usually associated with hearing loss but can also be associated with damage to the ‘touch’ or somatosensory system, such as temporo-mandibular joint (TMJ) disorder, dental work or injury to the head or neck. Interestingly, about two thirds of the individuals with tinnitus are able to modulate the loudness (or pitch) of their tinnitus by manipulations of the jaw or by applying pressure on certain neck and head regions. This phenomenon is clinically known as somatic tinnitus.”

I hope that this helps to answer your question about your tinnitus.

Jennifer Born, Editor

To share your own story or comment, write to editor@ata.org or Tinnitus Today Editor, ATA, P.O. Box 5, Portland, OR 97207.
Working Together to Make a Difference

Melanie West, Chair, ATA Board of Directors

On behalf of the Board and members of ATA, I’d like to thank Tom Lobl, for his dedication and tireless efforts during these past two years. ATA did make changes; positive changes.

As the new Chair, I’d like to personally represent you, the member. I too have tinnitus and understand from the inside out how you might feel. Professionally, I work with tinnitus, hyperacusis and misophonia patients at a clinic in Phoenix, AZ. Each day I listen to the challenges patients face. Based on this profound understanding and compassion, I serve you, the member. Now let’s talk about what we can accomplish together.

With the operational improvements ATA has made, we are poised to advance to a new level. The ATA Board of Directors and staff have poured over your responses to surveys. Responsibly, your directives, needs and desires will be reflected in an updated mission statement. From the top down ATA is researching, reevaluating, and refining the organization to provide tangible benefits, applicable solutions and grant funds for resolution of tinnitus.

As trusted stewards of the donations given to ATA, the Board is examining every expense to maximize the utilization of funds toward ATA’s mission. New avenues of income have been initiated and at the same time, expenses reduced.

Currently, ATA is investigating the feasibility of holding webinars. Once implemented, ATA will provide updates on treatment options as well as detailed scientific research information. Technology may allow ATA to synergistically bring the researcher and the member together allowing you to ask your questions and have them answered.

Technology will not only allow us to communicate with one another, but it will catapult tinnitus research and information into the public eye. As a brand new member benefit, you can participate in the webinar for free. Non-members will be invited to join in, but for a fee. You will not want to miss this new medium of communication. As a member, you will receive an email reminder or can check the new ATA website for details.

The new ATA.org is configured for ease of navigation. It can lead you directly to the closest tinnitus health professional in your geographic area. These skilled professionals are available at the touch of a button, as are interesting articles, research and helpful tinnitus tips.

On the horizon is collaboration with like-minded organizations that share interests with ATA. There is power in numbers. Working together with other tinnitus and hearing-related organizations only makes sense. The preponderance of associations uniting as a coalition can strike at core issues affecting the tinnitus community.

ATA concurrently has developed a means for you, the member, to become involved with ATA. Does ATA want you to donate? Yes, of course. But non-profit organizations thrive on volunteer hours. Volunteers are an integral part of the success of most non-profit organizations. Work and learn beside other individuals who have tinnitus and share in the mission to mitigate this condition.

So, how do you volunteer? ATA is seeking individuals to serve on committees and subcommittees of the Board of Directors. If you have experience in business, non-profits, research, revenue development, finance, advocacy or marketing you may qualify to be appointed to an ATA Board committee or subcommittee. We need your involvement.

ATA is the premier organization that gives its members a stake in curing tinnitus. We exemplify what it means to advocate for tinnitus patients and educate the public at-large about the condition while also supporting individuals who have it. The American Academy of Otolaryngology-Head and Neck Surgery (AAO-HNS) has published that ATA is “the leading patient membership and advocacy organization.” Tinnitus needs ATA and ATA needs and appreciates your support. Collectively, we can make a difference.

If you are interested in volunteering your time or talents email us at volunteer@ata.org.
A Fresh New Look for ATA.org

The first time you log in as a member you will have to create a NEW user account. Your member number is the same as its always been but new passwords must be established.

If you have trouble logging in or need assistance we can help you. Contact us anytime at tinnitus@ata.org or by calling us at (800) 634-8978.

Create your new member account in 5 quick steps

2. Click on “Member Login” at the very top of the screen.
3. Click the tab at the top of the form that says “Create New Account.”
4. Follow the onscreen prompts to enter your member number, email address, last name, and create and confirm your new password.
5. Click the “create new account” button at the bottom to submit your information and voila! Your new member account will be created.

NEW WEBSITE = NEW ACCOUNT

Because we have a brand new website you are REQUIRED to create a brand new account. Even though you had a pre-existing account on our old website, you still must create a brand new one. Your member number is still the same and will appear on the address label of your printed Tinnitus Today. You can also always call or email ATA to find out your member number if you have misplaced it.
Taking Control of Tinnitus: Never Give Up Hope!

Melissa Dupree

December 18, 2009 ended up being one of the darkest days of my life.

I had been very sick with a cold for about a week and kept hearing a buzzing sound in my left ear off and on. Later that evening I got up to blow my nose and then returned to the sofa, sat down - and then it happened. A loud hissing sound in my left ear. I thought for sure it would subside, but it continued and didn’t stop!

When this hissing sound started, I knew immediately what it was. My sister-in-law had a terrible battle with tinnitus and hyperacusis and told me how she had suffered over the years. So as soon as I realized I had the same battle in front of me, I was filled with fear! Many panicked questions raced through my mind. How could this have happened? How could this sound have invaded my body? And perhaps most importantly - how do I rid myself of it? Tinnitus brought out every insecurity that I never knew I had and made the ones I recognized even worse.

After several days of crying and no sleep I decided that no matter what it took, I was going to find a solution to this nightmare. I knew it was going to take every bit of inner strength and more to proceed on this path and find some answers, any answers. I knew I must succeed in this investigation, which, in the end ultimately saved my sanity and my life.

Initially, I made an appointment with an Otolaryngologist (ENT) and as many of you have probably experienced, that was useless. He told me there was nothing I could do for my tinnitus, and that I would have to “learn to live with it.” I now know that there are some ENTs who are knowledgeable about tinnitus and others who are not. The individual I saw was the latter.

After that ENT appointment, I was beyond discouraged. As many people with tinnitus do, I turned to the internet for information. In addition to realizing that I was not alone in this fight, I read about others tinnitus experiences which empowered me even more to take charge of my own situation. The internet also proved to be useful in finding a doctor who could help me in managing my tinnitus.

In my online search I found that Michael Robb, M.D., an Oto-Neurologist who treated tinnitus was located in Phoenix where I live. I called his office and spoke with his personal assistant Melanie, who was so informative, understanding and whose gentle demeanor renewed hope for me that my tinnitus could and would be managed. I made an appointment to see Dr. Robb who proved to not only be one of the kindest individuals I’ve ever met, but one of the most knowledgeable about tinnitus too. He made me feel so safe and took the fear out of my tinnitus for me at a time when I really needed it. We had a thorough consultation and he suggested I try sound therapy to treat my tinnitus. The sound therapy that was suggested for me was a simple broadband sound given to me on disc that I was able to easily transfer to my iPod. During the treatment period I still had anxiety attacks and couldn’t sleep when my tinnitus flared up. I have what’s referred to as reactive tinnitus – the name

...I read about others tinnitus experiences which empowered me even more to take charge of my own situation.

Melissa and her husband Bob
says it all. The goal of my sound therapy program was to change my reactions to my tinnitus and hopefully bring the perceived volume down some.

I wore ear buds every day for eight months and despite my initial reaction to wearing them, they did not interfere in my life at all. The treatment worked – but let me be clear in telling you that I still hear my tinnitus every day. However, I am free from the anxiousness, fear and desperation that it made me feel. The sound therapy helped desensitize me to it. I have learned to live with my tinnitus but in a strategic and clinically-based way. Not just by someone telling me to “learn to live with it.” I think that the most important thing I can tell others who are thinking about sound therapy treatment is that it does not work overnight. It requires patience and time — something that is very difficult for those of us with tinnitus!

Especially those who are desperately seeking relief NOW. However if you are truly motivated to not let your tinnitus control you, then a little bit of time and patience goes a long way in taking control of tinnitus!

Today, in 2015, those dark days when I first got tinnitus are all behind me. Five years later I’m stronger than I’ve ever been and I couldn’t be happier. And even though I still hear my tinnitus, I am not bothered by it and continue to enjoy doing all the things I have always loved doing.

Dr. Robb, Melanie and my husband became my support system during that time. I thank god for all of them every day! And Melanie has become one of my dearest friends.

I also have to give myself some credit – tinnitus is definitely one of the biggest challenges I have ever faced. Getting tinnitus taught me to have patience and I never gave up hope that I could find a solution. I was motivated to take control of my tinnitus – and if there’s one thing you take away from my story – it is to not let your tinnitus control you – empower yourself to take control of your tinnitus!

Melissa and Melanie

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Editor’s note: ATA has tools to help you take control of your tinnitus on our website at ATA.org. We can help you get connected with a tinnitus health professional in your area, and we have our brand new Patient Roadmap that can assist you in navigating and choosing tinnitus treatment options with your tinnitus healthcare professional.
Over the last four years, Wisconsin native Joy Kennedy, 58, has suffered from constant ringing in her right ear. While she has some hearing loss in her left ear, the tinnitus in her right ear made hearing things difficult and enjoying peace and quiet impossible.

“It was a constant ringing, and it was getting pretty loud at night,” Kennedy said. “I thought if I could just hear above the ringing in my ears, it would be a whole lot better. I was also noticing that I was asking ‘What?’ a lot and that peoples’ voices sounded like they were mumbling even when they weren’t. Sounds were always muffled.”

Kennedy reached out to Advanced Ear, Nose & Throat Specialists in Milwaukee for help with her tinnitus in March 2015. Ellyn Szewczyk, Au.D., explained that Kennedy suffers from bilateral moderate to moderate-severe high-frequency sensorineural hearing loss in both ears and constant tinnitus in her right ear. “The tinnitus makes it difficult for her to enjoy peace and quiet,” Szewczyk said. “She has difficulty hearing in background noise and found that she was increasing the volume on her TV a lot more recently.”

Szewczyk fit Kennedy with Starkey Hearing Technologies hearing aids with MultiFlex Tinnitus Technology to treat her hearing loss. The hearing aids are a good balance for Kennedy in terms of features, sound quality, noise reduction and overall lifestyle value. “For many,” Szewczyk said, “treating their hearing loss can also be helpful with their tinnitus, which was the case for Joy.”

Over the last four months, Kennedy said her hearing aids have not only helped with her hearing loss but have also helped reduce the effects of her tinnitus. “I told my grandkids I had bionic ears,” Kennedy joked about her hearing aids.

“But in all seriousness, the hearing aids have really helped turn down the volume of my tinnitus. It used to be a constant ringing, and now it’s just a soft hum. I can hear everything now.”

For more information about Starkey Hearing Technologies tinnitus solutions and hearing aids visit Starkey.com.
Calling All ATA Members!

ATA wants YOU to volunteer. No matter if you’ve been a member for 20 years or if you are new to ATA, we want you to share your time and talents with us. We are seeking volunteers who are interested in serving on Board committees that will focus on both operational and programmatic functions of the organization.

Some of these areas include:

- Marketing and Public Relations
- Fundraising and Revenue Development
- Strategic Planning and Governance
- Research and Professional Outreach
- Advocacy and Community Outreach
- Support and Education

ATA is currently seeking ways to raise the organization’s visibility.

Maybe you have connections to a public relations firm and can help ATA with media coverage. Do you own a small business that can donate services to ATA in some capacity? Or maybe you can help to raise money to support ATA’s programs focused on advancing tinnitus research and can host a fundraiser in your community. Or maybe you have another idea on how to help ATA advance its mission by volunteering in some way.

If this sounds like you please contact us at volunteer@ata.org! We welcome your ideas and thoughts on how ATA can better serve YOU our dedicated members and supporters.
Celebrating 20 Years of the Denver Tinnitus Support Group

An Interview with Leader Rich Marr

Jennifer Born, Editor, Tinnitus Today

The American Tinnitus Association would not have the connection to tinnitus patients in their communities if it were not for our support groups and help network volunteers. Support groups in particular play a significant role in helping connect tinnitus patients with one another and provide a forum to discuss and learn about tinnitus with others who truly understand what it means to have and live with the condition.

All ATA support groups are volunteer led. Some of these groups have been around for decades and have helped hundreds of people with tinnitus who otherwise may have had nowhere else to turn.

One such group is the Denver, Colorado tinnitus support group. This group was started 20 years ago by longtime ATA member Rich Marr. I was fortunate enough to have the opportunity to chat with Rich about his experience leading the Denver group. We also discussed what motivated him to start the support group and what he’s learned about leading it over the past two decades.

Jennifer Born (JB): What made you first start the Denver tinnitus support group?

Rich Marr (RM): I first got tinnitus in 1988 – I was about 32 at the time. I’m a musician and I’m pretty sure I got it from listening to rock music, going to concerts and cranking up the volume on my stereo at home. At first it was very mild and after the first month or so I got accustomed to it. I usually didn’t notice it unless it was quiet late at night.

In 1995 my tinnitus permanently increased and I’m certain it was due to ototoxicity (from drugs I was prescribed to treat another ailment). I called the prescribing doctor and he couldn’t refer to me to anyone who could help. I went to three Otolaryngologists (ENTs) and they couldn’t help me either. I was even
told the dreaded “learn to live with it” by two of the ENTs I saw. Because of this, I was extremely depressed and couldn’t sleep. I was sleeping maybe two hours max per night. I was becoming desperate for some help – I knew I couldn’t be the only person in Denver with tinnitus!

I then found the ATA website and called to find out if there was a support group in the area. They told me that there used to be one but that it no longer existed. They gave me the contact information for my local help network volunteers and said that if I wanted to start a group that they could help me. Given my current situation, it didn’t take long for me to decide that I wanted to start a group.

**JB: Tell me about your first meeting.**

**RM:** Forty-seven people showed up to the first meeting and I heard 47 different stories of how tinnitus can start and how it can affect a person. One of the things that really made an impression on me as a result of the meeting was that I no longer felt alone. I didn’t realize just how isolated I had become. There were others who truly understood what I was going through.

**JB: How do you choose meeting topics?**

**RM:** Sometimes I will do my own research on the internet or through networking. Sometimes I will use the ATA website and *Tinnitus Today* as a way to talk about research that ATA funds. However my greatest resource is the membership of the group. I often ask them what they want to know more about and ask them for guest speaker suggestions.

**JB: What are the biggest changes in tinnitus research and treatment from your perspective in those 20 years?**

**RM:** Technology has significantly advanced the depth and pace of tinnitus research. With the development of imaging techniques and advances in neuroscience, we are light years beyond where we were in the 80’s. We are now exploring the brain, neural physiology, and getting a clearer understanding of how the nervous system processes information and how tinnitus plays a role in all of that.

Technology has also expanded the menu of treatment options for tinnitus patients. We now have several forms of sound therapy available in helping patients experience some degree of control over their tinnitus. That being said, the current technology goes only so far and we need to continue to push forward to identify new avenues to a cure.

A trend in treatment that I’m seeing is the use of mindfulness techniques to learn how to modify our response to tinnitus. What I’m referring to here is Mindfulness-Based Stress Reduction and the pioneering work of Jon Kabat-Zinn, Ph.D. His work teaches us that we may not be able to eliminate the sounds we hear, but we can change the way we respond to them. MBSR is pretty mainstream these days and classes are available through many healthcare providers. Meditation and yoga also figure in to this treatment mode. Cognitive Behavioral Therapy is extremely useful in coming to terms with tinnitus but I think it’s underutilized. The great thing about the mindfulness-based techniques is that they’re very effective in dealing with any stressor in your life, not just tinnitus. It takes some discipline, but these are tools and life skills that can enhance quality of life in the long term for tinnitus patients.

**JB: What value do you feel people find in a group that’s in a face-to-face setting versus an online forum for example?**

**RM:** I think a major factor that brings value to the face-to-face group setting is that it helps break down the sense of isolation and alienation you can feel having a condition like tinnitus. Tinnitus is an internal, experiential phenomenon, and it’s hard to articulate verbally what that experience is like to others. So here’s a place you
can go, in your own neighborhood, in your own town, where there are folks who understand what’s going on with you. There’s a sense of camaraderie.

That brings up another thing I’ve learned over the years. Once in a while someone will bring their spouse or another family member to a meeting. I wish that more people would do that – frequently I suggest that people should bring their family. I do this because tinnitus can interfere with your ability to communicate with other people. This issue comes up a lot in our group. For example, you may not know that someone has directed a comment towards you because tinnitus commands a certain amount of your attention. This can be especially hard in a family setting, because complications in communication can lead to misunderstandings and frustration.

Do what’s in your capability. It is easy to get burned out – finding guest speakers and preparing for meetings consumes a lot of my time. Alternating between having a guest speaker one month and then having an open forum the next helps me keep things balanced while satisfying the needs of the group. Some people come because they want to learn – others because they want to talk about their tinnitus.

If you are looking for a physical meeting space, try a hospital – often times they donate their space for free to a non-profit organization.

**JB:** What are the most important things you can tell “would be” support group leaders?

**RM:** Despite what you might think, you don’t have to spend any money to get a group going and keep it going. But you do have to spend time preparing for the meeting and answering phone calls or emails. If you feel overwhelmed, ask other group members to help you out. Use technology and social media to establish your presence, keep people informed, and to reach out to others who need you. We send out monthly meeting announcements via email and the ATA posts announcements on their website.

20 years ago. And that support continues today. The majority of the referrals we receive come from ATA’s website or Facebook page. ATA is the best source of information about tinnitus that we know of. We often discuss topics we’ve read about in *Tinnitus Today*. We encourage everyone to visit the website to learn more about how to manage tinnitus, treatment options available, the tremendous research that ATA funds, and the proactive advocacy ATA has engaged in over the years. The staff at ATA are very accessible and are always open to discuss any questions you may have about tinnitus or its treatment. It’s not an exaggeration to say that the ATA has been a godsend to the tinnitus community.

I think it’s important to create an environment that is supportive and feels safe for participants to share in. This can be difficult when someone who has just acquired tinnitus joins the group as they may be in distress. The Denver group excels when it comes to compassion, empathy, emotional support, and providing suggestions for what might help. Many of the folks that attend bring an uplifting sense of humor that can jettison me out of a funk.

As a facilitator you need to establish some ground rules for interaction. For example, reminding folks not to cross-talk when someone is speaking. Sometimes...
the discussion goes off-topic, and you need to assess if that's a productive turn or if you need to re-direct the group back to the original topic.

Part of what a facilitator does is monitor the group dynamics and keep things in balance. The ideal goal is that everyone has a chance to speak, receive feedback if they want it, and walk away feeling they've been heard and learned something.

JB: Is there anything else you’d like to add that we haven’t covered?

RM: Yes, I’d like to give some special recognition to several people who have been instrumental to the Denver tinnitus support group’s success and longevity.

Chuck Aune hasn't been coming to meetings but remains a help network volunteer. For years he helped me keep this group organized and served as our Communications Director. He sent out all notices of the meetings and created our membership database. He also set up meeting rooms in advance.

Donna Brown has worked with the group over the years. At one time she started a group in Broomfield, Colorado closer to where she lives, but eventually we combined the groups in north Denver. Donna has done so much over the years for ATA (like literally climb mountains!) and for the group – she’s our star!

LuAnn Kirsch came to the group and later worked with Donna Brown to get the Broomfield group going. She and Donna were responsible for putting out our newsletters. She also no longer attends meetings but is still a help network volunteer.

Claudia Reische, M.A., started a group in Boulder, Colorado and is a psychologist who specializes in tinnitus. She has supported our group and helped so many in the tinnitus community over the years.

If it weren’t for people like these individuals, we wouldn’t have made as much progress over the past 20 years. We certainly could not have helped so many people.

On behalf of the ATA Board of Directors, Scientific Advisory Committee and staff at the American Tinnitus Association, we thank you Rich for your dedication to the Denver tinnitus support group. It is volunteers like you who truly enable ATA to continue our tireless efforts to find new solutions to tinnitus and what we all hope for one day – a cure.

Rich Marr
The 9th International Tinnitus Research Initiative (TRI) tinnitus symposium took place in Ann Arbor, Michigan from June 7-10, 2015. This year’s meeting explored basic mechanisms underlying tinnitus including cochlear damage consequences, synaptic plasticity (the ability of neurons and synapses in the brain to strengthen or weaken over time), the involvement of non-auditory (limbic, attentional, somatosensory) networks in tinnitus generation and maintenance, and also included a number of diagnosis and treatment studies. Through 47 lectures and 62 poster presentations from researchers across the globe we learned about the latest and greatest in the field of tinnitus research. Many of these lectures and presentations were given by members of ATA’s Scientific Advisory Committee, past, present and hopefully future. I share with you in this article some highlights from the meeting that are bringing us closer to a tinnitus cure.

Several animal studies highlighted mechanisms that contribute to the possible onset of tinnitus. For example, we learned about different types of cochlear damage profiles and the brain’s responses associated with them. This included possible resulting hearing loss, tinnitus and hyperacusis. Another study reported that noise exposure and aging interrupt communications between inner ear hair cells and cochlear nerves which may contribute to hearing difficulties and to both tinnitus and hyperacusis. We also heard about a protein called Neurotrophin-3 or Ntf3 which restores the cochlear response and hair cell synapses following noise trauma. This suggests a target for treating noise-induced hearing loss and tinnitus.

There were many new findings shared about the brain structures involved in tinnitus generation and maintenance. We learned how tinnitus is likely mediated through neural interactions between cortical and subcortical brain centers. A report found that salicylate-induced tinnitus, hyperacusis and hearing loss are accompanied by hyperactivity in the cerebellum, reticular formation (the part of the brain that deals with overall consciousness) and amygdala, which plays a major role in the processing of emotions. There were discussions about how to disentangle tinnitus and hyperacusis that manifest differently since one affects auditory signaling in silence (tinnitus) and the other affects the response to sound (hyperacusis). Information was also presented that gene therapy and stem cells may be used to generate hair cells and their connectivity with the cochlear nucleus (the body’s main hearing center structure) to influence tinnitus.

There were also many provocative human studies discussed. Among these was a study that addressed why measurable hearing loss does not always lead to tinnitus, and why tinnitus associated with cochlear damage is not revealed by audiograms. Of particular interest to veterans and military personnel, we learned that blast-induced tinnitus is associated with neuropsychological deficits on cognitively demanding tasks.

Another emerging area of research is the development of objective diagnostic tools for tinnitus. One such tool that was presented is the gap prepulse inhibition of acoustic startle measures for tinnitus and hearing loss.

With regards to tinnitus management, somatosensory and brain stimulation, as well as pharmacological approaches were mostly discussed. For example, it has been found that combining auditory and somatosensory stimulation results in suppression or enhancement of auditory neurons. It was emphasized that identification of and tailored treatments for patients with head/neck/jaw related tinnitus are essential.
In brain stimulation studies using animal models, it was demonstrated that electrical stimulation of the main auditory pathway (inferior colliculus) suppressed tinnitus in rats. We learned that auditory, cortical and amygdala stimulation can suppress tinnitus in both auditory and non-auditory centers. Studies showed that repetitive transcranial magnetic stimulation (rTMS) reduced tinnitus-loudness, tinnitus awareness, and annoyance. The benefits of combined auditory and electrical stimulation was also discussed.

As far as drug therapies, a study that used a combination of sarcosine (a glycine reuptake inhibitor) and a combination of Piribedil (to reduce noise-induced nerve damage), Memantine, and Vitamins A, C and E, plus magnesium (an anti-oxidant mixture), found that these drugs protected hair cell-auditory nerve connections and suppressed tinnitus. It was discussed that cannabinoids, the chemical compounds released by marijuana, may promote tinnitus development instead of providing therapy. The progress of clinical trials on AM-101 (a glutamatergic compound) were also presented.

Results of studies on sound therapy using acoustic coordinated reset neuromodulation, and a modified Neuromonics device were discussed. Preliminary results from a clinical trial on vagal nerve stimulation paired with auditory tones showed that some patients showed some benefit using this method. A study that looked at combined audio, visual and somatosensory stimulation reduced unilateral tinnitus in patients. Interestingly, it was demonstrated that a significant reduction in tinnitus handicap is found, as well as depression and anxiety following an eight week mindfulness-based tinnitus stress reduction program.

Towards the end of the conference, Jos Eggermont, Ph.D., shared his thoughts on how to better investigate tinnitus by suggesting that tinnitus should be regarded as an “auditory object”. He encouraged focusing on neural population behaviors as well as the linkage between awake animal models and human findings.

In summary, renowned scientists and clinicians, post-docs, students, as well as other attendees, enjoyed a lively and thought-provoking conference. As demonstrated by the scientific and clinical evidence, tinnitus research, diagnosis and treatments are constantly evolving and pushing the boundaries of what is currently known about the condition. Having attended many of these conferences and being a longtime tinnitus investigator, I can tell you confidently that all of the studies presented at the 9th International Tinnitus Research Initiative symposium are helping us in the scientific community better understand tinnitus and are paving the way for new solutions and ultimately a cure.

Tinnitus research and treatment is advancing rapidly thanks to the dedication of researchers around the world. This article shares a snapshot of the intricate work being done each and every day to alleviate this condition we call tinnitus. Due to space limitations, we could not include the names of these brilliant scientists who deserve the credit in making these important advances in the understanding and treatment of tinnitus. If you are interested in learning more about any of the studies that were presented at the 9th International Tinnitus Research Initiative conference, and the investigative teams who are responsible for these findings, you can visit ATA’s website to view the conference program and abstract book in PDF format.

To view the conference program visit: ATA.org/sites/default/files/Tinnitus_2015_Program.pdf

To view the abstract book visit: ATA.org/sites/default/files/TRI_2015_Abstract_Book.pdf

1See Tinnitus Today Winter 2014 “Clinical Trial to Validate Drug Treatment for Acute Inner Ear Tinnitus.”
I have started to experience severe tinnitus following cervical spine surgery. I asked my surgeon about it and he said he has never heard of that in other patients. It is constant and very disturbing. Have you heard of tinnitus caused by this type of neck surgery?

By anecdotal report, tinnitus can occur following surgical procedures and may be related to general anesthesia. This typically resolves within a few days. Musculoskeletal problems in the head and neck, in particular TMJ dysfunction and cervical spine issues, have been associated with tinnitus, so it is possible that the tinnitus onset is related to spinal manipulation. Generally, the brain subconsciously enhances the tinnitus signal when onset is associated with pain, discomfort, and/or anxiety, caused by or associated with surgical procedures. This may then result in tinnitus that is perceived as constant and disturbing. There is a good possibility that the tinnitus will resolve over the next few weeks to months as you heal from the surgery. It is sometimes possible to make the tinnitus less prominent by using sound such as a tabletop water fountain, sound spa, or music played at a low volume. If your tinnitus persists at a disturbing level, consult with a qualified medical professional.

I have diverticulitis and have been prescribed Metronidazole and Levofloxacin, both which are on the list of drugs associated with tinnitus. Is there an equally informative list of alternatives for these medications?

There are hundreds of medications that list tinnitus as a side effect. During drug trials, all side effects must be reported, so in many cases, the medication may be associated with tinnitus in a very small percentage of people. However, not everyone will experience the side effects listed for a given medication. According to the Physician’s Desk Reference (PDR interaction guide), which lists all currently available medications and associated side effects/adverse reactions, neither Metronidazole nor Levofloxacin have tinnitus listed as a side effect. You might consider taking the medication, and if your tinnitus changes, discuss alternate medications with your physician.
Q My tinnitus and hyperacusis are becoming very unnerving and affecting my sleep. I am considering cutting my auditory nerve. Will my tinnitus and hyperacusis go away if I proceed with this?

A There is a common misconception that tinnitus results from the ear sending an abnormal signal that the brain perceives as sound and therefore, if the nerve between the ear and the brain is severed, the signal will no longer be transmitted and tinnitus will be eliminated. Although the exact mechanisms of tinnitus are not yet fully understood, it has been shown that cutting the nerve does not eliminate tinnitus permanently. About half of the patients who have pursued this option ended up with tinnitus that was worse. Other patients experienced relief for a while, but the tinnitus returned. You have many more options for getting relief from your tinnitus and improvement in your sound tolerance if your auditory nerve is intact. These options include, but are not limited to: Tinnitus Retraining Therapy, Progressive Tinnitus Management, Tinnitus Activities Treatment, and Neuromonics Tinnitus Treatment. All of these treatment options incorporate sound therapy to help reduce the intrusiveness of tinnitus and improve your tolerance for sound. You might also benefit from Cognitive Behavioral Therapy or mindfulness meditation.

Q What effect, if any, does altitude have on tinnitus? I live at 7,000 ft. and I am curious if that has any impact on the severity of my tinnitus which never lets up.

A The ear is sensitive to changes in pressure. Sudden changes in atmospheric pressure may produce tinnitus; however, there are no known studies systematically evaluating the effect of living at high altitudes on tinnitus. It is unlikely that living at a certain altitude affects the severity, because tinnitus severity is related to the subjective reaction to tinnitus rather than the presence of tinnitus itself. Therapies that promote habituation can be very effective at reducing the perceived severity of tinnitus. Habituation is defined as a decline in a conditioned response (perception of constant severe tinnitus) to a bothersome stimulus (the tinnitus signal).
Scientists around the world are studying tinnitus, to better understand the condition, and to find new treatments and cures. Below is a summary of just some of the research that has been published over the last few months.

Full abstracts for all research papers are available at PubMed.gov, an online service of the U.S. National Library of Medicine, National Institutes of Health.

**Research Review**

**Understanding Tinnitus**

**Tinnitus Neural Mechanisms and Structural Changes in the Brain: The Contribution of Neuroimaging Research**

*International Archives of Otorhinolaryngology* (July 2015)

P. Simonetti, J.Oiticica

Chronic tinnitus impacts many aspects of patients' lives, including emotional stress, sleep disturbance, and concentration difficulties. These reactions are attributed to the body’s central nervous system involvement. Neuroimaging has revealed the implication of brain structures in the auditory system relative to tinnitus. This study reviewed literature that identifies the brain structures involved in the generation and persistence of various forms of tinnitus. Functional imaging research has revealed that tinnitus perception involves both auditory and nonauditory brain areas, including the front parietal area which processes our senses; and the limbic system, hippocampal and parahippocampal areas, which handle cognition and emotions. The review confirmed that the involvement of these parts of the brain are related to the persistence of perception, anxiety, distress, and suffering associated with tinnitus.

**The Impact of Tinnitus on Cognitive Performance in Normal-Hearing Individuals**

*International Journal of Audiology* (June 2015)

S. Waechter, KJ Brännström

The aim of this study was to investigate whether the previously reported differences in cognitive performance between individuals with and without tinnitus is present in normal-hearing individuals. Forty individuals participated in this study. Twenty had tinnitus and 20 did not. The groups were age- and sex-matched and all participants had normal hearing thresholds.

No difference in terms of cognitive performances were found between individuals with tinnitus compared to individuals without tinnitus. This conclusion is in counter to studies of hearing-impaired subjects with tinnitus where signs of cognitive interference were present suggesting that the hearing loss is responsible for this and not the tinnitus itself.

**Quality of Life in Vestibular Schwannoma Patients Managed by Surgical or Conservative Approaches**

*Otology & Neurotology* (June 2015)

N. Jufas N, S. Flanagan, N. Biggs, P. Chang, P. Fagan

This study assessed quality of life (QOL) among patients who underwent surgery of a vestibular schwannoma (VS), a benign tumor that grows on the hearing nerve, compared with those managed conservatively (no removal). The surgically managed group had a worse QOL when compared with the conservatively managed group. The worse QOL

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**HOW TO READ THESE RESEARCH SUMMARIES:**

**Article Title**

**Journal Publication** (Date of Publication)

Author(s)

Summary

**Remember:** Every research study is a small snapshot of information, based on specific study groups and methodologies. No single study is “definitive” and research must always be evaluated collectively.
scores were more significant in the areas of physical role limitation and social functioning. Handicap due to disequilibrium seems to have the greatest negative impact on QOL. The study helps point to factors that should be considered when a management strategy is being developed for VS patients.

Tinnitus and Related Conditions

Seasonal Affective Disorder in Patients with Chronic Tinnitus
*Laryngoscope* (July 2015)
YH Kim

This study investigated the prevalence of Seasonal Affective Disorder (SAD) in patients with chronic tinnitus. The investigators used widely accepted clinical tinnitus assessment tools including the Tinnitus Handicap Inventory (THI), Visual Analog Scales (VAS) and audiograms to assess both tinnitus prevalence and disturbance to the individual. The researchers found significant correlations between the SAD assessment and THI scores. The study concluded that SAD in chronic tinnitus patients was correlated with THI, anxiety, and depression and suggests that understanding SAD in tinnitus patients is important to managing these patients effectively.

Audiometric Characteristics of Hyperacusis Patients
*Frontiers in Neurology* (May 2015)
J. Sheldrake, PU Diehl, R. Schaette

Hyperacusis is an auditory disorder where sounds of normal volume are perceived as too loud or even painfully loud. There is a high degree of co-morbidity between hyperacusis and tinnitus, most hyperacusis patients also have tinnitus, but only about 30-40 percent of tinnitus patients also show symptoms of hyperacusis. In order to clarify the mechanisms of hyperacusis, detailed measurements of loudness discomfort levels (LDLs) across the hearing range would be desirable, however previous studies have only reported LDLs for a restricted frequency range. This study measured audiograms and LDLs in 381 patients with a primary complaint of hyperacusis for the full standard audiometric frequency range. On average, patients had mild high-frequency hearing loss, but more than a third of the tested ears had normal hearing thresholds (HTs). LDLs were found to be significantly decreased compared to a normal-hearing reference group. There was a moderate positive correlation between HTs and LDLs and LDLs tended to be higher at frequencies where hearing loss was present. This suggests that hyperacusis is unlikely to be caused by HT increase whereas with tinnitus, hearing loss is a main trigger. The finding that LDLs are decreased across the full range of audiometric frequencies, regardless of the pattern or degree of hearing loss, indicates that hyperacusis might be due to a generalized increase in auditory gain. Tinnitus on the other hand is thought to be caused by neuroplastic changes in a restricted frequency range, suggesting that tinnitus and hyperacusis might not share a common mechanism.

Risk Factors for Tinnitus

Tinnitus and its Relationship with Muscle Tenderness in Patients with Headache and Facial Pain
*Journal of Laryngology and Otolgy* (June 2015)
M. Pezzoli M, A. Ugolini, E. Rota E, L. Ferrero, C. Milani, L. Pezzoli, G. Pecorari, F. Mongini

This study examined tinnitus prevalence in patients with different types of headache and the relationship between tinnitus and pericranial muscle (which include the neck, chewing, facial, and inner ear muscles) tenderness and cervical muscle tenderness scores. The analysis showed that in a population of patients with headache and craniofacial pain, tinnitus was related to increased cervical muscle tenderness and pericranial muscle tenderness scores, rather than to any particular form of headache.

Tinnitus Reported by Children Aged 7 and 12 Years
*International Journal of Pediatric Otorhinolaryngology* (August 2015)
Piotrowska A, Raj-Koziak D, Loren A, Skarżyński H

Tinnitus is often thought of as a problem that older people face. This study assessed the prevalence of tinnitus as reported by 7 and 12 year old children from primary schools in Warsaw, Poland. They also tested the relationship between hearing loss and tinnitus prevalence in this group. Overall, six percent of the 7- and 12-year-old students reported tinnitus lasting for five minutes or more. The prevalence of tinnitus was significantly related to hearing loss and age. The frequency of tinnitus was equal between sexes and also between the children with unilateral and bilateral hearing loss. The results suggest that hearing loss and young age can be considered potential risk factors for tinnitus in school-age children.
Each year, the ATA Board of Directors is given the tough task of deciding which grants, recommended to them by our Scientific Advisory Committee (SAC), will be funded. Our SAC reviews each grant application that ATA receives through a rigorous peer-review process and then, together as a group discusses each grant’s merits and opportunity to advance the science. The grants are each given a score and only the highest ranked proposals are forwarded to the ATA Board of Directors for funding consideration.

One of the most important criteria that each grant is considered against is ATA’s Roadmap to a Cure – a document created by SAC that outlines four paths of research that are designed to help lead to new treatments and ultimately, as its name suggests, a cure.

ATA’s Roadmap to a Cure

Scientific progress doesn’t work on a set timeline, but it generally does follow a certain cumulative progression. ATA’s Roadmap to a Cure is a framework for understanding the incremental research process that will lead us to a definitive cure for tinnitus. The Roadmap identifies general investigatory paths and highlights specific research questions and objectives within each pathway.

### Roadmap Paths

**Path A**  
**Identification of Tinnitus Generator(s):** Determine sites in the ear or brain where tinnitus-producing signals arise.

**Path B**  
**Elucidation of Mechanisms of Tinnitus Generation:** Determine the nature of abnormal signals and their underlying cellular and molecular causes.

**Path C**  
**Development of Therapy:** Assess the potential of intervention, manipulation, or treatment as a means of suppressing tinnitus.

**Path D**  
**Optimization of Therapy:** Define parameters of treatment that optimize suppression of tinnitus and minimize side effects.

### Roadmap Path Details

- **A1.** Identify areas in the auditory system exhibiting tinnitus-related abnormality.
- **A2a.** Measure the changes in activity identified in A1.
- **A2b.** Use or develop scientific metrics to assess tinnitus percepts in human or animal subjects with abnormalities identified in A1.
- **A3.** Demonstrate that measures of tinnitus established in A2b are causally related to the abnormalities measured in A2a.
- **B1.** Identify neural or cellular populations giving rise to tinnitus-generating signals.
- **B2.** Determine the altered cellular processes in the cell populations defined in B1.
- **B3.** Define the cellular triggers that induce the alterations identified in B2.
- **C1.** Test therapeutic approaches to suppress tinnitus (electric/magnetic stimulation, drugs, surgery, acoustic stimulation).
- **C2.** Use these approaches to target tinnitus generation sites defined in Path A.
- **C3A.** Determine magnitude of therapeutic benefit of tinnitus treatment.
- **C3B.** Assess side effects or risks associated with treatment.
- **D1.** Refine therapeutic approaches to target specific tinnitus generators identified in Path B.
- **D2.** Improve mode(s) of treatment delivery to reduce any side effects identified in Path C.
- **D3A.** Establish dose/response relationships to maximize benefit and minimize side effects of treatment.
- **D4.** Customize treatment to individual.
Role of the Cholinergic System in the Modulation of Tinnitus
James Kaltenbach, Ph.D., Cleveland Clinic, Cleveland OH

Roadmap Path C, Second Year of Funding

In the Summer 2014 issue of Tinnitus Today, we told you about the exciting first year of a study proposed by Dr. Kaltenbach. His aim in year one was to reduce or eliminate tinnitus attributed to hyperactivity of the brain’s auditory neurons (special cells that process sound information through chemical signals). When a person is exposed to a loud sound or other tinnitus-inducing trauma, the brain circuits get altered and neurons start firing excessively, resulting in tinnitus. In this model, tinnitus could potentially be eliminated by reducing or compensating for the hyperactivity of these neurons.

Dr. Kaltenbach had previously been investigating the role of the brain’s cholinergic system as a potential modulator of tinnitus-producing hyperactivity. His research team has been testing drugs that activate cholinergic receptors to determine their potential for reducing the hyperactivity underlying tinnitus. His previous work had shown that activation of cholinergic receptors abolishes tinnitus producing signals, but the finding was only a first step, since the compound tested had a number of major side effects.

In year one of this ATA funded project, Dr. Kaltenbach tested a drug that activates cholinergic receptors but has fewer side effects. The compound tested was found to have a significant suppressive effect on hyperactivity. The second year of funding will enable Dr. Kaltenbach and his team to continue to test this and other types of compounds for a suppressive effect on hyperactivity. In addition, his laboratory is performing studies to identify the specific types of cholinergic receptors that are present in the tinnitus generating circuit. The end goal of these studies is to determine a potential target for pharmacological intervention (drug therapy) for tinnitus.

Development and Validation of the Sound-Sensitive Tinnitus Index Scale
Benjamin Scott Greenberg (student pictured)
Bong Walsh, Ph.D., American School of Professional Psychology, Argosy University, Alameda, CA

Roadmap Path B

Although there is frequent co-occurrence of subjective tinnitus and increased sound sensitivity (hyperacusis), no studies have clarified the subjective experience of people whose tinnitus is exacerbated by sensitivity to sound. While much of the scientific literature regarding hyperacusis reports interventions that show positive response to environmental sound stimuli, little acknowledgement is given to the negative effects it can have on subjective tinnitus. This represents a gap in the understanding of how tinnitus and hyperacusis interact. While some scales have been developed to measure sound sensitivity in relationship to tinnitus, existing measures approach the hyperacusic component separate from tinnitus. The objective of this study is to develop a scale that measures the subjective negative impact of exposure to loud sounds in tinnitus patients. Mr. Greenberg will conduct his research through a series of online surveys designed to examine if the respondents’ tinnitus is susceptible to sound sensitivity. He will then compare these responses against validated scales and questionnaires for tinnitus and depression and anxiety to measure the occurrence and impact of sound-sensitivity on tinnitus.

More on next page >
Neural Bases of Transcranial Magnetic Stimulation in the Treatment of Tinnitus

Andrea Shawn Lowe (student)
Joseph P. Walton, Ph.D., University of South Florida

Roadmap Paths A, B, D

This project aims to determine the effects of Transcranial Magnetic Stimulation (TMS) on central auditory brain structures involved in the generation tinnitus perception. There is an insufficient amount of data on the molecular and neural basis of TMS in the treatment of tinnitus in the central auditory system. TMS is thought to be therapeutic because the magnetic flux generated from the electromagnetic coil induces an electric field in the brain, altering ion flow, and subsequently neural function, as the excitation and inhibition of cortical networks have been synchronized to the magnetic pulse. TMS is currently approved for the treatment of depression, and has been shown to decrease tinnitus perception in human subjects, although with variable results. Ms. Lowe plans to determine the part of the brain system that is most responsive to repetitive Transcranial Magnetic Stimulation (rTMS) in tinnitus and to optimize its success as a treatment by systematically varying the electromagnetic field intensity, pulse frequency, session duration, and applied location of the coil.
How to Support the Cause

ATA is the nation’s largest nonprofit organization dedicated entirely to helping patients access the best tinnitus management tools, funding research for a definitive tinnitus solution, and offering hope for people living with tinnitus every day.

*Will you help us achieve our goals?* Please consider making a gift to ATA in support of our mission. Your tax-deductible contribution advances ATA’s research, education, and patient support programs now and into the future.

*There are many ways to make a difference:*

**Donate using the return envelope in this magazine**
A gift of any amount helps us silence tinnitus! ATA will send a receipt and thank you as soon as we receive your contribution.

**Gifts of Stock**
It has been another great year for the stock market, and you can share the benefits of your good investments. Gifts of stock can be an effective way of advancing ATA’s mission. Contact us for more information on how you can support our work through this type of gift.

**Workplace Matching Gifts**
As a registered 501(c)(3) nonprofit organization, ATA can be designated for workplace matching gift campaigns, through both the United Way and the Combined Federal Campaign (CFC #11030).

**Bequests**
You can create a lasting legacy of care by including a gift to ATA in your will or estate plans. Become a member of the Jack Vernon Society—named in honor of one of ATA’s co-founders—by making a legacy gift. Check out ATA.org, or contact us directly for more information.

For questions and more information, please contact Paul Morris, ATA’s Development Director, at paul@ata.org or at 503-248-9985 x219.
Will we ever find a cure for tinnitus? Good question. To make the question more useful, let’s reframe it: What will it take to find a cure for tinnitus?

We know the answer to that question is not to be found in the over-the-counter shelves of your corner drugstore, pitching this year’s version of tinnitus snake oil.

Advocating With a Purpose: How ATA Put Your Tax Dollars to Work

Scott Mitchell, J.D., Vice Chair, ATA Board of Directors

What it will take to cure tinnitus is the accumulation of biomedical research that answers some fundamental questions: What starts tinnitus? What parts of the brain are involved? What can be done to suppress or eliminate the sounds of tinnitus and the negative reactions that often accompany it? What can be done to improve the quality of life of a tinnitus patient in the meantime?

Researchers are answering those questions one at a time. Jack A. Vernon, Ph.D., one of the founders of ATA, used to point out that when he first got into the field, the number of full-time tinnitus researchers could be counted on the fingers of one hand. Now there are hundreds, all poised to find a cure, from many different scientific approaches.

But having a cadre of smart, dedicated scientists is not enough to find a cure — you also have to fund a cure. Research takes money, and lots of it.

Because of this, in 2007, ATA approached the U.S. Department of Defense (DoD). Through its advocacy program, ATA investigated every possible source of government funding for tinnitus research. The National Institutes of Health (NIH), which has always been the go-to for basic science research, had seen its budget constricted by competing healthcare research claims and other Congressional priorities. But the ATA advocacy effort discovered a medical research initiative that had been set aside strictly for military-related health research, by design. It is called the Congressionally Directed Medical Research Programs, which in turn fund the Peer Reviewed Medical Research Program (PRMRP). The PRMRP was typically funded by a Congressional appropriation each year at $50 million — hardly a windfall in Washington, D.C., terms, but enough to get the attention of a small healthcare-related nonprofit like ATA. There was only one problem: to be eligible as a research target for these funds, your condition had to be on the list of medical conditions related to military health and readiness.

Tinnitus was not on the list.

So ATA dug into the databases of federal agencies, and put together a graph showing that the Department of Veterans Affairs (VA) was paying out hundreds of millions of dollars each year in disability payments for tinnitus to veterans, while only a fraction of that was being spent on tinnitus research by any government agency. And the cost of those disability payments was growing by an average of 15% annually beginning in 2001, primarily due to the conflicts in Iraq and Afghanistan. By 2009, tinnitus was ranked as the number-one service connected disability for veterans from all periods of service. That accumulated data gave ATA a rationale to promote the need for increased tinnitus research. What we would learn from military research could be applied to tinnitus in the public at large.

ATA began its focused advocacy work in 2007, educating Capitol Hill and federal agencies about this condition called tinnitus, which was not only

Your donations gave ATA the resources to support a serious, targeted advocacy program, far beyond a “write a letter to Congress” campaign.
costing the VA well over half a billion a year in disability payments by then, but was also very distressing to veterans who came back from war with their ears ringing like mad. And most importantly we advocated, this condition that had clear connections in many cases to military service, was not even on the list for qualified research conditions to be funded by PRMRP, the program aimed specifically at military medical conditions.

A year later, in 2008, tinnitus was put on the list. Since then, funding allocated to tinnitus research at the federal level, including DoD, VA and NIH has risen from around $1 million annually to over $13 million. How did ATA make that happen? Deborah Outlaw, an attorney whose government relations firm represented ATA in the effort said, “Our success during that time was based on concentrated efforts in three main areas: 1) targeting key Members of Congress who served on committees of jurisdiction that could advance tinnitus policies and educating them, on a one-by-one basis, about tinnitus; 2) meeting with agency officials at DoD, NIH, and the VA to convince them to ramp up their own efforts toward improving research to prevent tinnitus, as well as provide treatment for tinnitus sufferers, and 3) working with like-minded organizations and developing solid relationships with health care groups where we were able to work together toward a common goal.”

Once ATA successfully got tinnitus on the list of conditions for the PRMRP, researchers began submitting their proposals. ATA was also asked to nominate what the program refers to as Consumer Reviewers, who evaluate the research proposals from their perspective as patient advocates. ATA was able to nominate some of its board members as consumer reviewers who subsequently were chosen to serve, so the tinnitus community literally had a seat at the table in the grant selection process.

What follows next is a very carefully choreographed evaluation of the proposals, designed to analyze, test and challenge them, in order to allocate the limited funds available to the best possible research. Reviewers of these proposals are provided a very detailed explanation of the researcher’s hypothesis, the specific aims, a study design, and the impact the results are expected to have. The reviewer is then asked to grade each proposal and those grades are then shared with the full panel. The whole panel of reviewers then debates the strengths and weaknesses of the proposal, regrades it and a summary is written from the consensus of the discussion. And this is just the first step in a series of evaluations, through a process of sifting through the multitude of research ideas.

Much is done to protect the security of these proposals, with the names of the submitting researchers redacted and secrecy oaths obtained from the reviewers. This is the cutting edge of science, and it is thrilling to watch the process unfold. The system is designed to filter out bias, unstated assumptions, and flawed methodology through the fire of intense scrutiny. What research that remains gives us the best likelihood of leveraging that funding to find a cure that will help not only military personnel, but the rest of the population now coping with tinnitus.

So this is how it came together: Your donations gave ATA the resources to support a serious, targeted advocacy program, far beyond a “write a letter to Congress” campaign. That advocacy effort was able to leverage those resources toward government-funded research into an amount that was many times the cost of advocacy. The knowledge gained by this surge in research, in a relatively short time, has propelled science forward in several new directions. This is exactly how ATA put your tax dollars to work to fulfill its charge of finding a tinnitus cure!

Visit CDMRP.army.mil to learn more about the Peer Reviewed Medical Research Program and the tinnitus grants that have been funded since 2008. If you are interested in being an ATA advocate please email us at volunteer@ata.org.
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For more information on how to include ATA in your estate plans, contact Paul Morris, ATA’s Development Director, at 503-248-9985 x219.
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