ATA Tinnitus Advocacy in 2018
Charting a New Pathway to Advance Tinnitus Research, Prevention, and Treatment

By Deborah Outlaw

The American Tinnitus Association (ATA) first began a concerted effort in 2007 to raise tinnitus awareness among policymakers in Washington, D.C. What we found in those early years of advocacy outreach was staggering. Despite being the number one service-connected disability for Veterans, with hearing loss being second, federal research dollars devoted to tinnitus was low. Most tinnitus research was conducted by the National Institutes of Health (NIH), which continues to this day to provide much of the basic science research; but, budget pressures and growing competition among health groups for a shrinking pool of federal dollars often meant that tinnitus was given less attention than the tinnitus community believed was merited. Further compounding the problem was a large knowledge gap on Capitol Hill about tinnitus, its causes, effects, and its toll on society, both in terms of financial impact and human suffering.

In 2007, ATA set out to change the “tinnitus trajectory” and, by any measure, our efforts were met with resounding success. Between 2007 and 2013, we launched a comprehensive education and outreach program targeted not just at the NIH, but also the VA and the Department of Defense (DoD), meeting with countless legislators and agency officials to convince them to ramp up their efforts toward research on and funding for tinnitus. We obtained congressional report language urging NIH to increase its research efforts. Through congressional action, we were able to have tinnitus added as a researchable condition in a special program run by the DoD.

ATA actions included:
• helped establish a new DoD Center of Excellence devoted to tinnitus and hearing loss conditions,
• participated in a congressional staff briefing on tinnitus to raise awareness and garner more support,
• spearheaded a multi-agency workshop devoted to tinnitus, and
• were instrumental in causing a congressional hearing on tinnitus.

These and other efforts contributed to a dramatic increase in tinnitus research funding, from the original $1 million to almost $19 million between 2007 and 2013.

While ATA members can and should be proud of these accomplishments to date, we recognize that the battle is far from over. While the number of tinnitus grants funded through NIH has remained fairly constant, we know that the overall amounts funded per grant have decreased over the last few years. And, with the constant turnover of Members of Congress, we must continually re-engage to educate new members about tinnitus, if we are to be successful. Put simply, there are just too many competing issues within healthcare for tinnitus to stay on the front burner with Congress and other influencers without continued work to keep focus on it.

For these reasons, ATA decided to revitalize its advocacy outreach. To accomplish this, we have reached out to colleagues and allies in the hearing, defense, and veterans communities to work collaboratively where possible on issues of mutual interest. We also have contacted senior researchers at NIH, as well as staff in other agencies with tinnitus oversight, to reestablish our previous working relationships.

As of press time, many large-scale 2018 healthcare issues have yet to be fleshed out by Congress. Given recent experiences, however, we believe 2018 will present both challenges and opportunities for those
committed to advancing tinnitus research. There will continue to be financial pressures put on NIH that could impact the flow of tinnitus research dollars, and we must ensure that tinnitus is given the attention it clearly deserves. The VA has appeared interested in exploring privatization of certain health services for veterans. The ATA is working to ensure that the 2.7 million veterans who are awarded service-connected disability for tinnitus/hearing loss have access to the full continuum of care, from prevention to diagnostics to treatment and follow-up. And, over the next few years, the Food and Drug Administration (FDA) will be charged with implementing a 2017 law providing for the availability of certain Over-the-Counter (OTC) hearing aids. We must ensure that implementation is done responsibly to keep tinnitus patients from being inadvertently harmed through a law designed to make some hearing aids more affordable and accessible.

ATA’s advocacy efforts have helped propel tinnitus research forward in several important areas. We look forward to continuing to advance the tinnitus cause and keep moving toward better methods to prevent, treat, and ultimately find cures for tinnitus. 

Deborah Outlaw, ATA’s Health Policy Advisor, has spent more than 35 years in health and public policy arenas, serving in two presidential administrations and on Capitol Hill for a U.S. Senator. Since 2001, she has served as a healthcare consultant, providing federal legislative and regulatory services to numerous organizations with healthcare interests, including physician specialty groups, allied health providers, medical device manufacturers, safety net facility prescription drug providers, hospitals, and trade associations.