

## 2017 Association for Research in Otolaryngology (ARO) Meeting

The Association for Research in Otolaryngology (ARO) holds a major conference each year that brings together hundreds of medical researchers. Hyperacusis Research takes advantage of this opportunity to attend and collaborate with those researchers working on hyperacusis. This year's conference was held in Baltimore in February.



*Tanisha Hammill, U.S. Department of Defense, Rich Salvi, University at Buffalo, and Bryan Pollard, President of Hyperacusis Research*

## Roundtable Meeting at ARO

Hyperacusis Research sponsored an exciting roundtable event with 41 attendees, that focused on defining the key next steps for research to find a cure. Notable attendees included: Roger Miller, Ph.D., Division of Scientific Programs, NIH, NIDCD; Catherine Weisz, Ph.D., Division of Intramural Research, NIH, NIDCD; Jonathon Whitton, Au.D., Senior Audiologist at Decibel Therapeutics; Larry Roberts, Ph.D., Department of Psychology, Neuroscience & Behaviour, McMaster University; Nadine Dehgan, CEO, Hearing Health Foundation; Torryn Brazell, Executive Director & COO,

American Tinnitus Association; and Tanisha Hammill, Senior Research Administrator, U.S. Department of Defense, Hearing Center of Excellence.

Bryan Pollard, President of Hyperacusis Research, highlighted the progress made to date for the cause of hyperacusis:

- Media attention continues to grow with articles in Tinnitus Today, Hearing Health, USA Today, The New York Post, and Classical Singer Magazine describing the challenges of hyperacusis.
- Almost \$100,000 has been raised for hyperacusis research in the past two years.
- In the past four years, the number of research papers in PUBMED on hyperacusis has more than doubled.
- In the last five years, NIH funding for hyperacusis projects has more than doubled, with more than \$1.8 million in funding in 2016.

Bryan also gave a preliminary review of our comprehensive Sanford CoRDS hyperacusis survey. This preview was based on the first 100 participants (many more have now completed the survey). Some insights:

- There is a fairly even split between those whose hyperacusis started suddenly versus gradually.
- 90% also have tinnitus.
- 66% experience daily or continuous pain from everyday noises.
- The majority experience new onsets of ear pain when exposed to a new loud sound.

- For almost all participants, the new onset of pain is immediate upon a new noise exposure.
- For 28%, the new onset of pain lasts several days and for 25% it lasts for five to 24 hours.
- There is a broad distribution of pain types: sharp, dull, stabbing, burning and throbbing.
- To recover from a new setback, it takes several days for 41% and several weeks for 27%.

Researchers are starting to acquire this survey data-set to do a more rigorous analysis. We expect this to yield important new insights – particularly pertaining to those who experience hyperacusis with pain.



*Paul Fuchs of Johns Hopkins Medical School*

The roundtable then proceeded to a detailed discussion of progress in each of the four roadmap paths to a cure: 1) understanding hyperacusis mechanisms 2) elucidation of hyperacusis mechanisms 3) development and optimization of therapy and 4) determination of hyperacusis cures. Detailed technical discussions were presented to the group by a number of medical researchers:

- Xiying Guan, Harvard Medical School, discussed his research on conductive hyperacusis, which is caused by passive mechanical changes in the ear.
- Jaime García-Añoveros, Northwestern University, reviewed key questions that need in-

vestigation related to pain mechanisms with hyperacusis.

- Paul Fuchs, Johns Hopkins School of Medicine, discussed his work on Type II cochlear nerve fibers, which may contribute to hyperacusis pain.
- Kelly Radziwon, University at Buffalo Center for Hearing and Deafness, discussed development of animal models and analysis of reaction time as a measure of hyperacusis.
- Senthivelan Manohar, University at Buffalo Center for Hearing and Deafness, presented his work in developing an auditory nociception test with animals.
- Freddie Daver, University of Southern California, discussed the potential development of a product to attenuate sound that would benefit hyperacusis sufferers.
- Rich Salvi, University at Buffalo Center for Hearing and Deafness and Scientific Advisor to Hyperacusis Research, presented advances in imaging such as fMRI that may offer the potential to better understand the neural underpinnings of hyperacusis.
- Deborah Hall, University of Nottingham, England, described the process for prioritizing a research agenda with a pathway that spans basic discovery science through to clinical research and readiness for respective research activities.

## Collaborative Meetings at ARO

In addition to the roundtable meeting, Bryan Pollard held discussions with a number of other researchers at ARO.

One meeting was with Jonathon Whitton from Decibel Therapeutics, a new company that is pioneering a comprehensive approach to define the underlying biological causes of various hearing disorders and is developing a pipeline of breakthrough therapies. As an audiologist, Jonathon's interest in hyperacusis is in finding the best assessment method. Loudness Discomfort Level (LDL) is the standard assessment of hyperacusis, but there are some critical concerns with LDL testing, including significant variability

in how the test is administered and, more importantly, significant risk of worsening a patient's condition.

Another meeting was with Matthew Richardson and Katie Turner, who work in Professor Fan Gang Zeng's lab at the University of California, Irvine (Professor Zeng is one of Hyperacusis Research's Scientific Advisors). Katie discussed her poster at ARO titled "Suprathreshold Processing Deficits in Listeners with Hyperacusis." She analyzed otoacoustic emissions and auditory brainstem response data from hyperacusis patients along with speech recognition in noise to assess perceptual deficits. Her preliminary results suggest that hyperacusis sufferers may have difficulty in understanding speech in a noisy environment.

Bryan also held meetings with Charlie Liberman of Harvard Medical School; Martin Pienkowski of Salus University; Bo Hu of the University at Buffalo; and Marlies Knipper, Katrin Reimann, and Dorit Moehrle from the Tübingen Hearing Research Centre in Germany. Details of these conversations are available at [www.hyperacusisresearch.org](http://www.hyperacusisresearch.org).

## Partnership with The Mighty

Hyperacusis Research has entered into a partnership with The Mighty ([www.themighty.com](http://www.themighty.com)), a story-based health site focused on improving the lives of people facing disease and disability, including chronic pain conditions and rare disorders.



Our goal is to spread awareness about the reality of living with hyperacusis and noise-induced pain. People can share their stories either with their name or anonymously. We encourage people to submit their hyperacusis stories to The Mighty.

A recent submission called "16 People Explain How Noise-Induced Pain Has Impacted Their Lives" shared quotes that provide a window into life with a condition that is not visible to others. Issac from Arkansas wrote: "I have never felt so broken

in all my life. I am at the whole world's mercy. I feel completely hindered from living. This condition cost me my business, my home, my vehicle and my dog."



*Issac is a military veteran whose hyperacusis started after he used an electric concrete chisel without ear protection.*

Teresa from Michigan wrote: "At a doctor's office, the building did a fire alarm test. The pain I suffered was unforgivable. They didn't jump in to offer assistance. My explanations are pointless. People won't understand anyway. They wouldn't last a day in my shoes."

## Thanks to you, our donors

All of our work has been possible thanks to you, our donors. Your generosity has enabled continued progress in the research toward a cure for hyperacusis.

In addition to regular donations, we encourage the creation of online fundraisers where family, friends and colleagues may contribute to a customized campaign. We have a new tool available on our website ([www.hyperacusisresearch.org](http://www.hyperacusisresearch.org)) that makes this very easy. Fundraisers with family, friends and colleagues have been one of the most effective methods for generating funds to grow our research.

As always, contributions to Hyperacusis Research are tax deductible as allowed by law. We are incorporated as a 501(c)(3) non-profit organization. Both large and small contributions are important to furthering our work in awarding grants to medical researchers. Donations may be made by check to our mailing address or with a credit card on our website.

Thank you!

Hyperacusis Research Limited, Inc.  
P.O. Box 1295  
Marlboro, MA 01752

Non-Profit  
U.S. Postage  
PAID  
Permit No. 2782  
Merrifield, VA



Hyperacusis Research is a 501(c)(3) non-profit organization devoted to finding a cure for hyperacusis through accelerating research by connecting patients to researchers. Contributions are fully tax-deductible as allowed by law and are gratefully welcomed by credit card online at [www.hyperacusisresearch.org](http://www.hyperacusisresearch.org) or by check to our mailing address printed above.

In addition to our website, follow us on Facebook and Twitter:



[Facebook.com/hyperacusisresearch](https://www.facebook.com/hyperacusisresearch)



[Twitter.com/hyperacusiscure](https://twitter.com/hyperacusiscure)