

Donor Newsletter

Volume 6, Spring 2019

2018 Emerging Research Grant

Along with our partner, the Hearing Health Foundation, we announced our Emerging Research Grant for 2018. This grant demonstrates our commitment to uncover mechanisms associated with hyperacusis on our path to a cure. We are grateful for the donor support that makes this grant possible. The grant went to Kelly Radziwon, Ph.D., of the University at Buffalo.

Her project aims to characterize the relationship between changes in neural activity and loudness perception with and without noise-induced hearing loss. The long-term goal is to broaden our understanding of the neural mechanisms underlying loudness perception in order to find a potential therapeutic target to mitigate pain hyperacusis.



Bryan Pollard with Kelly Radziwon, Ph.D., and Senthilvelan Manohar, Ph.D., both of the University at Buffalo.

ENT & Audiology News Article

The January / February 2019 issue of ENT & Audiology News published an article by Bryan Pollard on "Unravelling the mystery of hyperacusis with pain." The article discusses how symptoms are ex-

perienced by patients who report that sound causes them pain.



A chart from the ENT & Audiology News article.

One aspect of pain hyperacusis most misunderstood by clinicians is the concept of setbacks. Most hyperacusis patients learn from painful experiences that a key to progress is to minimize setbacks, which typically result from additional noise exposure. Clinical advice rarely includes practical information about setbacks or how to reduce the risk of worsening. Importantly, clinicians should refrain from making ambiguous claims such as "everyday noise can't make your condition worse."

2018 Association for Research in Otolaryngology (ARO) Meeting

At the 2018 ARO, held in San Diego, CA, Hyperacusis Research organized a number of meetings between medical researchers to facilitate sharing and discussion of progress toward finding a cure for hyperacusis. The highlight of these meetings was a dedicated working session with 32 participants designed to enhance research collaboration, and was organized into four areas:

- Animal Models & Central Neural Function
- Cochlea & Central Neural Function



- Peripheral Function & Literature Review
- Diagnostics & Clinical Options

Each work group provided inputs on the following discussion topics:

- Current collaboration efforts in this area of research
- Expanded or new collaboration opportunities to pursue
- Significant gaps in research
- Work that may be accelerated in the near term to alleviate suffering

A total of 110 ideas were offered. A detailed summary of key themes from all groups is available on our website.



Charlie Liberman of Harvard Medical School presents findings at the dedicated ARO working session for collaboration on hyperacusis.

University of Iowa Conference

Hyperacusis Research president Bryan Pollard spoke to doctors and audiologists at the University of Iowa's 26th Annual International Conference on the Management of the Tinnitus & Hyperacusis Patient. Bryan's topic was "Innovating a Better Future for Sufferers of Hyperacusis with Pain."

Bryan shared patient stories, explaining that current treatment approaches vary greatly in terms of effectiveness, and further research is needed to find a cure for all – especially those who have noiseinduced pain. He shared key results from the Sanford CoRDS Hyperacusis Survey, which represents the most comprehensive source of data on patients with pain hyperacusis, with more than 200 participants:

- Prior to hyperacusis, about half had a history of loud noise exposure, with about a third having had a traumatic impulse noise exposure
- The vast majority experience pain at least every day and sometimes continuously usually as a result of being around a new noise
- The pain is a sharp stabbing or burning pain, or a dull ache
- For half of hyperacusis patients, the pain lasts from five hours to several days
- About a third have regular setbacks from new noises which make some patients worse than before
- For those who improve after setbacks, improvement takes several days or longer, depending on the loudness of the new sound exposure



Bryan Pollard presenting at the University of Iowa.

Also discussed was a new Hyperacusis Assessment Method by Greenberg and Carlos, a tool developed to measure symptom severity, treatment outcomes, and diagnostic differentiation, as well as a new research paper titled "A Case of Acoustic Shock with Post-trauma Trigeminal-Autonomic Activation," which focuses on middle ear effects as potential players in hyperacusis with pain.



"What sufferers care about most is the number of days they are in pain and the severity of that pain. Sound therapy had the least effect for those with the most days in pain. A critical factor that affects the number of days in pain is setbacks. Fewer setbacks result in less pain."

Quote by Bryan Pollard summarizing the patient experience at the University of Iowa conference.

Boston fundraising dinner

A vital part of our annual fundraising season is our Boston-area benefit dinner, which was a success, enabling our total fundraising for the year to exceed \$48,000 to find a cure for hyperacusis.



Professor Heidi Nakajima of Harvard Medical School, a keynote speaker at the Boston-area fundraising dinner.

Speakers at the dinner included Professor Heidi Nakajima of Harvard Medical School, who discussed her research on hyperacusis, and Neil Donnenfeld of the Acoustic Neuroma Association, who developed hyperacusis as a side effect of treatment for acoustic neuroma.



Bryan Pollard with Neil Donnenfeld, Vice President of the Acoustic Neuroma Association.

Looking ahead

2018 was a year of great progress, with research collaboration activities continuing to accelerate. We look forward to continuing on the path to a cure in 2019.

Our work is made possible by your generous support. We rely on your donations for our entire budget. Recently we started using the Facebook platform to allow individuals to easily create their own fundraising pages for Hyperacusis Research. Currently, there are no fees for Facebook fundraisers.

Facbeook fundraisers were particularly successful on GivingTuesday, held the first Tuesday after Thanksgiving. If you are a Facebook user, please consider creating a birthday or holiday fundraiser to benefit Hyperacusis Research.

As always, we continue to be grateful for contributions by check mailed to our address (printed on the last page of this newsletter) and for online contributions by credit card through our website, www.hyperacusisresearch.org. Hyperacusis Research Limited, Inc. P.O. Box 1295 Marlboro, MA 01752

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