HYPERACUSIS RESEARCH

Stop Noise-Induced Pain

Donor Newsletter Volume 10, Spring 2024

Letter from the President of Hyperacusis Research

Dear Friends and Supporters,

I am thrilled to report on our recent accomplishments. 2023 was our most successful fundraising year yet. Five individuals made planned gift intentions to **Hearing Health Foundation (HHF)**. Their gifts are being matched by an anonymous donor to fund pain hyperacusis research. In partnership with HHF, we anticipate having $1,500,000 to deploy on pain hyperacusis in the future.

Donations large and small came in from all over the world through our website, Facebook, and links from **Hyperacusis Central**. Our fundraising goal for 2023 was $100,000, with the aim of doubling the pace of research. We ended the year having raised $146,000. These funds support Emerging Research Grants (ERG) by HHF. This year's ERG recipient is **Wei Sun, Ph.D**., of the University at Buffalo. His genetics research will help illuminate neurological processes in hyperacusis that may lead to treatment.

We added three members to our Scientific Advisory Board. **Kelly Jahn, Au.D., Ph.D.**, of the University of Texas researches the perceptual, neural, and psychosocial consequences of hyperacusis and hearing loss. **Zachary Williams, Ph.D.**, of Vanderbilt University recently published a paper analyzing the symptom information provided by hyperacusis patients. **Megan Beers Wood, Ph.D.,** of Johns Hopkins University was the recipient of our 2022-23 Emerging Research Grant.

This year we tried some new fundraising ideas. Outreach to new foundations yielded a $25,000 grant. A pizza party at my home in Milton, Massachusetts, featuring a talk by **Daniel Polley, Ph.D.**, raised over $4,000. This was easy to organize and a lot of fun.

Michael Maholchic, President of Hyperacusis Research

ARO 2023 featured a well-attended Hyperacusis Symposium organized by **Fatima Husain, Ph.D.**, and **Ben Auerbach, Ph.D.**, and a separate brainstorming luncheon organized by board member **Steve Barad, M. D.** In both settings, board member **Jon Wallace** described his history with hyperacusis. Such stories are critical for giving researchers a view into what life with hyperacusis is really like. This year at ARO we will sponsor a dinner and panel discussion on how best to accelerate research to devise improved diagnostics and targeted treatments.

I am grateful to the **many volunteers and donors** who made our accomplishments in 2023 possible and will position us for an even more productive 2024.

Thank you and warmest wishes,

Michael Maholchic
President of Hyperacusis Research
michael.maholchic@hyperacusisresearch.org

Hyperacusis Research Supports 2024 Research Grant

Along with our partner, Hearing Health Foundation, we have funded an exciting Emerging Research Grant for 2024. This grant demonstrates our commitment to uncovering the 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 Wei Sun, Ph.D., of the University at Buffalo. The title of the project is "FOXG1 gene mutation-caused hyperacusis—a novel model to study hyperacusis."

Wei Sun, Ph.D., University at Buffalo

Hyperacusis is a common symptom in children with neurological disorders such as autism spectrum disorder, Williams syndrome, Rett syndrome, and FOXG1 syndrome (FS). The cause of hyperacusis in these neurological disorders has not been fully discovered. FOXG1 mutation is a recently defined, rare and devastating neurodevelopmental disorder. MRI studies show a spectrum of structural brain anomalies, including cortical atrophy, hypogenesis of the corpus callosum, and delayed myelination in children with FS. However, the impact of the FOXG1 mutation on the central auditory system and hyperacusis is largely unknown.

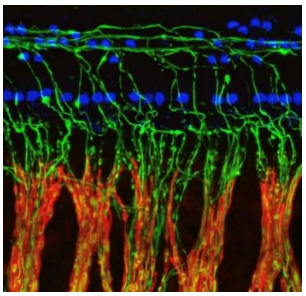
Children with FS show signs of hyperacusis, even experiencing seizures from loud sounds. The mouse model of FOXG1 mutation provides a novel model to study neurological dysfunction in the central auditory system resulting in hyperacusis. This project will use a mouse model developed by colleagues at the University at Buffalo that replicates gene mutations in FS children to study hyperacusis. Preliminary studies demonstrated that the mutant mice showed a lack of habituation in the startle tests and an aversive reaction in the open field test. Cortical neurons showed reduced neural activities and prolonged responses to sound stimuli, suggesting hypoexcitability and a lack of adaptation to sound stimuli.

The results point toward a novel neurological model of hyperacusis compared with the current "central gain" theory. Findings will provide mechanistic insights into the role of the FOXG1 gene on hyperacusis and shed light on detecting potential therapeutic targets to alleviate hyperacusis caused by FS and other neurological disorders.

The long term goal is to understand how the FOXG1 mutation affects central auditory function and hyperacusis. The results of this study will help with understanding the role of the central auditory system in hyperacusis as well as help design clinical studies to look at drug treatments and therapies for hyperacusis in children with FOXG1 syndrome and other neurological disorders.

Instagram!

Check out our new Instagram page, Instagram.com/hyperacusiscure, where we post relevant graphics. This one shows nerve synapses inside the cochlea!



Courtesy M. Charles Liberman

"What I Have Learned From My Hyperacusis Patients"

The Winter 2024 issue of Hearing Health Foundation's magazine includes in an interview with Dr. Shelley Witt, M.A., CC-A. Dr. Witt is a pioneering audiologist at the University of Iowa. She is one of only a few audiologists to recognize the seriousness of pain hyperacusis, including the fact that the conventional wisdom of the medical community can be actively harmful to pain hyperacusis patients.

> *"Pain hyperacusis patients are not overprotecting their ears. They are trying to survive. Sound is actually activating pain receptors, and it can cause catastrophic reactions. Without sufficient protection, they can readily worsen."*

Quote from Dr. Witt in HHF magazine

Dr. Witt discusses the symptoms of pain hyperacusis, such as burning and stabbing pain, as well as the delayed pain that is especially troublesome, because a patient may not know the level of damage inflicted until hours or days after the noise event.

She also discusses sound therapy, and how the common recommendation to treat patients with sound can cause further injury to pain hyperacusis patients. What patients need, instead, is protection from noise.

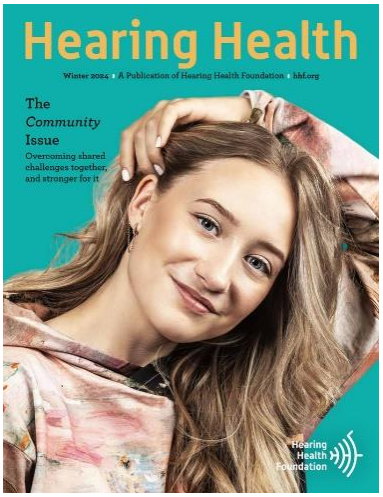
We are grateful to Dr. Witt for sharing the understanding of pain hyperacusis that she has gained through working with patients. We encourage people to read the full article on the HHF website https://hearinghealthfoundation.org/blogs/what-i-have-learned-from-my-hyperacusis-patients, and to share this article with relatives and medical providers to help them understand this challenging condition.

Finding Community for a Confounding Condition

Due to the rarity of pain hyperacusis, many patients report that their medical providers have never heard of the condition, much less encountered another patient suffering from it. Thanks to the internet and a growing number of patient support groups on different platforms, patients now can find community and gain support.

In an article published in the current issue of HHF magazine, Jon Wallace, a hyperacusis patient and member of the board of directors of Hyperacusis Research, discusses the importance of community. Says Jon, "Who, besides those who suffer from this confounding condition, could possibly understand that the sound from zipping a zipper can be painful?"

Read Jon's full article on page 13 of the HHF magazine https://view.publitas.com/p222-4764/hearing-health-winter-2024-issue/page/12-13.



Winter 2024 issue of HHF magazine – available online and in print. Subscribe for free at https://hearing-healthfoundation.org/hearing-health-magazine.

Looking Ahead in 2024

Our work is made possible thanks to your generous support. In 2024, we plan to continue to raise funds for research. If you have not signed up for our free email newsletters, please do so on our website – go to the bottom left side of our home page where it says "Subscribe to our newsletter."

As always, we are grateful for contributions by check mailed to our Massachusettes post office box (printed on the last page of this newsletter) and for online contributions by credit card via our website, www.hyperacusisresearch.org or on our Facebook page, www.facebook.com/hyperacusisresearch.

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HYPERACUSIS RESEARCH
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Hyperacusis Research is a 501(c)(3) non-profit organization devoted to finding a cure for hyperacusis by accelerating research for novel therapies and 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 or by check to our mailing address above.

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