Donor Newsletter Volume 11, Spring 2025

## Letter from the President of Hyperacusis Research

Dear Friends and Supporters,

Thank you for making us the foremost private charity sponsoring research on loudness and pain hyperacusis.

Our mission is to raise awareness and sponsor research on the type of hyperacusis in which patients find ordinary, everyday sounds that do not bother most people - or were perceived as normal to the patient before the onset of their hyperacusis - to be unbearably loud and/or physically painful.

Since 2012, we have been taking advantage of the vigorous review process of Hearing Health Foundation (HHF) to sponsor 11 Emerging Research Grants (ERG) for early-stage investigators. Currently we are funding two grants:

- Wei Sun, Ph.D., of the University at Buffalo, is undertaking genetics research to shed light on the neurological process of hyperacusis that may lead to treatment.
- Manoj Kumar, Ph.D. of the University of Pittsburgh, will test (on mice) drugs targeting noise-induced hearing loss, considered the root causes of tinnitus, hyperacusis, and other hearing disorders.

I thank our talented **Scientific Advisory Board** for their contributions in guiding us to sponsor the best research we can.

The midwinter meeting of the Association for Research in Otolaryngology (ARO) is a key event to bring our patient community in touch with almost 2,000 researchers and clinicians. In 2024, we hosted a well-attended brainstorming luncheon organized by board member **Steve Barad**, **M.D**., and we will do so again at the upcoming ARO meeting.

We welcomed new board member **Ana**, a hyperacusis patient with a background in creating brand experience and web design. She hit the ground running in helping to get our message out on social media sites.



Michael Maholchic, President of Hyperacusis Research

We also welcomed special member **Jonas** of Belgium, who has been active in many hyperacusis support groups and brings an international perspective to our board meetings.

Ana worked with a new volunteer, **Emily**, and a supporting team to create a video presentation with remarks from Scientific Advisory Board members **Kelly Jahn**, **Au.D.**, **Ph.D.**, and **Megan Beers Wood Ph.D.**, and patient representatives **Kenneth Devore** of California and **Karen Cook** of England. The team received permission from the BBC to share Karen's moving interview, which aired in the United Kingdom earlier this year. This video was shown at three local fundraisers for groups of friends and families, raising over \$12,000.

I thank the **H.G. Barsumian**, **M. D. Memorial Fund** for their generous grant award of \$22,000 for two consecutive years in 2023 and 2024.

I thank the anonymous donor who sponsored the highlight of our past year's fundraising - a successful \$37,500 matching donation campaign.

Finally, on behalf of the thousands who suffer greatly from the pain of hyperacusis, I offer my heartfelt



thanks to our many volunteers and donors large and small from all over the world. You enabled us to double the pace of research and sponsor two ERG grants in 2024. I now challenge those who are able to step forward and sponsor a matching donation campaign for the coming year. I hope and believe that working together we can keep up the momentum and sponsor even more research in 2025!

Thank you and warmest wishes,



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

### Putting the Brakes on Hyperactivity in the Brain

We asked Dan Polley, Ph.D., one of our scientific advisors, about his auditory research. Dan is a professor of otolaryngology at Harvard Medical School and the Director of the Eaton-Peabody Laboratories at Massachusetts Eye and Ear, the world's largest academic research center devoted to hearing.



Dan Polley, Ph.D., at his lab in Boston

Dan's research focuses on the connections between brain plasticity and the perception of sound, with a particular interest in how the brain's plasticity can be leveraged to eliminate the experience of tinnitus and loudness hyperacusis. We do not have space to print the entire interview with Dan in this newsletter, so we encourage you to read it here: https://hyperacusisresearch.org/putting-the-brakes-on-hyperactivity-in-the-brain/

## Hyperacusis Research Supports 2025 Research Grant

Along with our partner Hearing Health Foundation, we have funded an exciting Emerging Research Grant for 2025. We are grateful for the donor support that makes this grant possible. The grant went to Manoj Kumar, Ph.D., of the University of Pittsburgh.



Manoj Kumar, Ph.D., University of Pittsburgh

Dr. Kumar, an assistant professor of otolaryngology, will be researching the KCNQ2/3 potassium channel as it relates to the mitigation of noise-trauma—induced hypersensitivity to sounds in mice. Read more here: https://hyperacusisresearch.org/2025-hyperacusis-research-grant-awarded-to-manoj-kumar/

## New Paper on the Patient Experience

Dr. Kelly Jahn of the University of Texas at Dallas and co-authors have published a new paper in the February 2025 issue of The Journal of Pain entitled "Clinical phenotype and management of sound-induced pain: Insights from adults with pain hyperacusis." She is a member of our Scientific Advisory Board and has published extensively on hyperacusis.

The paper discusses the nature and frequency of symptoms reported by patients, such as burning (80%), stabbing (77%), and throbbing (73%). In addition, it shares how surveyed patients have fared with interventions for pain relief. Read the full paper here: https://www.sciencedirect.com/science/article/pii/S1526590024007193



# New Video: Introduction to Hyperacusis Research

"An icepick or razor scraping their ear canal." Kelly Jahn, PhD, and Megan Beers Wood, PhD, discuss their work in our new fundraising video. Dr. Jahn notes that, in her survey, every single patient reported "a lack of empathy and support" from people in their lives and from medical providers, too. Dr. Wood discusses cochlear neurons that respond to pain, not to sound.

The video ends with the BBC's piece on Karen Cook, who suffers from severe pain hyperacusis. "Everything that we knew as a family has changed," says her husband, Nick. Watch the video here: https://youtu.be/ih2l-Lo6DUQ

#### **Hyperacusis Card**

Our friends at Hyperacusis Central have developed an online tool to create and print a customized card that can be handed to people to explain about the difficulties of tolerating sound, and the actions they can take to help. This card can be used with medical providers, family, friends, police, airport security authorities, or in any situation to convey the patient's requirements with respect to hyperacusis. The tool also offers the option to print a QR code that links to the Hyperacusis Research website, for more information. Create your customized Hyperacusis Card here: www.hyperacusiscentral.org/hyperacusis-card

#### I HAVE AN AUDITORY DISABILITY

I have hyperacusis, an abnormal sensitivity to sound.

Most sound causes pain in my ears.

The pain can be so severe that I have trouble communicating and tolerating every day noise.

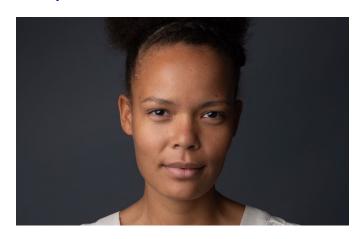


#### **MORE INFO ON BACK** -



#### **Hyperacusis Poem**

Berthina Kayembe has struggled with hyperacusis for five years. She has written a touching poem, *The smallest pot's lid.* "As a singer and guitarist, it's been heartbreaking to put my music aside," Berthina says. "I've begun to find a new creative outlet through writing." We share the first verse below. Read the full poem here: https://hyperacusisresearch.org/the-smallest-pots-lid-poem-about-hyperacusis-by-berth-ina-kayembe/



Bethrina Kayembe, of Norway

I have to remember how the smallest pot's lid, the one I've used to boil two eggs each morning, doesn't quite fit. How it slips, clattering onto the metal grates, each clang, a fresh note of pain on my fragile ears.

#### Looking Ahead in 2025

Our work is made possible thanks to your generous support. In 2025, we plan to continue to raise funds for research and fund grants to find a cure.

As always, we are grateful for contributions by check mailed to our Massachusetts 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 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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