November 2018

Hearing Loss Association of America

North Shore of Long Island Chapter

Meeting Location

Our meetings are now being held at the Katz Women's Hospital at Long Island Jewish Medical Center: 270-05 76th Avenue, Queens, NY 11040. It's the new building you see when you drive into the main gate at LIJ.

There will be free VALET parking for attendees; passes are distributed at the end of each meeting. Please arrive between 6:30pm–7pm.

As you enter the building, look to your left for signage to our conference room #132, located at the far left end on the main floor.

If you are in doubt as to whether there is a meeting, or if you'd like further information, please call Sal:
516-331-0231.

Meeting News

Our meetings are held bi-monthly, on the third Friday of the month.

Friday, November 16, 2018

6:30pm – 8:30pm

Please arrive between 6pm – 6:30pm for a free valet parking pass.

Topic: Nurturing Resilience In the Face of Hearing Loss

This presentation describes several psychosocial challenges with hearing loss and methods of nurturing one's resilience. These include managing traumatic influences, helplessness, anxiety and fear, anger and rage, self-esteem, and reconciling one's group identity. Methods of overcoming "internalized handicaps" will be explained. Persons with hearing loss too frequently accept a wide array of *self-deprecatory beliefs as self-evident truths which are beyond scrutiny.*

Presenter: Michael Harvey, Ph.D., A.B.P.P., Clinical Psychologist

Michael A. Harvey, Ph.D. provides training and consultation on mental health issues having to do with hearing loss, including consultation and training for audiologists regarding motivational interviewing and the psychological aspects of patient care. In addition to his more than 45 articles, his books include *Listen with the Heart: Relationships and Hearing Loss, The Odyssey of Hearing Loss: Tales of Triumph, Psychotherapy with Deaf and Hard of Hearing Persons: A Systemic Model,* and a co-edited book entitled *Culturally Affirmative Psychotherapy with Deaf Persons.*

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North Shore of Long Island Chapter

Meeting Dates

Our upcoming meeting dates are:

- September 21, 2018
- November 16, 2018
- January 18, 2019
- March 15, 2019
- May 17, 2019

Voice: 516-331-0231
http://hearingloss-longisland.org
hlaalongisland@gmail.com

Gene Makes Some Susceptible to Middle Ear Infections

By Science Daily

Researchers at the University of Colorado Anschutz Medical Campus have found multiple genetic variants within the FUT2 gene that makes some people especially susceptible to middle ear infections.

"Middle ear infections are very common in kids," said the study's lead author, Regie Santos-Cortez, MD, PhD, associate professor of Otolaryngology at the University of Colorado School of Medicine. "By the time they are 1-year-old around half have fever, ear pain or pus/fluid in the middle ear due to infection. Some of these infections may recur or become chronic thus requiring surgery."

The FUT2 gene is expressed in the salivary gland, colon and lungs but its expression in the middle ear has not been described previously.

Santos-Cortez and her colleagues discovered the role the gene played in middle ear infections or otitis media by initially examining DNA samples from 609 multi-ethnic families with the condition.

The study was published online today in the *American Journal of Human Genetics.*

The researchers found common variants of the gene in Filipinos and South Asians and a rarer variant associated with recurrent middle ear infections in European-American children. The most common variant occurs in 30-50% of individuals in almost all population groups except East Asians.

"A number of things predispose people to getting these infections including a lack of vaccinations, lack of breastfeeding and being around smoking

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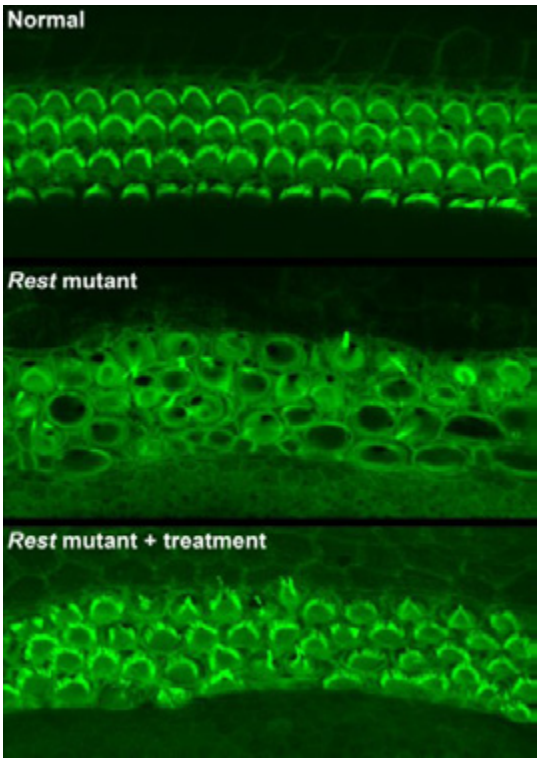
Novel Drug Therapy Partially Restores Hearing in Mice

By Science Daily



A small-molecule drug is the first to preserve hearing in a mouse model of an inherited form of progressive human deafness, report investigators at the University of Iowa, Iowa City, and the National Institutes of Health's National Institute on Deafness and Other Communication Disorders (NIDCD). The study, which appears online in *Cell*, sheds light on the molecular mechanism that underlies a form of deafness (DFNA27), and suggests a new treatment strategy.

"We were able to partially restore hearing, especially at lower frequencies, and save some sensory hair cells," said Thomas B. Friedman, Ph.D., chief of the Laboratory of Human Molecular Genetics at the NIDCD, and a coauthor of the study. "If additional studies show that small-molecule-based drugs are effective in treating DFNA27 deafness in people, it's possible that using similar approaches might work for other inherited forms of progressive hearing loss."

The seed for the advance was planted a decade ago, when NIDCD researchers led by Friedman and Robert J. Morell, Ph.D., another coauthor of the current study, analyzed the genomes of members of an extended family, dubbed LMG2. Deafness is genetically dominant in the LMG2 family, meaning that a child needs to inherit only one copy of the defective gene from a parent to have progressive hearing loss.

The investigators localized the deafness-causing mutation to a region on chromosome four called DFNA27, which includes a dozen or so genes. The precise location of the mutation eluded the NIDCD team, however.

A crucial clue to explain the DFNA27 form of progressive deafness arose from later studies of the mouse RE1 Silencing Transcription Factor, or Rest, gene conducted by researchers at the University of Iowa. Botond Banfi, M.D., Ph.D. and Yoko Nakano, Ph.D., lead authors of the current study, discovered that mouse Rest is regulated through an unusual mechanism in the sensory cells of the inner ear, and this regulation is critical for hearing in mice. Because the human counterpart of the mouse Rest gene is located in the DFNA27 region, the Iowa and NIDCD researchers teamed up to reexamine the mystery of DFNA27 progressive deafness.

The coding sequence of a protein is generated from a gene by stitching together segments called exons while editing out the intervening segments. The resulting molecule serves as the template

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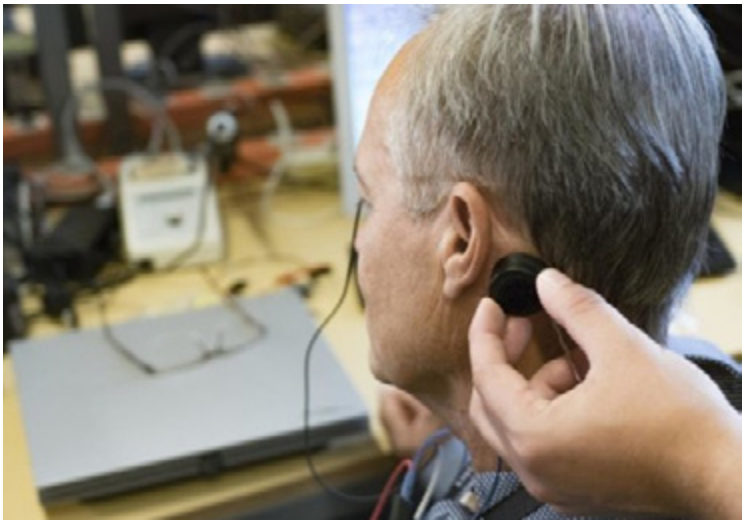
New Innovation Improves the Diagnosis of Dizziness

By Science Daily

Half of over-65s suffer from dizziness and problems with balance. But some tests to identify the causes of such problems are painful and can risk hearing damage. Now, researchers from Chalmers University of Technology, Sweden, have developed a new testing device using bone conduction technology, that offers significant advantages over the current tests.



The vibrating device is small and compact in size, and optimised to provide an adequate sound level for triggering the reflex at frequencies as low as 250 Hz. Credit: Johan Bodell/Chalmers University of Technology

Hearing and balance have something in common. For patients with dizziness, this relationship is used to diagnose issues with balance. Commonly, a 'VEMP' test (Vestibular Evoked Myogenic Potentials) needs to be performed. A VEMP test uses loud sounds to evoke a muscle reflex contraction in the neck and eye muscles, triggered by the vestibular system—the system responsible for our balance. The Chalmers researchers have now used bone conducted sounds to achieve better results.

"We have developed a new type of vibrating device that is placed behind the ear of the patient during the test," says Bo Håkansson, a professor in the research group 'Biomedical signals and systems' at Chalmers. The vibrating device is small and compact in size, and optimised to provide an adequate sound level for triggering the reflex at frequencies as low as 250 Hz. Previously, no vibrating device has been available that was directly adapted for this type of test of the balance system.

In bone conduction transmission, sound waves are transformed into vibrations through the skull, stimulating the cochlea within the ear, in the same way as when sound waves normally go through the ear canal, the eardrum and the middle ear. Bo Håkansson has over 40 years of experience in this field and has previously developed hearing aids using this technology.

Half of over-65s suffer from dizziness, but the causes can be difficult to diagnose for several reasons. In 50% of those cases, dizziness is due to problems in the vestibular

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Gene Makes Some Susceptible to Middle Ear Infections, *Continued from Page 2*

caregivers," said Santos-Cortez, who is also with the Center for Children's Surgery at Children's Hospital Colorado. "But even in the best case scenario, recurrent or chronic middle ear infections still happen in some kids, which may be due to genetic predisposition."

Those who possessed the genetic variants had a much higher chance of getting the infection. The researchers believe the gene modifies the microbiome of the middle ear in a way that makes it more susceptible to infection by specific bacteria.

"If you have these mutations, you will have a slightly different microbiota which could elevate the risk of disease," Santos-Cortez said.

The finding could eventually lead to new ways of determining who is likely to get the infection.

The study confirmed expression of FUT2 in the middle ear which is spiked within 24 hours of bacterial infection. But the FUT2 genetic variants decrease presentation of A antigen used by bacteria to gain access to the middle ear lining.

That causes a decrease in some bacteria while boosting the numbers of bacteria known to play a role in chronic or recurrent disease.

"The frequency of population-specific FUT2 variants makes this gene a potential target for preventative screening and future treatments for otitis media, including modulation of the middle ear microbiome," the study said.

Novel Drug Therapy Partially Restores Hearing in Mice, *Continued from Page 3*

for a specific protein. Most previous studies had missed exon 4 in the Rest gene because this small exon is not edited into the Rest mRNA in most cells. The normal function of the REST protein is to shut off genes that need to be active only in a very few cell types.

When Banfi's team deleted exon 4 of Rest in mice, inner ear hair cells died, and mice became deaf. Many genes that should have been active were shut off in hair cells prior to their death. Working together, Friedman's and Banfi's groups pinpointed the deafness mutation in the LMG2 family. They discovered that the mutation lies near exon 4, altering the boundaries of exon 4, and interferes with the inactivation of REST in hair cells.

"We found that incorporating exon 4 into the REST mRNA acts like a switch in sensory hair cells. It turns off REST and allows many genes to be turned on," said Banfi. "Some of these turned-on genes are important for hair cell survival and hearing."

The investigators used Banfi's exon 4-deficient mice as a model for DFNA27 deafness. Since REST suppresses gene expression through a process called histone deacetylation, they wanted to see if blocking this process could reduce hearing loss. Using small-molecule drugs that inhibit this process, the investigators were able to turn off REST and partially restore hearing.

"These results demonstrate the value of studying the molecular mechanisms that underlie inherited forms of deafness," said Andrew J. Griffith, scientific director of the NIDCD. "By following these genetic leads, we find novel and unexpected pathways that can, in cases such as this one, uncover unexpected potential treatment strategies in humans."

Hearing Loss Association of America

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Hearing Loss Association of America
North Shore of Long Island Chapter

HLAA opens the world of communication to people with hearing loss through information, education, support, and advocacy. HLAA is a 501(c)(3) organization.

MEMBERSHIP FORM

I'd like to: ☐ Become a member of HLAA ☐ Renew my membership ☐ Give a gift membership

My Membership/Renewal

Name: _____

Address: _____

City: _____ State: _____ Zip: _____ Country: _____

Email: _____ Phone: _____-_____-_____

Chapter I belong to: _____

How did you learn about HLAA?_____

Gift Membership

Name: _____

Address: _____

City: _____ State: _____ Zip: _____ Country: _____

Email: _____Phone: _____-_____-_____

	Annual USA Membership Fees	Annual Non-USA Membership Fees
Individual	☐ **$35 (1 year)** ☐ **$95 (3 years)** ☐ **$140 (5 years)**	☐ **$45 (1 year)**
Couple/Family	☐ **$45 (1 year)**	☐ **$55 (1 year)**
Professional	☐ **$60 (1 year)**	☐ **$75 (1 year)**
Library/Nonprofit	☐ **$50 (1 year)**	☐ **$75 (1 year)**
Student	☐ **$20 (1 year)**	N/A
Corporate	☐ **$300 (1 year)**	☐ **$325 (1 year)**

My membership fee is $ _____

Plus I'm adding a tax deductible donation of $ _____

My total is $ _____

3 Ways to Join, Renew or Give a Gift Membership

1. Return this form to your chapter with your check made payable to HLAA.
2. Mail or fax this form to the HLAA office at the address above with your credit card information.
3. Visit www.hearingloss.org/content/join and use your credit card online. (this is a secure website

Credit Card Payment Information: __American Express __Discover __MasterCard __VISA

Card Number: _____ Expiration Date _____ Security Code _____

Name: _____ (as it appears on card)

Signature: _____ (Include your billing address if different than membership address above.)

Revised 5/2014

If You're New, This is for You!

More than 48 million people in the US have a hearing loss, which can hinder daily communication. By age 65, one in three Americans has a hearing loss. This invisible condition affects the quality of life of the individuals with hear loss, as well as family, friends, co-workers and everyone with whom they interact. HLAA believes people with hearing loss can participate successfully in today's world.

HLAA
Hearing Loss Association of America

Information - Education - Support - Advocacy

Founded in 1979, the mission of HLAA is to open the world of communication to people with hearing loss through information, education, support and advocacy.

HLAA is the nation's foremost membership and advocacy organization for people with hearing loss. HLAA publishes the bimonthly *Hearing Loss Magazine*, holds annual conventions, a Walk4Hearing, and more. Check out: www.HearingLoss.org

The North Shore Chapter is a dynamic group of individuals working together as a team. To join, please fill out the Membership Form in this newsletter. Welcome!

Donating Hearing Aids to the Lions Club

By Michelle Gross

If you have used hearing aids to donate, please address the package to:

John McNamara, Au.D., Ontario Hearing
2210 Monroe Ave., Rochester, NY 14618
Put on the lower left corner of the package:
"Finger Lakes Region Lions Club"

(Cleaning tools, cases, most accessories, etc. have virtually no value and are discarded.) Aids that are usable are cleaned and checked and made ready for sending to the Lions Club for qualified recipients.

You can obtain a receipt for your donation (for tax purposes) but **you must request it**. And, thanks for considering donating your used aids.

New Location for HLAA Meetings

Come join us at our new home at LIJ Katz Hospital. It's the new building you see when you drive into the main gate at LIJ. There will be FREE valet parking for attendees; passes are distributed at the end of each meeting. Or you can still park at our old site and walk over. As you enter the building, look to your left for signage to our conference room #132, located at the far left end on the main floor. There will be time before and after the meeting for some one-on-one chatting. There is a large light food court if you come early and would like a meal or just coffee before the meeting.

Join us and learn how HLAA can make a positive impact on your life as a hard of hearing person.

New Innovation Improves the Diagnosis of Dizziness, *Continued from Page 4*

system. But today's VEMP methods have major shortcomings, and can cause hearing loss and discomfort for patients.

For example, the VEMP test uses very high sound levels, and may in fact cause permanent hearing damage itself. And, if the patient already suffers from certain types of hearing loss, it may be impossible to draw any conclusions from the test. The Chalmers researchers' new method offers significant advantages.

"Thanks to this bone conduction technology, the sound levels which patients are exposed to can be minimised. The previous test was like a machine gun going off next to the ear—with this method it will be much more comfortable. The new vibrating device provides a maximum sound level of 75 decibels. The test can be performed at 40 decibels lower than today's method using air conducted sounds through headphones. This eliminates any risk that the test itself could cause hearing damage," says postdoctoral researcher Karl-Johan Fredén Jansson, who made all the measurements in the project.

The benefits also include safer testing for children, and that patients with impaired hearing function due to chronic ear infections or congenital malformations in the ear canal and middle ear can be diagnosed for the origin of their dizziness.

The vibrating device is compatible with standardised equipment for balance diagnostics in healthcare, making it easy to start using. The cost of the new technology is also estimated to be lower than the corresponding equipment used today.

A pilot study has been conducted and recently published. The next step is to conduct a larger patient study, under a recently received ethical approval, in collaboration with Sahlgrenska University Hospital in Gothenburg, where 30 participants with normal hearing will also be included.