

On the Level

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Quarterly Newsletter of the Vestibular Disorders Association

First Vestibular Prosthesis Implant Is Surgically Inserted

On October 21, 2010, Jay Rubinstein, MD, PhD, a neurotologist and biomedical engineer at the University of Washington (and professional member of the Vestibular Disorders Association) and a team of specialists inserted the first vestibular implant into a 56 year old Washington man who has Ménière's disease. The goal of inserting this "UW/Nucleus Vestibular Implant" is to help restore his balance and stop his vertigo. "When a Ménière's attack occurs, you basically have to lie down and curl up into a ball," Rubinstein reflects. "It's not very conducive to a productive existence if these are occurring once a week."

The UW/Nucleus Vestibular Implant is modeled after a cochlear implant. It uses different electrodes, but "is actually the cochlear implant processor, where we've rewritten the software for it," Dr. Rubinstein explained. While a cochlear implant uses one electrode array inserted into the cochlea to stimulate the auditory nerve, this vestibular implant relies on three shorter arrays (see Figure, page 2). Each one is inserted into one of the three semicircular canals to stimulate the vestibular nerve.

The fluid-filled semicircular canals normally function as a type of gyroscope, sending nerve impulses to the brain about the direction of head rotation. Ménière's disease alters the delicate sodium-potassium balance of inner ear fluids. According to Dr. Rubinstein, this "short circuits" the nerve impulses in the canals so that the brain doesn't receive accurate signals about rotation from the affected ear. As a result, vertigo, nausea, and

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other symptoms occur because the brain receives inconsistent signals about head rotation from each ear.

The UW/Nucleus Vestibular Implant works by monitoring fluid movement within each canal and then supplying bursts of electricity to the vestibular nerve from the affected canal, thereby compensating for the disrupted signal.

Dr. Rubinstein indicates that, due to the unpredictable timing of Ménière's attacks, evaluating the effectiveness of this first implant may take awhile. In the meantime, the team will also proceed with a Food and Drug Administration (FDA) approved 10-person trial of the device. "The promise of this project is that it will give us clinical experience and safety data on vestibular implantation in humans," Dr. Rubinstein reports, adding: "There are other research centers studying vestibular implants with which we can potentially

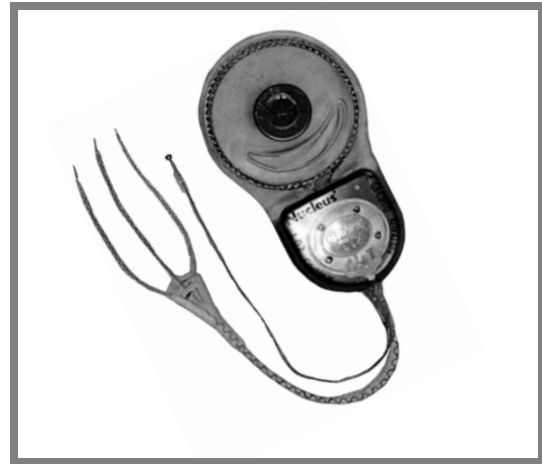


Figure: The UW/Nucleus Vestibular Implant is modeled after the cochlear implant.

collaborate and develop treatments for vestibular disorders which currently have no existing treatment."

To see a short video of the recent surgical implantation procedure, visit:

www.king5.com/health/UW-surgeons-perform-worlds-first-implant-to-treat-Menieres-disease-105483853.html.

News Briefs

Vestibular dysfunction caused by blasts worsens over time

Doctors analyzed the results of vestibular function and auditory tests administered to active-duty U.S. military personnel exposed to blast(s) in Afghanistan and/or Iraq. They found significant differences between the vestibular symptoms and disorders caused by blast exposure as

opposed to blunt head trauma. Blast exposure apparently produces vestibular symptoms and disorders that generally worsen over time. The authors indicate that designing long-term treatment strategies will require further research.

—Hoffer ME et al. *Otol Neurotol* 2010;31:232–236

Navy announces vestibular injuries have frequently been missed

On September 22, the American Forces Press Service released a ground-breaking statement made by U.S. Navy Surgeon General Vice Admiral Adam Robinson Jr., who announced “Nine years of conflict [have] revolutionized the way the military treats its combat-wounded ... We have finally, as a military and as a medical service—Army, Navy, and Air Force—come to grips with the fact that war creates injuries that are not seen, injuries that are just as life-changing and as devastating as amputations and other physical injuries.” Robinson reviewed the military’s recent progress in assessing, treating, and giving stability and context to those who have been injured in the war with these “unseen injuries—the ones you can’t make out, the ones that X-rays don’t show, the ones for which the blood work

doesn’t show the differences, but that certainly are there,” he stated.

Dr. David Williamson leads the Psychological Health and Traumatic Brain Injury Team at the National Naval Medical Center in Bethesda, MD. Working with the hospital’s trauma team to identify brain injuries in combat casualties and determine their severity, he said “We increasingly rely on vestibular testing to flag problems within the part of the inner ear that controls balance.” The vestibular organs can get damaged by blast waves, he observed. “Nothing physically hits your head, but a pressure wave through the skull can rupture these fluid-filled sacs inside bones in the skull and cause dizziness, coordination and balance problems, and sometimes, double vision ... That’s an injury that’s frequently been missed.”

—www.defense.gov/news/newsarticle.aspx?id=60955

Round window membrane thickness in Ménière’s disease

The round window is a soft-tissue barrier between the middle and inner ear. A thickened round window membrane (RWM) or the presence of a false RWM may explain why intratympanic injection treatment of Ménière’s disease fails in up to 20% of cases. Researchers in the U.S. and Japan compared temporal bones from patients with unilateral and bilateral Ménière’s disease with temporal bones from age-matched healthy individuals. They found that the middle layer of the RWMs from Ménière’s disease patients was significantly different (40% thicker) from those of healthy subjects. In addition,

false RWMs were observed in only 4.9% of the temporal bones of healthy subjects compared with 25% of the temporal bones from patients with bilateral Ménière’s disease, and 26.1% and 19% from the affected and unaffected sides of patients with unilateral Ménière’s disease. The researchers propose that the delivery of medication to the inner ear with intratympanic injection treatments may be impeded by a thickened RWM and the frequent presence of a false RWM in Ménière’s disease. —Shigetoshi Y et al. In: Program of the Annual Meeting of the AAO—HNSF, Sept. 26–29, 2010; Boston, MA. Poster SP450

(continued on page 4)

Can music influence balance? High intensity sounds, including music, are known to activate the inner ear's saccule and thus affect balance control. Researchers in Italy evaluated the influence of music on posture in 12 healthy subjects exposed to different types of music (Mozart, Köhler, and each subject's favorite music). Using static posturography with eyes open and eyes closed, with and without foam pads, the researchers recorded body sway and the use of visual, vestibular, and somatosensory (proprioceptive) information, while each subject listened to each type of music. Only one type of music included

in the study (Mozart's Symphony No. 41 in C major) was associated with a significantly reduced visual component, which was compensated for by increases in both the vestibular and somatosensory components. While additional research might be valuable for isolating the influence of specific characteristics within and across each music type (such as pitch, melody, harmony, and rhythm), this initial study may prompt interest in considering music as a potential factor in developing vestibular rehabilitation programs for people with vestibular disorders.

—Forti S et al. *J Vestibular Res* 2010;20(5):351–356

Students study virtual reality for balance During the summer, students at Temple University's Virtual Environment and Postural Orientation Laboratory in Philadelphia, PA, explored using virtual reality to build a tool to help people with dizziness and imbalance. The students' goal was to expand understanding of posture and balance adjustments made in a virtual-reality environment that incorporates real-life challenges such

as crossing a street or walking around a street corner while busy car traffic rushes nearby. With such enhanced animations, a person's balancing ability can be tested without subjecting the person to the risk of falling into actual traffic. To view a short video of the students' initial work on this and other virtual reality projects, visit: www.temple.edu/newsroom/2010_2011/09/stories/Vepo_lab.htm.

3-D TV technology bumps up against vestibular system The consumer electronics industry may have made its biggest and most costly mistake with 3-D TV, according to critics. The glasses worn with 3-D TV have polarized filters that create the 3-D effect by separating what is seen into two images. "The separation occurs so quickly that your brain may have difficulty accepting it," said Steven Nusinowitz, PhD, associate professor of ophthalmology at the Jules Stein Eye Institute in Los Angeles,

CA, in an interview with CNN earlier this year. "The movie is telling you 'Hey, I'm moving around in this scene,' but your vestibular system is telling you, 'I'm not moving anywhere,' and that disconnect will make some people feel sick," Nusinowitz said. Further research is needed to confirm reports estimating that up to 20% of 3-D TV viewers have a problem with motion sickness or headaches.—www.tvpredictions.com/3dsick110810.htm

Balance Awareness Week 2010

Established by VEDA in 1997, Balance Awareness Week occurred this year on September 19–25. To help draw worldwide attention to the importance of having good balance, VEDA designed and distributed color postcards to the public and posters to doctors, occupational therapists, physical therapists, audiologists, and other specialists for displaying in clinics and hospitals.

We also urged our professional members to get involved and help raise awareness. In return, we offered to advertise their events to our extensive online audience. We were thrilled by the results, which included many clinics offering free balance screenings, open-house gatherings, and public education lectures and support group presentations with titles such as *Better Balance*, *Demystifying Dizziness*, *Fall Prevention*, and *Neuro-Feedback for Adults and Children*.

We want to thank the following professional members for informing us about the public events they organized: Atlanta Ear Clinic (Atlanta, GA), Aultman Tusc Therapy (Canton, OH), Balance & Body Rehab (Toledo, OH), The Balance Centre (Dublin, Ireland), Dominic Servedio Audiology (New York, NY), Focus on Function Physical Therapy (Iron Mountain, MI), Lee Center for Rehabilitation & Wellness (Fort Meyers, FL), Physiotherapy Associates (Wheat Ridge, CO), and WWS PT and Associates (Doylestown, PA). In addition, we thank D. Sharon Pruitt, who donated the photograph used for this year's promotional materials.

VEDA also appreciates all of our members' efforts to elevate public awareness of vestibular disorders during Balance Awareness Week, and who support our work on behalf of people with these disorders all year long.

Mark your calendars for the 15th Annual Balance Awareness Week celebration on September 18–24, 2011!



Figure: VEDA's 2010 Balance Awareness Week color poster (11½" x 17½") was distributed internationally.

How do I know if I have a balance disorder?

Millions of individuals have disorders of balance they describe as “dizziness.” Experts believe that more than four out of ten Americans will experience an episode of dizziness significant enough to send them to a doctor.

What can be difficult for both a patient and his or her doctor is that the word “dizziness” is a subjective term. This means that the word can be used by people to describe different sensations they are experiencing, but it is hard for anyone but the person experiencing the symptoms to understand or measure the nature or severity of the sensations. In addition, people tend to use different terms to describe the same kind of problem. “Dizziness,” “vertigo,” and “disequilibrium” are often used interchangeably, even though they have different meanings.

Definitions

Describing your symptoms accurately can mean the difference between a successful diagnosis and one that is missed.

- *Dizziness* is a sensation of light-headedness, faintness, or unsteadiness.
- *Vertigo* is the perception of rotational movement or whirling—either of the self or surrounding objects.
- *Disequilibrium* is the loss of equilibrium. It can be experienced as a sensation of spatial disorientation or imbalance.

Almost everyone experiences a few seconds of dizziness or disequilibrium at some point—for example, when a person stands on a train platform and momentarily perceives an illusion of moving as a train rushes past. However, for some people, symptoms can be intense and last a long time, affecting a person’s independence, ability to work, and quality of life.

Balance disorders can be caused by medications or certain health conditions, including problems with the inner ear (vestibular) organs or the brain. Dizziness, vertigo, and disequilibrium are all symptoms that can result from a peripheral vestibular disorder (a dysfunction of the balance organs of the inner ear) or central vestibular disorder (a dysfunction of one or more parts of the central nervous system that help process balance and spatial information).

Ask yourself...

To help you decide whether you should seek medical help for a balance problem or dizzy spell, ask yourself the following questions. If you answer “yes” to any of these questions, talk to your doctor.

- Do I feel unsteady?
- Do I feel as if the room is spinning around me?
- Do I feel as if I’m moving when I know I’m sitting or standing still?
- Do I lose my balance and fall?
- Do I feel as if I’m falling?

- Do I feel lightheaded or as if I might faint?
- Do I have blurred vision?
- Do I ever feel disoriented, such as losing my sense of time or where I am?

How can I help my doctor make a diagnosis?

You can help your doctor make a diagnosis and determine a treatment plan by filling in the information called for in the list below. You may want to jot down your responses to help you prepare for your appointment with your doctor.

- The best way I can describe my dizziness or balance problem is: ...
- How often do I feel dizzy or have trouble keeping my balance?
- Have I ever fallen? If so, when, where, how often, and under what conditions?
- These are the medicines I take: ...

Take balance disorders seriously.

Balance disorders may lead to other problems including fatigue, difficulty walking, or disinterest in everyday and leisure activities. If you or your child, parent, friend, or co-worker has a balance problem, take it seriously. Talk to the doctor about what happens

when the dizziness or imbalance occurs. Be as careful as possible in describing the symptoms.

This article is adapted from information provided by the National Institute on Deafness and Other Communications Disorders, (NIDCD). For additional information, visit: www.nidcd.nih.gov/health/balance/balance_disorders.htm.

Definitions

Dizziness:

A sensation of lightheadedness, faintness, or unsteadiness.

Vertigo:

The perception of rotational movement or whirling—either of the self or surrounding objects.

Disequilibrium:

The loss of equilibrium. It can be experienced as a sensation of spatial disorientation or imbalance.

Spatial disorientation:

A sensation of not knowing where one's body is in relation to the vertical and horizontal planes.

News About VEDA

VEDA members vote to amend the Articles of Incorporation

With overwhelming support, members of the Vestibular Disorders Association (VEDA) approved the Board of Directors' recommendation to make a technical change to VEDA's Articles of Incorporation. By the end of the voting period on Oct. 26, 2010, an unprecedented 26% of members participated in the amendment ballot, with 96% of voters approving the decision to bring VEDA's corporate documents more closely into alignment

with the role members actually play within the organization. This large turnout reflects members' confidence in VEDA's dedication to serving people with vestibular disorders. The Board appreciates the decisive vote which allows VEDA to focus its attention and resources on continuing to serve its members and reaching more individuals coping with vestibular disorders.

Member discount increases and prices drop for VEDA books and DVD

We've dramatically lowered the price of many of our products and increased the member discount on them. For example, our DVD and the book *Balancing Act*, 2nd ed. are each now \$10 for members (\$15 for non-members). Our books *Ménière's Disease—What You Need To Know* and *Benign Paroxysmal Positional Vertigo (BPPV)—What You Need To Know* are

each \$15 for VEDA members (\$20 for non-members). Shipping and handling fees are additional, but we keep those charges as low as possible. To take advantage of your member discount in our secure online store (<https://vestibular.org/shop/>) you'll need to supply your VEDA member number, which you'll find in the address area on the back cover of this newsletter.

VEDA's first chairperson leaves legacy

We are sincerely grateful to hear of a bequest made to us by one of VEDA's champions, Jeanette Ann Welch. Before her death, we interviewed Jeanette about her volunteer work as VEDA's first chairperson during the 1980s. "Our early efforts were guided by three assurances the organizers thought members needed to hear," she recounted:

"You must educate yourself."

"You aren't alone."

"You aren't crazy."

Jeanette was committed to helping people with vestibular disorders. After finishing

each week teaching high school mathematics in Seaside, OR, she would climb into her car and drive over the Oregon Coast Range to VEDA's office in Portland, putting herself up in a local hotel so she could make the most of her working weekend. "People asked us for help," she declared, "and we gave it!"

Long after retiring, Jeanette continued to support VEDA as a dedicated member and donor for almost 30 years. Although she is no longer with us, her remarkable commitment to VEDA's work will carry on through her thoughtful bequest.

Planned-giving information available from VEDA

We all have personal reasons for supporting charities. Each time we donate, we make a statement of appreciation and hope. We also help strengthen work that is meaningful to us. Imagine the difference you can make with a special gift to VEDA, while also taking advantage of charitable-giving tax incentives offered by the Internal Revenue Service.

If you would like us to send you information about including VEDA in your will, monthly donations, and other planned-giving options, please e-mail VEDA staff member Kerrie Denner at development@vestibular.org or leave her a voice mail by calling 1-800-837-8428. We are always grateful for your support.



VEDA Members Ask About Research

VEDA receives comments from members who are frustrated with their perception of how little is known about vestibular disorders. They want to help advance scientific knowledge so that new treatment options become available to them, and so that other people don't experience the same difficulties they encountered during the process of seeking informed medical help. They ask: "Why does research about new treatments take so long?" And: "If I help the scientists by becoming a research subject now, would the results speed up the development of new treatments for me?"

Why does it take so long to develop new treatments?

Before any new diagnostic method or treatment can be used on a patient, it must be analyzed to determine how effective and safe it is. The scientific method is used to perform this analysis so that accurate and unbiased information is produced.

In preparation, scientists often wade through lengthy application processes to obtain funding for the project. They also devote large amounts of time to reading

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about related research to ensure that they add to existing knowledge rather than duplicate what is already known. Steps of a scientific experiment can include numerous elements. For instance, constructing the tests involves identifying what to test, how, when, where, and by whom, as well as the number of research subjects required to provide enough information (data) to validate the study. Researchers must decide how to analyze the data, build the testing device (or equipment), find the research subjects to participate in the test, collect data (recording measurements produced during the test), compile (add up or convert) and analyze the data, and then draw conclusions from the results of the data analysis. After that, the results and conclusions need to be written up, reviewed and approved by other scientists, and, finally, presented to the medical community.

The results of experiments frequently lead to additional questions that require clarification. Multiple, separate research projects are often involved in the development of a single diagnostic or treatment method.

What kind of personal benefits and consequences can I expect as a research subject?

Being a research subject can be a rewarding experience if expectations about the experience are well defined. Participation can improve a person's feeling of self-

worth because it contributes to the advancement of medical knowledge that will help people in the future. But it is also important to acknowledge that, for a research subject with a vestibular disorder, the physical consequences of participating in the experiment may include a temporary increase in symptoms.

The scientific method

1. Observe/describe a particular phenomenon.
2. Formulate a specific question or hypothesis (hypothetical explanation) about the phenomenon.
3. Predict what will happen if that hypothesis is tested.
4. Use experimental tests of those predictions to confirm or rule out the hypothesis.

Also, a frequent misconception is that medical research subjects will receive immediate physical benefit or better health care. This is not usually the case. The process is not oriented to providing individually tailored medical care for a specific person. Rigorous medical research is designed to answer very specific questions about a group of people. In fact, many research projects

are carried out by non-physician scientists who aren't licensed to provide health care or give advice.

What specifics should I know about becoming a research subject?

Prospective research subjects should be presented with a consent form that identifies all of the potential risks and benefits of participation. No one should sign a consent form before reading and thoroughly understanding it. This might involve acquiring a copy ahead of time in order to study it and seek help in understanding it, if needed.

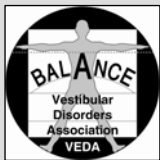
The consent form should describe what the test involves, how much time will be required, who will lead the research, whether payment will be given, and who pays if an injury occurs. Researchers work diligently to keep their experiments safe, but there is always some risk of injury when dealing with human beings. If the research facility does not pay for injuries, a potential research subject should, prior to signing the consent form, confirm that his or her own medical insurance company will cover any injuries that might occur during, or as a result of, participation as a research subject.

Many major research projects do not offer subjects financial compensation for their time and efforts. Others offer a small participation fee. But research subjects should not be expected to pay for any part of the research.

If asked, the researchers should be able to provide information about the validity of the project's administration (e.g., if the research has been approved by an institutional review board and what organization is funding this research) and about the research scientists' background (e.g., their special research training, other studies they've done, if they've received other competitive research grants, and if they've published results from other projects). They should also be able to tell participants if other researchers are studying the same issues and if the results will be presented at a research meeting such as those sponsored by the Association for Research in Otolaryngology.

Other sources of information on this topic include doctors or other health professionals; VEDA's Web page of ongoing clinical trials: www.vestibular.org/vestibular-disorders/research.php; and "Understanding Clinical Trials," a Web page sponsored by the National Institutes of Health: <http://clinicaltrials.gov/ct2/info/understand>.

Scientists who would like to submit a posting for research subjects may send a brief description of the study and contact information to copyeditor@vestibular.org.



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The Vestibular Disorders Association (VEDA) is a 501(c)(3) nonprofit organization with a mission to serve people with vestibular disorders by providing access to information, offering a support network, and elevating awareness of the challenges associated with these disorders.

On the Level is a quarterly publication of the Vestibular Disorders Association (VEDA), published in Portland, Oregon, USA and distributed to national and international members. Information in this newsletter is not intended as a substitute for professional health care. VEDA does not recommend any particular course of treatment, clinic, or health care practitioner. The opinions expressed in articles in *On the Level* are those of the authors and not necessarily those of VEDA's staff, medical and scientific advisors, or Board of Directors. The publisher reserves the right to accept, reject, or edit any materials received for publication. Editor: Lisa Haven, PhD. No part of this publication may be reproduced without written permission. ©All rights reserved.

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Thanks to VEDA, vestibular disorders are becoming recognized for their impacts on lives and our economy. We see new diagnostic tools and research studies, more accessible treatments, and a growing respect for how life-changing vestibular disorders can be.

VEDA provides tools to help people have a better quality of life: educational materials, support networks, professional resources, and elevated public awareness.

Your support of VEDA matters. Please help us to continue providing such great help by becoming a member or donor.

Members receive an information packet; discounts on purchases; a subscription to VEDA's newsletter, *On the Level*, containing information on diagnosis, treatment, research, and coping strategies; and the option of communicating directly with others who understand the personal impacts of a vestibular disorder. Professional members also receive the option to list training opportunities on our site, bulk-discounted prices on patient education materials, and a listing on VEDA's provider directory, the only of its kind serving patients seeking help from a vestibular specialist.

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