ONTHELEVEL A QUARTERLY NEWSLETTER OF THE VESTIBULAR DISORDERS ASSOCIATION



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I Got Vertigo For My Birthday

Michele Croteau's Battle With Vertigo, by Barbara Roggenbeck & Cynthia Ryan

Michele Croteau's battle with dizziness began in 1989, when she was plagued with acute episodes of dizziness ranging from general feelings of being off balance to full blown vertigo attacks. This continued for about 9 years, during which time she consulted with multiple medical specialists at some of the best vestibular centers in the country.

Michele's first episode of vertigo occurred on her 29th birthday. She was attending a friend's wedding and remembers turning to the left and standing up, then suddenly her world was spinning out of control. The vertigo lasted for hours and was accompanied by several days of dizziness and imbalance. That's when Michele sought help from her family physician, who referred her to an ENT. Her MRI, CT scan, and EEG tests were all normal. She attempted an ENG test, but couldn't complete it because of a serious intolerance that resulted in vomiting. The ENT prescribed Antivert, which did not resolve her symptoms. Michele had spent half of her career in the fashion industry working

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TOP LEFT: MICHELE AND HUSBAND, TOM, VOLUNTEERING AT THEIR CHURCH; BOTTOM LEFT: MICHELE, TOM, AND MICHELE'S MOTHER, ROSEMARIE, AT HER COUSIN'S WEDDING; BOTTOM RIGHT: MICHELE & TOM VOLUNTEERING FOR UGANDA FARMERS INC. **On the Level** is a quarterly publication of the Vestibu**On the Level** is a quarterly publication of the Vestibular Disorders Association (VEDA). 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 these articles 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. No part of this publication may be reproduced without written permission. \bigcirc All rights reserved.

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BIRTHDAY VERTIGO...CONTINUED FROM PAGE 1:

for several major companies and the other half as a high school and college teacher. She also had a personal jewelry business creating custom fine jewelry. When vertigo hit, everything changed. She couldn't ride the train into New York City for her jewelry business or attend family social occasions. She never knew when an attack would hit, and when it did she was so incapacitated a friend or family member had to stay with her to make sure she could get to and from the bathroom.

Eventually her episodic dizziness transformed into chronic dizziness in the form of constant imbalance with intermittent vertigo attacks exacerbated by head and body movements, bright lights, loud noises, busy visual environments, computer screens, ceilings fans, and traveling, and also accompanied by migraine related headache



WHEN SHE CLOSED HER EYES SHE WOULD SEE JAGGED TRIANGULAR SHAPES OF A MILLION COLORS, LIKE A KALEIDOSCOPE ON STEROIDS.

pain that increased in intensity and frequency over time.

Life as she knew it ceased to exist, and most of her friends thought she was exaggerating because she didn't look ill. Everywhere she went people offered "medical" suggestions and diagnoses. She felt frustrated, embarrassed, and emotionally drained.

In 1990, after several years with no answers and the beginning of what was now developing into a chronic problem, Michele had further testing done at the Yale Balance Disorder Center, including another ENG test. Doctors were still unable to explain her symptoms, except the possibility that there might be a cervical connection. Again, Antivert was prescribed for vertigo, as well as Compazine to control the associated nausea, neither of which provided Michele any relief.

This chronic phase became even more challenging with the addition of new symptoms, including right sided body numbness and numbness at the back of the skull with severe migraine symptoms. Typically a migraine would start with a knife-like pain through her left eye, and when she closed her eyes she would see jagged triangular shapes of a million colors, which she describes as "a crazy kaleidoscope on steroids." Sometimes a migraine could bring on vertigo, other times vertigo could bring on a migraine. Both were accompanied by vomiting and residual effects which lasted for days. Basically her life had become a living nightmare.

In 1998 Michele was referred to Neurotologic Associates in New York City. The examination involved a vast array of tests, including hearing tests, an MRI, balance tests including ENG and rotary chair testing, CAT scans of her temporal bones to look for any structural defects, and glucose testing, which is often performed when a metabolic inner ear disease is suspected. Michele was diagnosed with otosclerosis and hyperinsulinemia, for which she was prescribed several medications and diet modifications. Finally, some relief! Her symptoms were mitigated for about four

years, although sporadic episodes of vertigo still occurred.

However, in 2001, Michele's chronic phase took a turn for the worse. She suffered a severe attack of vertigo while looking through files at work and the daily dizziness resumed. Her neurootologist recommended that she continue the same regimen, even though her symptoms were becoming more difficult to manage.

In 2002, Michele sought medical treatment at New York Eye and Ear Infirmary, where she underwent hearing tests and a platform posturography test. Her medical treatment included Valium for daily symptoms, Compazine for nausea, Antivert for vertigo attacks, and vestibular rehabilitation. She was diagnosed with possible left sided Meniere's

AFTER 15 YEARS, MICHELE FOUND RELIEF FROM HER VESTIBULAR MIGRAINE SYMPTOMS, THANKS TO SUPERSTAR, DR. DAVID-NEWMAN TOKER

and an alternative diagnosis of recurrent viral neuronitis. At this point, Michele was informed that if the vestibular rehabilitation did not help there was nothing they could do for her. The vestibular rehabilitation caused her symptoms to flare and left Michele confined to her home, so she discontinued treatment.

That same year Michele was evaluated by a naturopathic doctor and another general physician

in Westport, CT. She was tested for Lyme's disease, prescribed a 30-day treatment of antibiotics, histamine drops, mold drops, vertigo heel tablets, and lipoflavonoid tablets for dizziness. Unfortunately, the treatments were unsuccessful and the daily dizziness prevailed.

Finally, in 2003, Michele was diagnosed with vestibular migraines by Dr. David Newman-Toker at John Hopkins University. Once he figured out the right formula of medications she slowly started to feel better. Car rides from Baltimore to Connecticut became easier, and even

though she still experiences severe migraine pain and occasional brief episodes of dizziness, she is able to function and even be productive.

Finally, after 15 years of searching for relief, Michele has found an effective regimen for controlling her debilitating vestibular migraine symptoms. She credits Dr. Newman-Toker with her recovery success, elevating him to the height of "superstar." Throughout her vestibular journey Michele's husband, Thomas, and best friend, Joanne, have stood by her side and supported her. Michele's story is yet another example of the importance of getting an accurate diagnosis, which starts with finding a qualified vestibular specialist. Thanks to Dr. Newman-Toker, and all of VEDA's professional members, for their service to the vestibular community.

What To Expect During Your Vestibular Evaluation

By Cammy Bahner, M.S., CCC-A



Seeking appropriate medical attention for dizziness and/or imbalance can be an overwhelming task for many patients. What kind of doctor should I see? Will s/he be able to figure out what's causing my dizziness? How will it be treated? What kind of tests will I have?

There are many tests that can help your physician determine why you are feeling dizzy. To help you better understand what to expect during your vestibular evaluation, we will explore a few of the more common diagnostic tests for dizziness.

VIDEONYSTAGMOGRAPHY (VNG)

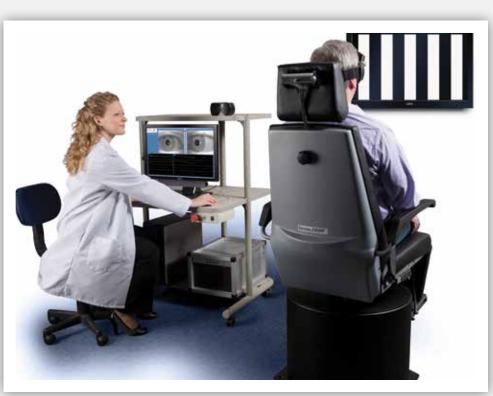
Videonystagmography (VNG) is the most common vestibular test. VNG utilizes cameras that are imbedded into goggles to monitor and measure

eye movements. Specifically, a VNG is a series of several tests that will help the medical professional determine how well your eyes communicate with your inner ear balance system and your brain.

While wearing the goggles, you will be asked to perform several tasks while watching a screen. These tasks are very simple, but will yield important information about how well your eyes are communicating with your brain. The next step in the VNG process is for the examiner to assist you into several different postural positions. This helps to determine whether a change in the position of your head and/or body will evoke the dizzy symptoms. The final VNG test is known as caloric irrigation. During calorics, the examiner will put either warm or cool air (or water) directly into one ear at a time, during which you may experience a "spinning" or "floating" sensation. The examiner will perform this procedure a total of four times, to determine if your inner ear balance organs are functioning equally when compared to each other. The entire VNG should take less than one hour to complete.

ROTARY CHAIR

The rotary chair test provides additional information about a patient's vestibular system. During the rotary chair test, you will be seated in a comfortable chair with security straps to keep your body and head stable during the rotations. Your eye movements will be monitored during rotations using the same goggles that are used in the VNG. The chair spins at various speeds throughout the test while the goggle cameras record eye movement in response to the spinning. The rotary chair test aids in diagnosing vestibular problems by yielding information about how well the balance systems are functioning.



VIDEO HEAD IMPULSE TEST (VHIT)

vHIT is another common test used to evaluate your vestibular system. Once again, you will wear a lightweight goggle with a camera and motion sensors built in. You will be instructed to focus on a target in front of you while the examiner will assist you in making small, quick, random head movements, called impulses. When your head moves to the left your eyes should move to the right. This reflex, called the Vestibulo-Ocular Reflex (VOR), keeps our eyes on a stationary target while we move our head and allows us to read a sign while we are walking. vHIT measures and analyzes this reflexive eye movement and provides the examiner with immediate information about whether your symptom of "dizziness" is caused by one (or both) inner ear vestibular systems. The entire process takes less than 10 minutes.

There are several other tests that your physician may order as well, but VNG, Rotary Chair, and vHIT are some of the most common tests used to evaluate the inner ear vestibular system. They will provide your physician with valuable information regarding how well your vestibular system is relaying information to your brain and other parts of your body and will help your physician to make appropriate recommendations to treat the underlying problem causing the dizziness.

BROUGHT TO YOU BY MICROMEDICAL TECHNOLOGIES

Ambassador Spotlight

By Verity Joyce



VERITY FORCED HER BRAIN TO LEARN TO SWIM AGAIN AFTER SURGERY FOR MENIERE'S DISEASE.

I have been deaf since I was a baby and I've had balance problems from the age of six. At 11 years old I was diagnosed with Meniere's disease.

I underwent surgery when I was 17, which was designed to destroy my balance system while

preserving any remaining hearing, during which I had 42 intra-muscular streptomycin injections. Ultimately the surgery was unsuccessful.

Prior to my surgery I was ranked 3rd in the world for (high school) Senior Deaf Women in the 200 meter backstroke, but following the injections I was unable to swim without knowing which way was up. I forced my brain to learn to swim again, but never got back in the rankings, which led to years of learning to deal with loss and grief.

The neuro-plasticity I learned through my vestibular rehabilitation helped me on land, and kick started my career in physiotherapy and later psychological therapy. As such, I developed a daily tool box to manage my symptoms, particularly related to my vision problems.

I become a VEDA ambassador because I am keen to encourage people to find a way to become masters over their lives, even when what they feel and see seems such a muddle, as this can make them doubt themselves and their identity.

CORRECTION: IN THE WINTER 2016 ISSUE OF ON THE LEVEL, SUSAN WHITNEY WAS ACKNOWLEDGED AS A CHAMPION OF VESTIBULAR MEDICINE, BUT THE PHOTO IN THE PRINT EDITION WAS OF SUSAN HERDMAN. WE SINCERELY APOLOGIZE FOR THE ERROR AND THANK SUSAN WHITNEY FOR HER MANY CONTRIBUTIONS TO THE VESTIBULAR COMMUNITY.

An Old Drug Makes A Big Difference

A collaboration with Dr. Joel F. Lehrer and his patient, Barbara Strongin (with Sherron Laurrell)

Barbara Strongin has struggled with vestibular problems for over fifty years. Few treatments had provided her with relief, but she had learned to cope with her symptoms.

Barbara suffered a mild head injury when she was three years old, along with hospitalization for severe dehydration from an unknown virus, and has had spinning and non-spinning dizziness since that time. Barbara's symptoms included positional vertigo, a sensation she calls "swimminess," and imbalance, which at times could be quite severe and has been intermittently present her entire life, with positional vertigo episodes lasting from four to nine hours.

Barbara initially consulted with Dr. Joel F. Lehrer, MD., F.A.C.S, a specialist in Otology/Neurotology, twenty-five years ago, but never followed up with him because her symptoms came and went, and she was unwilling to endure some of the tests



DR. JOEL F. LEHRER

required to ascertain a proper diagnosis. Then, on the night of February 16, 2014, Barbara awakened with right ear pain, fullness in the right ear, and severe imbalance. Her primary doctor treated her with Bactrim, Levaquin, Benadryl and Antivert; none provided any relief. She continued to have a lingering sense

of fogginess, and while the symptoms would occasionally subside for several days they were unpredictable. Her ear pain was sharp at times, an ache at times, and a deep fullness at other times. Although ear "fullness" is not uncommon in patients with vestibular disorders, ear pain is less common, and can occur even with a normal examination of the outer and middle ears. Barbara's symptoms of earache and fullness, and severe imbalance continued through February and March. In early April, she turned again to Dr. Lehrer for help.



BARBARA CREDITS HER HUSBAND, ROGER DIXON, AS A CONTINUAL SOURCE OF STRENGTH AND SUPPORT

During that visit Barbara described a dreadful and relentless imbalance that occurred even when she was still, along with ear pain and fullness that were nearly constant. She did not look "sick," which is typical of most vestibular patients and can throw off both the doctor and their family. It is also a source of great distress to the patient, who may feel anxious and terrified since nothing can be found to explain their symptoms, or relieve them.

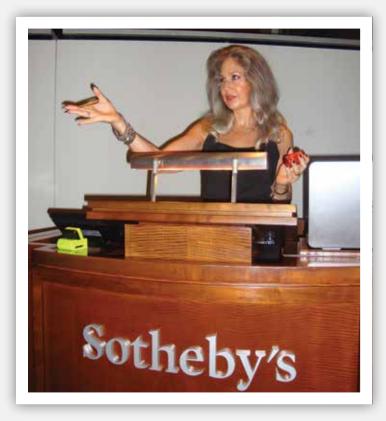
When Dr. Lehrer originally consulted with Barbara 25 years earlier her symptoms included both spinning and non-spinning vertigo, but this time she described a swimmy feeling but no spinning. There was no evidence of spontaneous or positional nystagmus, so disorders such as vestibular neuritis and BPPV were ruled out. Barbara's imbalance was confirmed via the Quix and Romberg Tests.

The Quix Test, described by Professor F.H. Quix in 1924, and updated by Professor C.W. Hart in 1983, is performed much as police officers do when examining a driver for being intoxicated. The feet are together, the chin is up, and the arms and index fingers are outstretched. One looks for a sway or shakiness as abnormal findings. It is more sensitive than the Romberg Test, which is also performed with the feet together but with the arms at the sides or crossed over the chest. In Barbara's case, there was slight shakiness on the Romberg test and a sway to the right on the Quix test.

After a series of other diagnostic tests Dr. Lehrer narrowed his consideration to the less understood non-spinning

vestibular disorders. The most common of these in his practice are Nucleo-Reticular Vestibular Syndrome (NRVS), disorders of the inner ear fluid system, Perilymphatic Fistula (PLF) and Perilymphatic Hypertension (PLHT). Ultimately Dr. Lehrer determined that NRVS was the cause of Barbara's condition.

NRVS was first described in the European literature in 1959 as a syndrome localized in the brain stem that can cause both spinning



BARBARA IN HER ROLE AS DIRECTOR OF ADMINISTRATION OF SOTHEBY'S INSTITUTE OF ART

BARBARA CREDITS DR. LEHRER WITH "GIVING HER BACK HER LIFE." and non-spinning symptoms. Dr. Lehrer began using the drug Cyproheptadine (CH) (brand name Periactin, a Merck product) in the early 1970's to treat NRVS after Gordon Gilbert's paper in *The Journal of the American Medical Association* in which he suggested a connection between vertigo and migraine. CH is an anti-serotonin and an anti-migraine drug, although it is better known for being an antihistamine.

According to Dr. Lehrer, who has done research on the distribution of Serotonin (5HT) in the brain, the brain stem is rich in 5-HT and neurons that utilize 5-HT in transmission. In 1976, he posited that the brain stem, which receives vestibular impulses, could be the site of pathology in dizzy patients who respond to CH. More recently Halbertadt and Balaban have described 5-HR transporter fibers as being most dense in certain vestibular nuclei in the brain stem.

When Barbara was examined on April 7, 2014, a hearing test was performed as well as tympanometry, both of which were normal. Fistula testing was negative. CH was prescribed for her imbalance and proved to be successful in controlling her symptoms.

Barbara's balance has improved considerably. Her ear pain resolved over a period of months. Follow up balance examinations were normal. In November, 2015, she reported that she was 90% symptom free on a small dose of CH.

Barbara credits Dr. Lehrer with "giving her back her life." If she is tired she may experience blurry vision but her symptoms are nothing compared to what she suffered in the past. She was in a bad way when she went to see Dr. Lehrer in 2014 and is now able to work and function normally. The positional vertigo that she suffered comes and goes but that is also much decreased since she has begun taking CH. She is deeply grateful to Dr. Lehrer for helping her get her balance back, for the first time in her life.

Journaling Your Vestibular Experience

By Kelly Gregory and the Vestibular Disorders Association



KELLY GREGORY, VESTIBULAR PATIENT

Journaling can help you work through the emotional challenges you face as a result of your vestibular disorder. Journaling is not a perfect science. Try to stick with it long enough to see if it is helpful to you. There is no one "correct way" to journal. The following instructions can help you get started. Don't hold back or get caught up in

what to say or how to say it. Just let it flow.

- 1. Choose an experience that is emotionally difficult for you and that you have a hard time talking about or thinking about. It may be the point at which you were diagnosed with a vestibular disorder, or perhaps your first episode of dizziness, for example.
- 2. Tell yourself a story in which you describe both the experience and your feelings about it. Don't hold back. What has your illness taken away from you? How have you changed? Have you lost support from your family? Your job? How does that make you feel?
- 3. Don't worry about details. Spelling, grammar

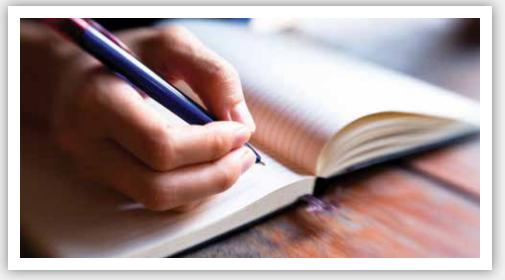
and punctuation aren't important. Your writing doesn't have to be perfect. It's more important to stay true to your emotion.

- 4. Write for 15-20 minutes without stopping or re-reading until the time has passed. Try to write continuously.
- 5. Write for 4 consecutive days.
- On the second or third day, if you haven't already, write about

how this experience has impacted your life. How did it shape you? How has if affected how your life has evolved? What impact has it had on your relationships? On your family life? Be honest with yourself.

- 7. Notice your feelings as you write and afterwards. You may feel upset for a couple hours or even a couple days. This is normal.
- 8. Your journal is yours and private. You may want to let your family members know about it and ask them to respect your privacy.
- 9. You can use a hard copy (paper) journal or your computer. If you are using a hard copy journal you may want to draw pictures or cut out images from magazines, etc. and paste them into your journal.
- 10. If you are having a hard time beginning, relax, take a deep breath, and get into a comfortable position. Let images to flow through your head. The thoughts will come.
- 11. If you have vision or cognitive problems, consider keeping a voice recorded journal.

*Become a VEDA Sustaining Member and receive a complementary journal and additional guidance on how to track your symptoms.



Meet Terri



VEDA is excited to welcome Terri Baltus to our team where she will be serving as our Development Director and leading the Balance Awareness Week campaign. Terri has over 20 years of experience working in the development field for health-related non-profit organizations. She held the position of Chief Development Officer for the American Tinnitus Association and the National Psoriasis Foundation, where she worked with many patients, physicians and donors. She began her development career with the American Cancer Society, where she developed and directed the Relay For Life (RFL) program for the western United States, then went on to develop and lead the International RFL program. Terri is a third generation Oregonian and has four grown daughters and a rock & roll musician husband, Tim.

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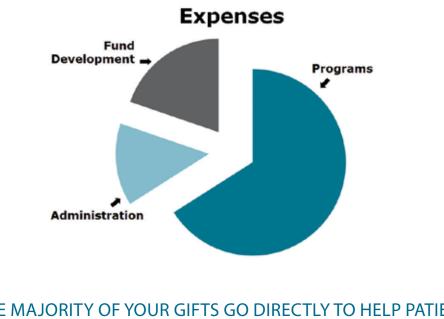
To join with VEDA as a 2016 Balance Awareness Week Sponsor, contact Terri Baltus at (800) 837-8428 or terri.baltus@vestibular.org

*If you know a company that you think might be interested in sponsorship, let us know!

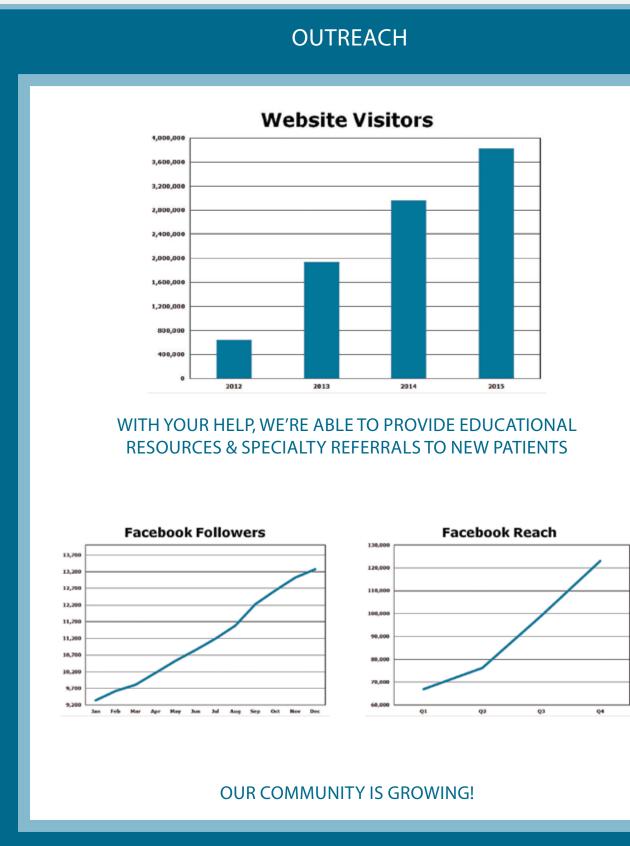
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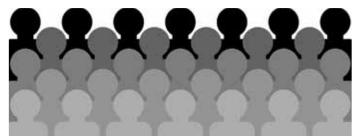
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DOES HEARING LOSS LEAD TO DEPRESSION?

Objective: To study the backgrounds of patients with audiovestibular disease regarding what influences their psychological state.

Methods: Cornell Rating Index and Self-Rated Depression scales were used.

Results: Neurosis and depression were diagnosed in 62.7% and 82.4% of bilateral Meniere's, 32.7% and 48.9% of unilateral Meniere's, 15.7% and 38.6% of sudden deafness/vertigo, 12.7% and 31.3% of vestibular neuritis patients.

Conclusion: Mental disorder increased in accordance with solo vertigo, vertigo/hearing loss, repeated symptoms, and bilateral lesions. Treatment strategies should be carefully constructed for patients with persistent nystagmus, long disease duration, and hearing loss in the secondary affected ear to avoid psychological disorders.

Source: Auris Nasus Larynx. 2016 Feb 24. pii: S0385-8146(16)30043-8. doi: 10.1016/j. anl.2016.02.006.

DO INTAKE QUESTIONNAIRES IMPROVE DIAGNOSIS?

Objective: To develop a statistical model for predicting vestibular diagnosis prior to clinical evaluation from an intake questionnaire.

Methods: Retrospective review of 414 vestibular patient intake questionnaires.

Results: Of the 414 questionnaires analyzed, 381 (92%) had clinician information necessary to define a final diagnosis.

Conclusion: A pre-encounter history questionnaire can provide useful diagnostic information for common vestibular disorders.

Source: JAMA Otolaryngol Head Neck Surg. 2016 Feb 25. doi: 10.1001/jamaoto.2015.3663.



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RESEARCH UPDATE

