

On the Level

Quarterly Newsletter of the Vestibular Disorders Association

Life Can Change In a Minute

MY EXPERIENCE WITH BILATERAL SEMI-CIRCULAR CANAL DEHISCENCE By Laurie Rainey

When I hear people casually say that life can change in a minute I shudder at how true that really is. In June of 2010 I was enjoying a balmy weekend in wine country with my beloved husband, indulging in good food, wine, and appreciating the romance of our lives. The next morning on my way to the bathroom I was overtaken by a sudden, violent, and terrifying vertigo attack. Never having had one before I was thoroughly confused and ended up falling, hitting my head, and landing in the ER. As my husband escorted me into the hospital I was crying and trying to tell him that I knew in my heart something life altering and dreadful had happened. I was right.

Within five months I was diagnosed as having a rare condition called bilateral semi circular canal dehiscence. Simply put, I had no bones covering my semicircular canal and my poor brain and vestibular system were under attack. I could barely walk, my head felt like a 500 pound cat was sitting on top of it, when I stood up it felt like I was being punched in the head over and over again, I couldn't track in conversations, got stuck on words, and I was

unable to navigate in the dark or walk down aisles at stores. After a series of doctor visits and tests. a CT scan confirmed the diagnosis and I was scheduled for surgery for December 2010. I could no longer work after the first few weeks of school. I am an elementary school counselor and my attempts at walking into my school were like walking into the epicenter of an earthquake. Everything moved. I had to hold onto the walls and I looked terrified. I'm sure I looked drunk which is not a good way to look in any elementary school. I lasted six long

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Balance

Week

September 16-22, 2012

Help VEDA
Defeat Dizziness by
participating in BAW
activities.

Stay tuned for details!

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Listening Effort

VEDA is accepting applications for board

Pupil Dilation

membership

Uncovers Extra

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Life Can Change in a Minute (continued from pg 1)

weeks that school year and collapsed. I flew to LA before my diagnosis and actually did collapse at LAX . The LAPD were quite suspicious when I kept telling them I was experiencing a "vehicular homicide" instead of a vestibular disorder. They thought I had just killed someone. The brain fog was bad that day. That was not a pleasant day for my husband either who got the call from the LAPD stating they had his wife with them!

I had a craniotomy in December and was still trying to sneak out from my husband's watchful eye in the hospital right up until the last minute. I was as slow as a slug so I can't imagine where I thought I could get to anyway but I wanted to escape. I went to the bathroom about ten times before they finally put me out. The surgery went well but I woke up to new and equally terrible symptoms: migraines and tinnitus. I still struggle with those and am currently looking at additional surgical interventions as I'm becoming increasingly symptomatic in my right ear. I no longer am able to work and have been forced to make dramatic life changes because of this condition.

I went from being an avid outdoors person, worked out daily, worked hard, played hard to being a scared weakling. I credit a wonderful physical therapist and neurologist in LA for helping me last August in gaining some strength and confidence back. I'm able to walk again, shop alone, drive, go out with friends, garden...just not in the same way as before.

I have learned many things as well these past 18 months. Some I can share: it's OK to slow down, to not feel obligated to confess my condition to everyone I meet, to share openly when I'm comfortable, to let people help, to defend, and if necessary distance myself from the few people who seem to want to reduce this condition to a mental health issue, to not

let this condition define who I am.

I also have to say that I have found a truly supportive network in a most unusual place: my neighborhood dog park. Yes it smells, my clothes are ruined, and it seems many dog owners think their pets are gifted, but nothing has been as surprisingly pleasant as an unbalanced jaunt to the dog



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Life Can Change in a Minute (continued from page 2)

park where everyone truly knows your name. A significant number of people who spend the day at a dog park usually have some medical malady and are ready to share. I got a lot of practice in talking about my diagnosis there and that helped get it out of my system.

So my life goes on and I value each day, even though the awful ones are harder to be thankful for. I think of my darling son who has suffered here with me, worried sick and trying to be brave. A good son. My faithful funny husband guides me through this. He lives in LA and I live in Salt Lake City. The distance has

always been a challenge but more so now. I will move soon to be with him. Without his calm, intellect, and love I cannot imagine what would have happened. Through all this we are thankfully still in love, laughing, and committed to each other. It's helpful to be deeply in love with your spouse through sickness and in health. I'm still looking for a way to minimize the sickness part so we can spend more time in wine country sooner than later.

Good luck and warm wishes for progress and recovery for all those out there struggling with a vestibular disorder.

The Four Flavors of Dizzy

Many vestibular patients suffer from a combination of dizziness and balance problems, which can make it difficult to describe the kinds of sensations they are experiencing.

In a Boston Globe article, Dr. Steven D. Rauch, an ear, nose and throat specialist at Massachusetts Eye and Ear, explained that half of his patients come to him with balance problems and are trying to sort through what he calls the "four flavors of dizzy."

This first "flavor" is characterized by a sense of **blacking out** while standing up and can be caused by low blood pressure, dehydration, and abnormal heart rhythms, but typically not an inner ear problem.

The second "flavor of dizzy" is **unsteadiness**, which may be a result of an inner ear disorder but could also be caused by a stroke or neurological problem.

Vertigo - the third "flavor" - is a sense that the world is **spinning** around you. It can be caused by migraines, stroke, or epilepsy, but is most often the result of an inner ear disorder.

Last but not least, *lightheadedness* is the fourth "flavor of dizzy" – the feeling that you are weak and about to faint. Very often light-

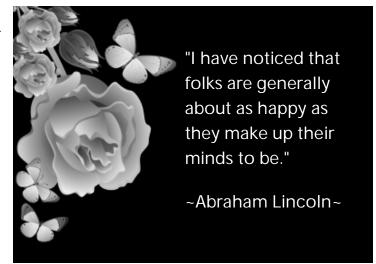
Understanding the "four flavors of dizzy" can help patients describe how they are feeling, leading to a more accurate diagnosis.

headedness can be traced to a panic attack or anxiety.

Treatment for balance problems can vary greatly once the "flavor of dizziness" is identified, says Rauch. Visit VEDA's website at www.vestibular.org for information on treatment for vestibular disorders.

Reference:

Lazar, Kay. *Learning to restore balance*. The Boston Globe. January 16, 2012.



Benign Paroxysmal Positional...what?



By Bonni Kinne, PT, MSPT, MA

It was the middle of the night. I rolled over in bed, and WHAM! The world tumbled out of control. My first thought was, "I'm having a stroke!" My second thought was, "I'm going to die!" Al-

though the severe spinning sensation didn't last very long, it left me feeling disoriented, nauseated, and extremely afraid.

I sat in a recliner the rest of the night, and by morning, I thought everything was going to be all right. Then it happened two more times while I was getting ready for work, once when I tipped my head back while washing my hair and another time when I bent over to tie my shoes. "That's it", I thought, "I'm definitely not okay!"

I had a neighbor drive me to a local emergency room where I remained for several hours receiving a number of different diagnostic tests. Finally, the emergency room physician declared, "The tests look fine. Based upon your symptoms, I'm diagnosing you with benign paroxysmal positional vertigo."

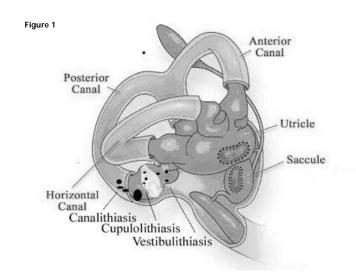
"Benign paroxysmal positional . . . what?" I exclaimed, and I began bombarding him with questions.

Question #1 – What is benign paroxysmal positional vertigo?

Benign paroxysmal positional vertigo is one of the most common types of vestibular disorders. Benign means it's not life-threatening (unless you're in a dangerous situation when it occurs). Paroxysmal means it comes and goes. Positional means it occurs as the result of specific head movements. And vertigo refers to a true spinning sensation. A common acronym used for this vestibular disorder is BPPV.

Question #2 – What causes BPPV? If you look at this picture you'll see that there

is a structure in the inner ear called the utricle. There are numerous calcium carbonate crystals (or otoconia) attached to the utricle. In BPPV, some of these otoconia become dislodged and travel into one of the semicircular canals.



Question #3 – Why do the otoconia become dislodged?

Most cases of BPPV are idiopathic. This means that the actual cause is unknown. Some of the known causes of BPPV include an inner ear infection, a head trauma, and/or the aging process.

Question #4 – Can the otoconia travel into all of the semicircular canals?

Otoconia usually only affect one semicircular canal at any given time. Although the most commonly affected canal is the posterior canal, otoconia may also travel into the horizontal canal or into the anterior canal (the least commonly affected canal).

Question #5 – What symptoms are associated with BPPV?

If otoconia travel into the posterior canal or into the anterior canal, individuals often experience a spinning sensation (or true vertigo) whenever they look upward, bend over, lie down in bed, roll over in bed (usually only in one direction), and/or get out of bed. If otoconia travel into the horizontal canal, individu-

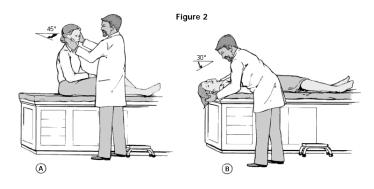
als most commonly experience their vertigo whenever they roll over in bed (usually in both directions).

Question #6 – What should I do if I ever experience these symptoms?

You should immediately seek medical attention in order to rule out other possible causes of your vertigo. Once a physician has diagnosed you with BPPV, you should be evaluated and treated by a health care professional who specializes in vestibular rehabilitation. You can locate these types of specialists in your area by accessing the Vestibular Disorders Association's professional provider directory at www.vestibular.org.

Question #7 – How will this specialist evaluate my condition?

The vestibular system is very intimately connected with the eyes and with the muscles. Therefore, the specialist will probably evaluate your vision and your balance before more closely examining whether BPPV is the primary cause of your symptoms. The most common diagnostic procedure is the Dix-Hallpike maneuver (figure 2). A positive test occurs if you experience a spinning sensation and demonstrate abnormal eye movements when the maneuver is administered. Although the Dix-Hallpike maneuver is most useful for identifying posterior canal BPPV, it's sometimes able to identify anterior canal BPPV as well. Another type of test, the supine head roll test (not shown), is the most common diagnostic procedure for identifying horizontal canal BPPV.



Question #8 – If BPPV is the primary cause of my symptoms, how will it be treated?



The most common treatments for posterior canal BPPV are based upon the Epley canalith repositioning procedure, the Parnes particle repositioning maneuver, and the Semont liberatory maneuver.³ In some specialized vestibular rehabilitation clinics, the Epley Omniax System⁴ (see figure 3) is also a treatment option. The Epley Omniax System⁴ consists of a chair that can be positioned 360 degrees in any direction, infrared video goggles, and a computer software package. Although these particular treatments are effective in some cases of anterior canal BPPV as well, horizontal canal BPPV is generally addressed with a very different treatment approach. Despite the wide variety of interventions available for BPPV, the primary purpose of these treatments is to facilitate the movement of otoconia out of the affected semicircular canal and back into an area where they will no longer cause vertigo. It should be noted that vestibular suppressants such as antivert (meclizine) are generally not effective for BPPV. In addition, antibiotics are usually not indicated.

Question #9 – How will I feel after the treatment has been administered?

This can vary greatly from individual to individual. Although some individuals feel light-headed immediately after the treatment has been administered, most individuals report a complete resolution of their symptoms within

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BPPV (continued from page 5)

a day or two. In addition, if the treatment has been successful, you shouldn't experience a spinning sensation or demonstrate abnormal eye movements when the vestibular rehabilitation specialist reevaluates your condition during a follow-up visit.

Question #10 – Are there any posttreatment precautions?

When the interventions for posterior canal BPPV were first developed, individuals were instructed to remain in an upright position for approximately 48 hours and to avoid lying on their affected side for approximately one week after the treatment had been administered. The need for these precautions has since been challenged, and your specialist may provide alternative instructions. The post-treatment instructions for anterior canal BPPV and for horizontal canal BPPV are also highly variable.

Question #11 – Can BPPV be treated at home?

The most common in-home treatment for posterior canal BPPV is the Brandt-Daroff exercise. Although variations of the Epley canalith repositioning procedure, the Parnes particle repositioning maneuver, and the Semont liberatory maneuver have also been used, your vestibular rehabilitation specialist will instruct you on the best approach for your specific condition.

Question #12 – Once my BPPV has been successfully treated, will the symptoms ever return?

Approximately 25 percent of patients do experience a recurrence of their symptoms. In order to decrease the chance of these recurrences, your vestibular rehabilitation specialist may have you perform one of the in-home treatments (described under question #11) on a regular basis.

Bonni Kinne is an assistant professor in the department of physical therapy at Grand Valley State University, where she has been conducting research in the area of vestibular rehabilitation. Bonni also works part-time in a clinic where she specializes in the treatment of patients with vestibular disorders. Bonni received her bachelor's degree in biomedical sciences and master's degrees in exercise science and physical therapy.

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- Epley JM. The canalith repositioning procedure for treatment of benign paroxysmal positional vertigo. Oto-laryngol Head Neck Surg. 1992; 107:399-404.
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- Epley Omniax System. Vesticon. http://www.vesticon.com/ The_Epley_Omniax/.
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In Memory

VEDA would like to recognize the late Dr. Margaret Moeller for her dedicated service to the Vestibular Disorders Association, and send condolences to her family.

Dr. Moeller supported VEDA in many ways, including contributions to VEDA's "Ask the Doctor" column in our quarterly newsletter.

Memorial donations can be sent to: VEDA, P.O. Box 13305, Portland, OR 97213

News Briefs

New Waterproof Hearing Aids & Implants

Hearing aid and cochlear implant technology has been evolving rapidly. According to an article in the Hearing Journal (March, 2012), Siemens and Advanced Bionics have developed hearing assistance tools that are completely waterproof.



The Siemens' Aquarius hearing aid is not only waterproof, it's dustproof and shock resistant,

which is good for sweat inducing activities such as hiking, jogging and construction work.

According to August Hernandez, AuD, the senior manager of training at Siemens, the microphones are covered by a membrane that insulates them and a spine that provides additional protection and keeps the microphones quiet. The battery door is sealed, and there is a small membrane that allows for air exchange.

Advanced Bionics' Neptune cochlear implant has a sound processor that is hermetically sealed. It is protected down to three meters depth while swimming and is intended to function for 3 to 5 years, even after being submerged hundreds of times.

Tracy Kruger, vice president of marketing for Advanced Bionics, says, "We've had parents shed tears when they realize they can do things with their child they couldn't do before, like communicate with them at bath time."

Hearing Loss in Children

According to the Centers for Disease Control (CDC), hearing loss can affect a child's ability to develop communication, language, and social skills. The earlier children with hearing loss start getting services, the more likely they are to reach their full potential.

CDC's National Center on Birth Defects and Developmental Disabilities data have shown that ~1 to 3 per 1,000 children have hearing loss. Other studies have shown rates from 2 to 5 per 1,000 children.

The National Institute on Deafness and Other Communications Disorders (NIDCD) estimates that up to two-thirds of children with acquired deafness have severe vestibular deficits (NIDCD, 1995).

If you are a parent and suspect your child has hearing loss or balance problems, speak with your pediatrician about your concerns.



Vestibular Migraine & Vertigo—Are they connected?

Recognition of an association between migraine and vertigo dates back almost 150 years when the English physician Edward Living noted that six out of 60 patients with migraine had spontaneous attacks of vertigo. In more recent history, during the 1970's there were case reports linking migraine to child-hood vertigo, yet today there is still no general consensus about the definition of vestibular migraine, according to Jeffrey P. Staab with the Department of Psychiatry and Psychology at the Mayo Clinic in Rochester, Minnesota.

Both migraine and vertigo/dizziness rank among the most common complaints in the general population. About 16% of people worldwide suffer from migraine¹ (headaches), and ~20-30% are affected by vertigo/dizziness. Many patients report both symptoms.

Recent studies have shown an increase in the prevalence of vertigo in patients with migraine, and vice versa. Vertigo is two to three times more common in patients with migraine than in headache-free controls. Researchers are beginning to suspect that this association

is not merely a chance occurrence.

- Benign paroxysmal positional vertigo (BPPV) is the most common vestibular disorder in migraineurs presenting to a dizziness clinic.
- An increased prevalence of migraine in patients with Menière's disease is also well documented.
- Motion sickness is more prevalent in patients with migraine (30% to 70%) than in headache-free controls or tension headaches (20% to 40%).

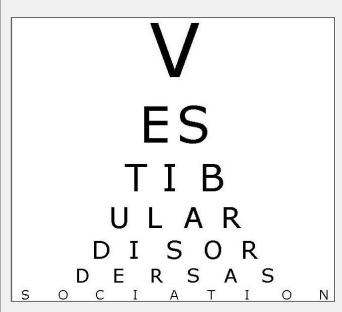
As researchers develop a better understanding of the relationship between vertigo and vestibular migraines, they can also develop better diagnostic tools and treatment options.

For more information on migraines & vertigo, visit VEDA's website at www.vestibular.org.

Reference:

1. Lempert, T., Neuhauser, H. Epidemiology of vertigo, migraine and vestibular migraine. (2009) Journal of Neurology, 256 (3), pp. 333-338.

Speaking from experience: Tips to make your journey easier

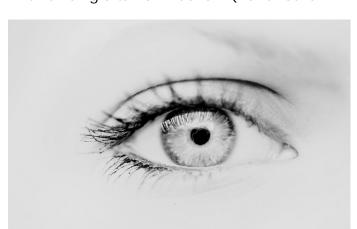


"It sounds so obvious, but clear vision is essential for a vestibular patient...I'm not sure how much worse my balance problems were as a result of poor vision, but it was clear that they weren't going to improve until I successfully corrected the problem. Be sure to have your vision checked as part of addressing balance problems." – Sue Hickey, Finding Balance – Healing from a Decade of Vestibular Disorders

Pupil Dilation Uncovers Extra Listening Effort in the Presence of Noise "Maskers"

Recent research has demonstrated that pupil dilation – a measure of mental effort – is sensitive to differences in speech intelligibility. A new study examines the effects of noise maskers and age on the speech reception threshold (i.e. the minimum noise intensity at which a patient can understand 50% of the spoken word) and mental effort.

The study measured pupil dilation in young and middle-aged adults while they listened to spoken sentences that were presented with stationary noise, fluctuating noise, or with a "single talker masker" (i.e. another



person speaking). The masker levels were adjusted to achieve 50% or 84% sentence intelligibility.

The results showed that participants required more mental effort for speech perception with the "single talker masker" than with either type of background noise. Peak pupil dilation, reflecting mental effort, occurred with the single interfering speaking condition, while no difference in peak pupil dilation occurred when comparing the stationary noise masker with the fluctuating noise masker.

This research underscores the importance of including measurements of pupil dilation as an index of mental effort during speech processing in different types of noisy environments and at different intelligibility levels.

Reference:

1. Koelewijn T, Zekveld A, Festen JM, Kramer S. Pupil Dilation Uncovers Extra Listening Effort in the Presence of a Single-Talker Masker. *Ear & Hearing*. March/April 2012. Volume 33, Issue 2, p.291-300.

VEDA is accepting applications for membership on our Board of Directors.

The Vestibular Disorders Association is looking to expand our board of directors and is accepting applications from people interested in working with a dynamic team dedicated to serving the vestibular community.

Our board is diverse in composition and geographic distribution. We invite anyone with the time and passion to help further our mission and grow our advocacy program. We would especially welcome professional members such as physical therapists, and individuals with development experience.

For more information, please contact Board President Deanne Bonnar at boardofdirectors@vestibular.org.



Thank You!

We thank the following individuals and organizations for their generous donations and pledges to VEDA received January 1, 2012 through March 31, 2012.

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With your support we can reduce diagnosis times, improve treatment outcomes, and enhance the quality of life for people with vestibular disorders.

Sylvia Martin

What Will Your Legacy Be?



Jeanette Welch—a founding VEDA board member was dedicated to supporting the mission of the Vestibular Disorders Association during her lifetime, and beyond. As a charter member of VEDA's "Balance Society," Jeanette left a legacy that will continue to help people suffering from vestibular disorders now and into the future.

When you make a planned gift to the Vestibular Disorders Association, you'll become a member of our "Balance Society" - a memorial to your commitment to improve the lives of people with vestibular disorders.

For more information about including VEDA in your Will or estate plan, contact executive director, Cynthia Ryan, at 800.837-8428 or via e-mail at Cynthia@vestibular.org.

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