



On the Level

Quarterly Newsletter of the Vestibular Disorders Association

An Epic of Dizziness

By Melissa Jo Elliott

July 16, 2011 was a day in my life that I will never forget. I awoke suddenly at 3:30 am. Something felt wrong, like a sort of spinning sensation. I waited for the feeling to pass; it felt like an eternity. I started to panic - I was shaking and the palms of my hands and my whole chest were covered in sweat. Finally, I slowly rolled over onto my left side and worked up the nerve to sit up on the edge of the bed. As soon as I did it felt as if something was pulling me down, a force of gravity so strong I had no control over it. I was near tears.

It took another 15 or 20 minutes before I attempted to get up. I couldn't stop shaking and felt nauseous. I tried to go back to sleep but couldn't. I was scared to lie back down so I stayed awake.

I made an early appointment to visit my doctor. I felt sort of spaced out, like a cloud of fog was covering my brain. I couldn't concentrate. I figured fear and anxiety were the culprit. I'm sure that was part of the problem, but not all of it, as I would later find out.

I walked into the clinic looking and feeling like a zombie. I had to fill out a bunch of forms and sign my name but I could hardly read. It felt like the lines were moving. While in the waiting room I felt an odd sensation as I looked across the room to the other side where chairs were lined up along the wall. It felt as if the chairs were pulling towards me.

After my vital signs were tested I was sent to the exam room. The doctor checked my ears and noted that the right one looked like there was fluid in it. Then he asked me to lie back on the exam table. Anxiety rose up inside me; I was afraid to lie down. And for a good reason because as soon as I did the room started spinning. He sat me up quickly and held me steady while I sat on the edge of the table, still feeling woozy and coming out of the spinning sensation. He didn't say what I had, but gave me some steroid nose spray and anti-nausea medication. I was told to get some rest and then follow-up with an ENT in a week.

I spent most of the next four days sitting upright on the couch with a big pillow behind my head. It seemed to help stabilize my head and lessen the feeling of



"Everything was going well in my life. Nothing new, just the same old day-in, day-out chores and responsibilities we all have. Actually, a little boredom had set in. I would soon long for a normal routine day."

- Melissa Jo Elliott

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An Epic of Dizziness (continued from p. 1)

motion I was continuing to have. Every few minutes I would feel a tremor or shaking sensation flow across my forehead or the back of my head. I tried to read to pass the time, but it was difficult to focus and it took so much of my energy. Watching T.V also made me feel sick.

After about four days on the medications I decided to stop taking them. The side effects were just awful. I was asleep all the time. I'm generally a very healthy person so being really sick was out of the norm for me.

There were times after the first few days that I'd feel better for a few minutes and I would get on the computer and re-search dizziness. I pieced together that I might have BPPV (Benign Paroxysmal Positional Vertigo). The only problem was I had other symptoms also, and that confused me.

The big day finally arrived! It was time for my visit to the ENT. He proceeded to lay me way back in this special chair while turning my head to one side. The room began to spin and I felt a funny movement with my eyes, like they were jerking from side to side. He sat me up after the spinning sensation stopped then laid me back to the other side and I felt the same sensation, however it was less intense.

The ENT diagnosed me with BPPV in my left ear and said there is a procedure that a physical therapist can do to move the crystals in my left ear back into the right place. When I researched it later I found out that procedure the ENT performed to diagnose the BPPV is called the Dix Hallpike maneuver.

I couldn't wait until my appointment with the PT. I wanted relief and fast! I called to make the appointment and was told it would be at least two weeks before I could get in. Twelve days into my experience I decided to start a journal. I felt like I was the only one on the planet with this type of problem and I wanted to share my story with others, so no one would have to suffer the anxiety I initially felt.

You can read more about Melissa's journey on her blog at <http://melissajoelliott.wordpress.com/2012/05/22/an-epic-of-dizziness-part-1>.



Dr. F. Owen Black, M.D., F.A.C.S.—A Vestibular Hero

The vestibular world lost a true champion when Dr. Owen Black passed away on May 18, 2012. Dr. Black was a neurotologist in Portland, Oregon, who dedicated his professional life to the diagnosis and treatment of inner ear disorders.

Owen Black was an internationally recognized research scientist who advocated tirelessly for greater funding for vestibular research. His research received two decades of funding from NIH and he was honored to serve as a balance doctor to NASA – translating findings on the vestibular challenges of space travel to better understanding of vestibular disorders. He was revered by his peers for his understanding of the highly complex vestibular system and his leadership in the field.

Driven by his compassion for the individuals suffering with vestibular disorders, Dr. Black maintained an active clinical practice and was in the forefront of developing new diagnosis and treatment alternatives. As his patients will attest, Dr. Black was unassuming and refrained from making a show of his vast knowledge and experience. Yet it took only minutes to recognize his medical brilliance and his

deep understanding of the challenges vestibular patients confront in their daily lives. He never stopped trying to make life as full as possible for each of his patients.

Equally as important as his medical expertise was his remarkable humanity. He was a mentor and father figure to many of his employees, colleagues and friends. He brought out the best in people by showing them how his combination of extraordinary competence, compassion and humility could be so effective in changing lives for the better.

Owen Black was also a major influence in the founding of VEDA. He believed strongly in the importance of VEDA's mission and contributed generously as a member of the Medical Advisory Board. He leaves the world a better place and inspires us to continue his legacy.



**MEMORIAL DONATIONS IN HONOR OF DR. F. OWEN BLACK CAN BE SENT TO VEDA,
P.O. Box 13305, PORTLAND, OR 97213.**

"Always remember to slow down in life; live, breathe, and learn; take a look around you whenever you have time and never forget everything and every person that has the least place within your heart."



Speaking from Experience: Tips to make your journey easier

"I needed to find a new life that was satisfying and fulfilling and respected my limitations. This is the key to getting on the path to healing – to finding balance."

- Sue Hickey, Finding Balance – Healing from a Decade of Vestibular Disorders

Searching for Stillness

WITH BIOIDENTICAL HORMONES

By Claire Haddad
Boston-Area Support Group Leader

It was a beautiful July day for a boat ride in Newport, RI, until Jeanne Driscoll, age 46, stepped off the boat and the rocking didn't stop. Jeanne had two similar experiences several years earlier, the first after an airplane flight and another after a week on a cruise ship. In those previous experiences Jeanne gradually felt better after a few weeks and her life returned to normal.

This time was different. Jeanne not only experienced what she called a constant rocking sensation of "phantom motion" but also vision difficulty, migraine headaches, cognitive lapses and unrelenting fatigue.

Over a period of 21 months Jeanne was examined by her primary care doctor, an ENT, a vestibular specialist, two neurologists, and a gynecologist. Given that Jeanne's symptoms began after a boat ride, she was given the diagnosis of Mal de Debarquement and told she should "learn to live with it." Determined to find an answer, she explored alternative therapies including frequency-specific micro current therapy, acupuncture, and even a master intuitive. Despite her efforts, Jeanne spiraled into a deep depression and could barely function. Her doctors recommended that she apply for disability. Jean refused and instead tirelessly continued seeking the root cause of her vestibular symptoms.

In January 2011 Jean was examined by Dr. Charlotte Richards, a gynecologist. Dr. Richards tested Jeanne for hormonal deficiencies and started her on bioidentical hormone replacement therapy (BHRT). Her medication was tweaked twice and within 3 months Jeanne's vestibular symptoms completely resolved. She did not change anything else in her life (e.g. diet, exercise, other medications, nutritional supplements, etc.).

"I got my life back. I never gave up. I knew I

just had to find the right doctor," Jeanne remarked.

To complete the last piece of her "wellness puzzle" Jeanne replaced her synthetic thyroid prescription medication with Armour Thyroid, a natural thyroid prescription medication, which gave her health and energy level an even bigger boost. With new-found enthusiasm and a zest for life Jeanne turned her attention toward helping others.

With the help of an Internet support group Jeanne reached out to Kim B. of Jupiter, FL. Jeanne thought that Kim's symptoms of constant rocking sounded much like hers. In 1999, at age 36, Kim started feeling a rocking sensation 5 weeks after her son was born. She was given antibiotics, anti-depressants and anti-anxiety meds. Nothing took away the rocking, although some medications made it more tolerable. It was extremely challenging taking care of her baby while hardly being able to get out of bed.

In August 2011, Jeanne recommended BHRT to Kim (then age 48) and after 12 years with vestibular symptoms Kim saw the intensity of her symptoms decrease from a 9-10 to a 1-2 (10 being the highest and 1 being the lowest). Kim shared, "My quality of life is drastically improved and at times I feel symptom-free without any rocking." Like Jeanne, Kim didn't change anything else in her life other than taking BHRT medication.



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Searching for Stillness (continued from p. 4)

"I got my life back. I never gave up. I knew I just had to find the right doctor," Jeanne remarked.

More recently, Jeanne contacted Kristin M. of Hoover, Alabama. In 2010 at age 43, Kristin went on a cruise and like Jeanne, when she got off the boat her rocking did not stop. She wondered if her recent migraines and partial hysterectomy had anything to do with her symptoms. After 9 months her Mal de Debarquement went into remission, only to return in March 2012. With Jeanne's help Kristin found a physician who works with bioidentical hormones. In short order Kristin felt much better. She is nearly symptom-free but sometimes has mild symptoms when she lies down at night. She added, "I don't feel like I'm going up and down hills anymore when I walk across the floors in my house. I also have the concentration to read books again."

To share her success with bioidentical hormones Jeanne created a Facebook page titled, "Searching for Stillness – Phantom Motion." There she offers a wealth of resources on bioidentical hormones, thyroid and natural thyroid replacement medication, adrenal fatigue, migraine headaches, and other related topics. Jeanne also highlights environmental factors such as fluoridated water that she believes negatively influence the delicate hormonal system.

Jeanne is in the process of helping at least a dozen other people with vestibular symptoms explore bioidentical hormones. She says that "despite little scientific research on the subject hormone and thyroid deficiencies may play a role in a person's vestibular disorder – men included. It's worth investigating. A primary care doctor can order blood tests for a hormone and thyroid panel. A person might have to follow up with a gynecologist or alternative/naturopathic physician. However, not many doctors work with bioidentical hormones. I recommend Googling 'functional medicine' in a person's local area. I realize that bioidentical hormones may not be the answer for every-

one, and even if a person has a hormonal deficiency it can take a while to find the right balance of different bioidentical hormones. This is not a 'one-size-fits-all' approach."

While Jeanne has successfully completed her search for stillness, she continues to help others overcome the phantom motion of their vestibular disorders.

Recommended Reading/Resources:

- Jeanne Driscoll's Community Facebook page: "Searching for Stillness – Phantom Motion"
- Women in Balance: www.womeninbalance.org
- "Health, Hormones, and Happiness: A Natural Medical Formula For Rediscovering Youth with Bioidentical Hormones" by Steven F. Hotze, MD
- Hotze Health & Wellness Center: www.hotzehwc.com; you can take a test on this website that can guide you to investigate a hormonal and/or thyroid deficiency.
- "Why Do I Still Have Thyroid Symptoms? When My Lab Tests are Normal" by Datis Kharrazian, DHSc, DC, MS
- List of naturopathic doctors in the United States: www.naturopathic.org
- List of Compounding Pharmacies in the United States: www.ecompoundingpharmacy.com

What are Bioidentical Hormones?

Bioidentical hormones can be used for both men and women. They are made from natural substances that are molecularly identical to the body's naturally occurring hormones. They are not the synthetic hormones often associated with managing menopause. A health care provider can test a woman's levels of hormones such as estrogen, progesterone, testosterone, DHEA, cortisol, and pregnenolone. For a man testosterone and DHEA are typically tested.

Bioidentical hormones require a prescription from a doctor. They come in different forms: creams, capsules, and liquids. Prescriptions can be filled at special pharmacies, known as compounding pharmacies.

Sources: Women in Balance, www.womeninbalance.org and Hotze Health and Wellness Center, www.hotzehwc.com

Inner Ear Infections

WHAT ARE THEY AND WHY DO THEY MAKE ME DIZZY?



By Bonnie Kinne, PT, MSPT, MA

I woke up one morning and felt like I was sea-sick; I was so dizzy that I couldn't even walk straight. I was also extremely nauseated and felt like I was going to vomit

(thankfully, I was saved that indignity!). I was glad it was Saturday because there was no way I could have gone to work. I decided to make an appointment with my family physician the following week if my symptoms hadn't resolved by then.

By Monday I was feeling somewhat better. My nausea had subsided and I only felt dizzy when I turned my head quickly or pivoted while walking. I figured the rest of my symptoms would disappear within the next few days. However, one month later I was still experiencing symptoms. I learned how to avoid getting dizzy by keeping my head still and by walking more carefully. "I've had enough of this", I thought, "I want my life back!"

When I saw my family physician the next day he performed a thorough examination. "What's wrong with me, doc?" I queried. "You've had an inner ear infection," he replied. "Let me explain."

Fact #1

What's the difference between an inner ear infection and any other type of ear infection?

There are three parts associated with the ear (figure 1). The outer ear extends from the pinna

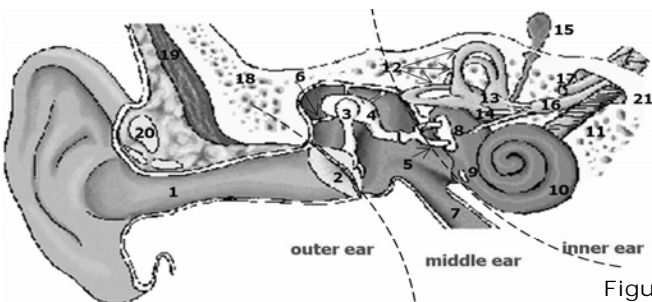


Figure 1

- | | | |
|--------------------------------|-------------------------|--------------------------------------|
| 1. external auditory canal | 8. oval window | 15. endolymphatic sac |
| 2. tympanic membrane (eardrum) | 9. round window | 16. vestibular nerve |
| 3. malleus | 10. cochlea | 17. facial nerve |
| 4. incus | 11. cochlear nerve | 18. temporal bone |
| 5. stapes | 12. semicircular canals | 19. muscle |
| 6. ligament | 13. utricle | 20. cartilage |
| 7. Eustachian tube | 14. saccule | 21. internal auditory canal to brain |

(the visible part of the ear) to the tympanic membrane (the eardrum). Infections of the outer ear, such as swimmer's ear, are very painful and are generally treated with ear drops.

The middle ear includes the malleus (the hammer), the incus (the anvil), and the stapes (the stirrup) as well as the Eustachian tube that connects the middle ear with the back of the throat. This tube allows the middle ear to drain and keeps the middle ear pressure equal to the outside air pressure. Infections of the middle ear are also very painful. These infections are treated with antibiotics and, in some cases, with surgically implanted ear tubes.

The inner ear is composed of the vestibular system (including the semicircular canals), the hearing system (including the cochlea), and cranial nerve VIII (a combination of the vestibular nerve and the cochlear nerve). Inner ear infections are classified as either labyrinthitis (see figure 2) or

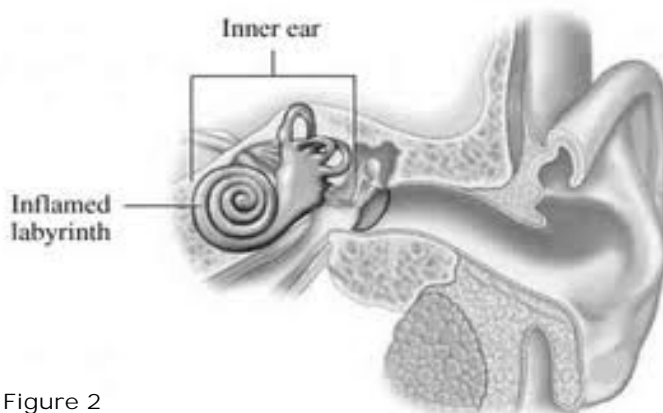


Figure 2

as vestibular neuritis (see figure 3). These infections aren't painful as long as they don't also involve the outer ear and/or the middle ear. Instead, these infections cause vestibular problems such as dizziness and imbalance and/or hearing problems.

Fact #2

Why am I dizzy when I turn my head quickly or pivot while walking?

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Inner Ear Infections (continued from p.6)

There are three primary systems that detect where our body is in space and thus keep us balanced. They are the vestibular system, the visual system and the somatosensory system (the muscles). In the case of a normal vestibular system the following two situations apply. If the vestibular system on the right side is sending the same rate of signals to the brain as the vestibular system on the left side, the brain interprets this situation as 'the head is still.' Because the eyes are looking straight ahead and because the cervical muscles haven't turned the head, the visual system and the somatosensory system are also informing the brain that 'the head is still.' When you turn your head to the right, the vestibular system on the right side sends a faster rate of signals to the brain than does the vestibular system on the left side. Because the eyes are now looking to the right and because the cervical muscles have turned the head to the right, the visual system and the somatosensory system are also informing the brain that you've turned your head to the right. In both of these normal situations, all three systems are in agreement. When you've had an inner ear infection the vestibular system on the side of the infection is often

ing the brain that 'the head is still.' It's this conflict of information between the three systems that causes your dizziness.

Fact #3

OK, what's next?

"I'm going to send you to a vestibular rehabilitation specialist," my doctor explained. "This specialist will primarily examine the connection between your vestibular system and your eyes (the gaze stabilization portion of the evaluation), the connection between your vestibular system and your muscles (the balance/gait portion of the evaluation), and the response of your vestibular system to head/body movements (the motion sensitivity portion of the evaluation). Depending upon what your examination reveals, you'll probably be treated with a home exercise program consisting of habituation exercises (if the motion sensitivity portion of the evaluation was abnormal), adaptation/substitution exercises (if the gaze stabilization portion of the evaluation was abnormal), and/or a walking program (if the gait portion of the evaluation was abnormal). You may also receive supervised balance retraining if the balance portion of the evaluation was abnormal. In cases such as yours, though, the use of supervised balance retraining is not as common as the use of a home exercise program.

"The main purpose of the treatment techniques is to facilitate what's called physiologic compensation. This term means that when the head isn't moving but the non-damaged vestibular system is sending a faster rate of signals to the brain than is the damaged vestibular system, the brain will learn that this situation is the new normal for 'the head is still.' Since the eyes are looking straight ahead and the cervical muscles haven't turned the head the visual system and the somatosensory system will also be informing the brain that 'the head is still.' Because the three systems are once again in agreement the dizziness should subside."

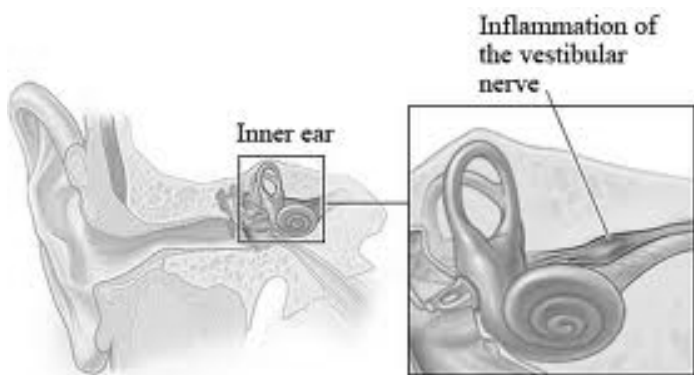


Figure 3

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damaged. In this case, when the head isn't moving, the non-damaged vestibular system will be sending a faster rate of signals to the brain than will the damaged vestibular system. The brain will interpret this situation as 'the head is turning to the right.' Because the eyes are looking straight ahead and because the cervical muscles haven't turned the head, though, the visual system and the somatosensory system are inform-

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Fact #4

When will I get better?

“Physiologic compensation may take up to three months to be completed,” he said. “However, if you’re compliant with your home exercise program, you should begin to feel a lot better within the first couple of weeks. If you hadn’t attempted to avoid your symptoms by keeping your head still and by walking more carefully during the past month, it’s likely that you would have physiologically compensated on your own without the need for any specialized intervention.” (Gee, and I thought I was trying to prevent the dizzies! Now I know that I have to re-train my brain to adjust to a “new normal.”)

Fact #5

Should I take any medication?

“No, I’m not going to give you any medication,” my doctor told me. “Although antibiotics are sometimes prescribed shortly after the onset of symptoms, they’re only helpful if the inner ear infection is caused by bacteria. Most inner ear infections are caused by viruses, and these viruses die within a relatively short period of time. Your dizziness isn’t caused by the presence of a virus. Rather, it’s caused by the conflict of information between the vestibular system, the visual system, and the somatosensory system.”

For more information on inner ear infections, including labyrinthitis and vestibular neuritis, visit VEDA’s website at vestibular.org/labyrinthitis-and-vestibular-neuritis.

VEDA Executive Director Chosen for DIA Patient Advocate Fellows Program



VEDA is excited to announce that executive director, Cynthia Ryan, has been awarded a full scholarship to attend the DIA (Drug Information Association) Annual Conference as a Patient Advocate Fellow.

“I couldn’t be more pleased to represent VEDA and vestibular patients at this important event,” says Ryan. “Advocating for patient rights is essential to our mission. As VEDA moves forward I hope to have more opportunities to partner with the medical community to share the patient perspective and learn about the challenges faced by public and private agencies involved in the development of better diagnostics and treatments for people with vestibular disorders.”

In a recent press release the DIA reports:

“Patient organizations are key stakeholders in helping DIA achieve our mission and vision. Through the Patient Advocate Fellowship Program, DIA works to ensure that the voice of the patient is heard globally in every facet of the life cycle management of pharmaceuticals, medical devices, and related healthcare products. This Program is designed to educate the patient community and actively engage them in the drug development process.

“In June, this Program will give twenty-one patient representatives, chosen through a competitive process, opportunities to develop, strengthen, and support collaborations with policymakers, industry, academia, and health professionals by taking part in all facets of DIA 2012: Collaborate to Innovate, our 48th Annual Meeting in Philadelphia, as important contributors to DIA’s annual forum for sharing best practices, stimulating cooperation, and facilitating a two-way dialogue across the entire global healthcare community.”

Balance Awareness Week—2012

“DEFEAT DIZZINESS”

The Vestibular Disorders Association (VEDA) celebrates its 16th annual Balance Awareness Week September 16th – 22nd, 2012 by launching a campaign to “Defeat Dizziness” through public education and advocacy.

How Can I participate?

Join VEDA in raising awareness about the challenges of living with a vestibular disorder – it’s fun and easy! Just select one or more of the sample activities listed below, or be creative and design your own event!

Fundraising Activities & Events

- Host a spaghetti dinner & ask for donations.
- Have a bake sale at work, at your school or church, or in front of a local grocery store.
- Hold a yard sale – Clean out your closet, garage, kitchen and home office.
- Organize a walk, run or bike ride - Get pledges from friends, family & coworkers.
- Partner with a local business - Ask them to donate a portion of their proceeds to VEDA.
- Fundraise at work - Make a contribution to VEDA and ask your employer to match it.
- Ask your doctor – Tell your doctor that you’re raising funds to promote awareness for vestibular disorders and ask them to sponsor you.
- Raise money online - Create your own fundraising page and ask your friends, family and coworkers to support you by making a donation.

Help Spread the Word

- Posters – Download a BAW poster or flier and hang it at your local senior center, doctor’s office or bulletin board.
- Press Release - Download a press release and send it to your local paper.
- Public Service Announcement (PSA) – Download a recorded PSA and ask your local radio station to run it.
- Newsletter Ad – Download an “ad” to post in your organization’s newsletter, your school or church bulletin, etc.
- Share with your friends – Send an e-mail or post on Facebook to tell your friends that you support VEDA.
- For Professionals – Host a free ‘balance screening’ at your clinic and distribute BAW Fact Sheets.

VEDA has materials to make planning your event easy – visit our website at vestibular.org/BAW to download a sample press release, PSA, fact sheet, and other informational templates.

Running to Raise Awareness for Vestibular Disorders

VEDA member, Andrew Galloway, recently completed a 10K run to raise awareness for vestibular disorders.

Andrew reports, “I was very pleased with my time of 59 min 41 sec. I’ve attached a photo of my finish. You can see the pain! As always, pushing myself that hard, the old dizzies are now complaining a bit, so I’m taking it easy for a few days. I’m sure it will settle down soon, and it was worth it!! ”

Congratulations, Andrew!

Andrew sent an email to his friends and posted a message on his Facebook page announcing his event and including information about vestibular disorders.



Thank You!

We thank the following individuals and organizations for their generous donations and pledges to VEDA received April 1, 2012 through June 30, 2012.

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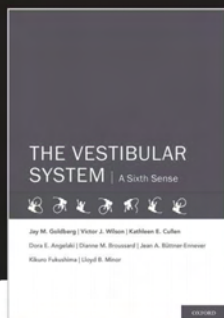


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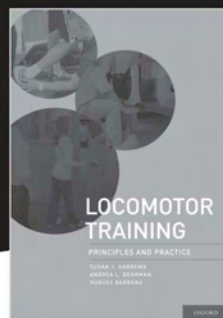
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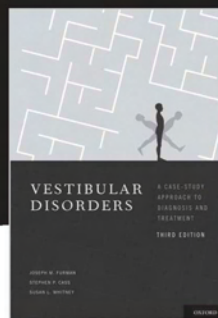
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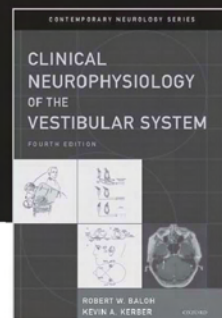
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