

ON THE LEVEL

A QUARTERLY NEWSLETTER OF THE VESTIBULAR DISORDERS ASSOCIATION



INFORMATION

SUPPORT

AWARENESS

ADVOCACY



Just Breathe ...

By Marsha Moore

I was your typical workaholic who tried to do everything to meet my family, work and volunteer commitments. I was (and still am) the director of public relations/marketing for Deaf Services Center, a non-profit organization in Columbus, Ohio. I used to spend 60 to 80-hour work weeks presenting, exhibiting and working on special projects. My job required a lot of traveling, lifting for exhibits and researching information for our customers.



In the summer of 2013, I began to experience a series of symptoms, including severe neck and back pain caused by poor sitting posture from spending hours on the computer. On top of my work responsibilities, I also had 4 children, ranging from 6 to 16 years old, who were very involved in marching band, soccer, baseball and volleyball. I was always driving them everywhere and volunteering for everything! By the time we left for our annual trek to Maine to see my husband's family, I was thoroughly exhausted.

CONTINUED ON PAGE 2

IN THIS ISSUE

Dream Team Creates Petition for Change	4
Post-Op Balance Issues	
Following Cataract Surgery	6
Effects of Multiple Chemical Sensitivity	7
Documenting the Patient Perspective	8
Antivert: Medical Miracle or Myth?	11
Styx the Wonder Dog	13
Invest in VEDA	15



TOP LEFT: MARSHA EXERCISES TO SUPPORT HER VESTIBULAR REHABILITATION
BOTTOM: MARSHA'S FAMILY SUPPORTS HER PHYSICALLY AND EMOTIONALLY.

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.

© All rights reserved.

BOARD of DIRECTORS

President: Louise Geib, M. Ed - *Atlantic Beach, FL*

Vice President: Stacey Buckner, DPT - *North Potomac, MD*

Treasurer: Gary Breitbord - *Holliston, MA*

Secretary: Kathleen Stross, DPT - *Pearland, TX*

Jill Craig, MA - *Hillsboro, OR*

Dennis Fitzgerald, MD - *Philadelphia, PA*

Sheelah Woodhouse, BScPT - *Calgary, AB Canada*

Matthew Crowson, MD - *Durham, NC*

Holly Fisher - *Coppell, TX*

Rebecca Rubin - *Sherman Oaks, CA*

Bryce Salvador - *Westfield, NJ (Honorary)*

EXECUTIVE DIRECTOR

Cynthia Ryan, MBA - *Portland, OR*

MEDICAL & SCIENTIFIC ADVISORS

Chair: P. Ashley Wackym, MD - *New Brunswick, NJ*

Richard Clendaniel, PT, PhD - *Durham, NC*

Joel A. Goebel, MD, FACS - *St. Louis, MO*

Timothy C. Hain, MD - *Chicago, IL*

Janet Helminski, PT, PhD - *Chicago, IL*

Gary Jacobson, PhD - *Nashville, TN*

Jeffrey Kramer, MD - *Chicago, IL*

David Newman-Toker, MD, PhD - *Baltimore, MD*

James Phillips, PhD - *Seattle, WA*

Steven Rauch, MD - *Boston, MA*

Jay Rubinstein, MD, PhD - *Seattle, WA*

Michael Schubert, PT, PhD - *Baltimore, MD*

Alain Semont, PhD, PT - *Paris, France*

Neil T. Shepard, PhD - *Rochester, MN*

Hinrich Staecker, MD, PhD - *Kansas City, MO*

Jack J. Wazen, MD, FACS - *Sarasota, FL*

Judith White, MD, PhD - *Seattle, WA*

JUST BREATHE ...CONTINUED FROM PAGE 1:

While we were on vacation my face started flaring up, like it was on fire. It would come and go, and by the time we got home it was still a problem, so I finally went to my doctor. Unfortunately, she was no help. At this point, I was not able to wear my contact lenses anymore and was wearing my glasses all the time. My eyes were burning a lot of the time and no one could explain why this was happening. I saw the same doctor two more times between September and January 3, 2014, but she made no progress in figuring out what was going on for me.

On January 9, 2014, I woke up with my balance off and everything distorted. I was terrified and had no idea what was going on. I couldn't sit, walk or do anything at all. I was very athletic before my illness. I thought initially it would resolve on its own, but after 10 days with no improvement I saw my doctor again, and again she was no help.

I finally switched primary care doctors and was able to see the new doctor within one week. By then it had been three weeks since my world changed. She immediately referred me to an ENT for further diagnosis and treatment. I saw him in March. He ran tests on me and came back with a diagnosis: vestibular neuritis (VN). The fact that I had 88% caloric loss in my left ear was not good. He said that it would take months and months of recovery and physical therapy to get back to what I used to be able to do. To this day we still have no idea what caused my VN, but possibly a combination of a virus contracted while in Maine and the extreme stress I had been experiencing.

I started seeing a physical therapist, but after a month with no improvement I asked my ENT to be referred to a facility that was equipped to deal with vestibular neuritis. He recommended Ohio State University's (OSU) ENT department's Outpatient Rehabilitation Services. By then I was frustrated by the lack of not being able to do a whole lot for my family, and I had to go on medical leave from the job I had held for 7 years because I couldn't function very well.

My first appointment with the OSU Physical Therapy team was not until late May 2014, so more waiting ensued. However, it was around this same time that a friend who happened to be a physical therapist heard about my situation. She wanted to help, so she started seeing me at her office. She was instrumental in my getting much-needed vision therapy and referred me to an excellent optometrist, Dr. Laird Ackerson. He had me do different eye and spinning exercises designed to help my eyes and brain compensate for my vestibular loss. He was wonderful and very supportive and believed that I could regain my abilities eventually. I continued physical therapy with my friend while I was seeing the OSU PT. Everyone had a

different approach on how to treat my problems, but everything I learned to do during rehabilitation benefitted me. Eventually the OSU OT team said that I had reached my goals and could go back to work part-time. She said that I just needed time to fully heal. My therapy ended with them, as well as with my friend, because my insurance ran out of benefits.

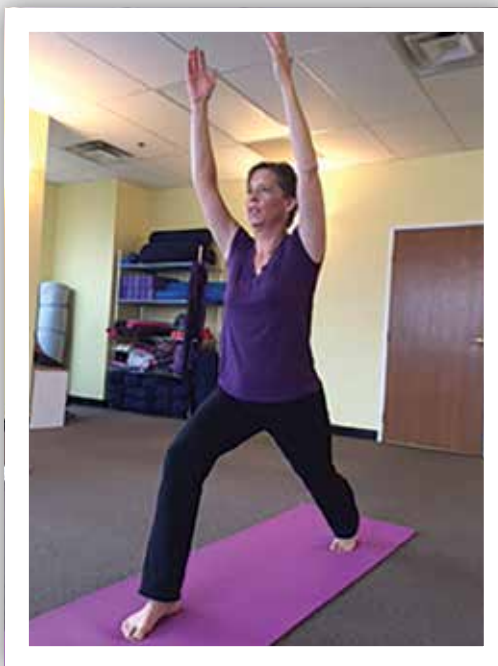
By this point it was January 2015. I felt like I had come a long way but still had some more work I needed to do before I would be fully recovered. My balance was still not 100% but I was able to drive short distances and walk my dog, Minnie, for 30 minutes each day. I also took up roller blading. However, my neck and back issues were still causing problems for me. The physical therapy would help me feel better for a day or two but then my symptoms would come back. I realized I needed to find permanent solutions to my neck and back pain.

I started researching online for some help and came across a place called Good Bodies, located in Dublin, Ohio. They were only about seven minutes from my home and provided exercise classes, strength fitness and many other services. I decided to go in and talk with the owner, Jack Mouglin, who eventually set me up with Constance Piwtorak, who has become one of my strongest cheerleaders. She is constantly finding ways to help me tackle my balance issues. During our weekly strength trainings she has me do different exercises, strengthening my neck, shoulders and back so that my neck is strong enough to support my head. I also joined her weekly Pilates and Yoga classes, which have helped me so much with regaining my balance and strength. I am forever grateful to Constance, and I continue to work with her three days a week.

While I was working with Constance, she referred

me to Chad Simmons, owner of Muscle Activation Techniques (MAT). He evaluated me and started me on a program to help me get my neck, shoulder and back muscles reactivated so that they would work better for me. I now see Amy Radcliff, a MAT specialist, who helps me maintain my range of motion. This process took over a year.

Even with all the improvements that I was making, my balance was still not 100%, so I started researching and somehow found VEDA, LifeMark Health and Sheelah Woodhouse, who played an important role in the last phase of my recovery. Sheelah suggested that I block out my vision while I do certain exercises, such as rocking on the BOSU (balance training) ball. This helped me realize that there was a visual component to my balance issues. Eventually, I started to see a lot of improvements in my balance. I also found a lot of helpful information on VEDA's website.



"YOGA HAS TAUGHT ME TO BREATHE WHEN STRESS GETS TO ME, AND IT HAS WORKED WONDERS."

I am now able to roller blade, bike, swim and do many other activities that I used to do before my illness. However, I don't work 60 to 80-hour weeks anymore. Instead, I pace myself, knowing that I will get everything done eventually and that not everything is a life or death situation. Of course, it helps that my oldest 3 kids, Jason, Sara and Megan, are now able to drive themselves and I just have my youngest one, Jack, who is now 10 1/2 years old, to drive around for soccer and baseball practices and games.

I must give much credit to my husband, John, for his patience with me during the early days when I was so sick and helpless. He was very supportive and always encouraging, telling me that I would eventually recover with my determination and commitment to exercising. My children were wonderful as well, just by being supportive and not critical. My oldest son, Jason, was very patient

CONTINUED ON PAGE 4

and helped me out when I couldn't drive, getting his younger siblings to where they needed to be. My mother was also very supportive and was at my side every day for the first 3 months of my illness when my children and husband had to be at work/school.

I am now back to working 30 hours a week in my former position. I am getting everything done, but in different ways. For example, I have a marketing team that goes out to do presentations and/or exhibits. I take frequent breaks during work hours and balance my work/home needs much better now. I go to my Pilates, Yoga and Strength Training sessions each week without fail except for vacations! Yoga has taught me to breathe when stress gets to me, and it works wonders.

I have one more goal I want to accomplish, and that is to fly again in a commercial plane. I have been cleared by my doctors and physical

therapists to fly for over a year now, but I have yet to take that step. However, I know that I will in the next few months. Every day is a new beginning, I enjoy every single minute of it, and I am so grateful for my health and for the health of my children, John and my mother.

I wish that there was a place in every state where vestibular patients could go to be taken care of, where their health issues could be coordinated by qualified professionals in multiple specialty areas. That would have saved a lot of aggravation and frustration on my part in trying to figure out what the next steps were. Support, love and understanding from family and friends are keys to a person's success in recovering from vestibular neuritis. It's a long road back, but when you make it, celebrate!

Dream Team Creates Petition for Change

By Tania Staadsbader, Margaret Byrne & David Morrill

Imagine a world where "dizzies" received a fast diagnosis, appropriate treatment and even a cure. Wow! If this were a contract for life, wouldn't you sign immediately?

Reality shows us a very different picture. Doctors report that they are often poorly trained in vestibular conditions. Young ENTs are more likely to choose surgical specialties. Not enough focus is placed on accurately diagnosing balance issues or referring patients to physical therapy, as appropriate. Treating dizzy patients with success requires a multidisciplinary approach, with knowledge in otolaryngology, neurology neuro-ophthalmology, and psychology, among other specialties. Today this is more of an exception than the rule. Misdiagnosis is a very common phenomenon.

IMAGINE A WORLD
WHERE "DIZZIES"
RECEIVE FAST
DIAGNOSIS,
APPROPRIATE
TREATMENT AND
EVEN A CURE. WOW!

When you read the threads in many Facebook groups, vestibular patients all agree that there needs to be a change in the way the medical

community approaches the diagnosis and treatment of patients with inner ear balance disorders. But change will not come if we wait for some other person or some other time. We are the ones we've been waiting for. We are the change that we seek. Change is waiting for us. We can make a difference, if we take action, to awaken the world.

This is why our group of eleven empowered patients initiated a petition to the World Health Organization (WHO) calling for better awareness of vestibular disorders among medical professionals.

OUR GOAL?

To give vestibular patients a better chance to get an accurate diagnosis, appropriate treatment, and perhaps even a cure. We are asking for worldwide agreement on the education of medical students and further training for existing specialists, as well as the establishment of clinical practice guidelines for all vestibular disorders.

WHO ARE WE?

Verony, David, Chris, Tamar, Kim, Polly, Margaret, Richard, Beth, Liesbeth and Tania. Eleven patients from the USA, Australia, the UK, the Netherlands and Belgium. Many of us are VEDA Ambassadors. All of us are dedicated to doing whatever we can to raise awareness about vestibular disorders.

HOW DID WE DO IT?

It was a huge effort to get this started. Arranging a time to talk via Skype was too difficult because of different time zones, and long email threads were confusing (scrolling issues - you know, dizziness can't handle that!). But nothing could stop us from working together. Using Messenger groups with several themes (e.g. one for brainstorming, one for gathering petition material, and one for listing people to contact) we got it done. After a few initial drafts, our petition came to life.

HOW CAN YOU HELP?

If you want to make a difference when knocking on the door of an international organization like WHO you have to have a compelling argument. What could be more compelling than a group of patients who have experienced misdiagnosis first hand?

The idea is to show the world that patients are getting empowered, raising their voices in a positive way. Many doctors have signed the petition and even commented, showing their support. Hurray!

Many patients have also commented. Reading the comments shows us that this petition was the best thing we have ever initiated as a team.

As of today we've gathered almost 1,900 signatures. Working together to achieve this was the most wonderful thing to do, with lots of happy, funny, even emotional moments, and some new friendships formed along the way.

Please join and support this important action. We must reach at least 2,500 signatures - and hope to get many more - before we can send this to WHO. Will you be part of our movement to raise the bar on how the medical profession manages patients with inner ear balance disorders?



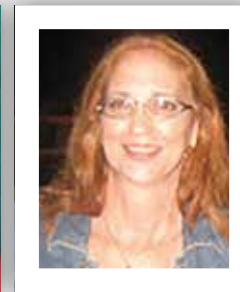
TANIA'S DAUGHTER CREATED A PICTURE TO CAPTURE THE IDEA OF A MULTIDISCIPLINARY MEDICAL TEAM.

THANK YOU SO MUCH!

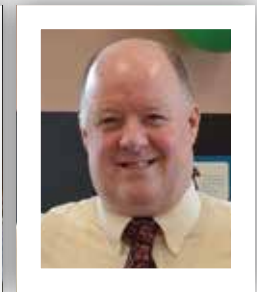
Your Dizzy Dream Team



TANIA



MARGARET



DAVID

SIGN THE PETITION ONLINE:

<https://goo.gl/tyogSv>

Post-Operative Balance Issues Following Cataract Surgery

By Dr. Nathan Davis, OD, COVD, NORA

The visual and vestibular systems work together to allow a person to move about. Because these two systems are so closely integrated, any disruption in the processing of either system can have a negative impact on a person's sense of balance.

Cataract surgery can cause a dramatic change in the way a person visually experiences their world, and most of the time the effect is positive. However, if the brain is used to seeing the world from a certain perspective, and that perspective has suddenly been shifted, the disruption in the visual system can cause sensory incoherence with the visual-vestibular connection.

Patients who have a pre-existing vestibular dysfunction are more at risk after cataract surgery. There are also various visual characteristics that may increase the likelihood of disrupting the visual-vestibular connection. Patients with significant corrections in their eyeglass prescription may have trouble adjusting to a new prescription, especially during the time between the first and second cataract surgery. Between the two procedures the prescription in one eye will typically be neutralized while the other eye remains the same. The difference between the two prescriptions can be hard for patients to adjust to at first. Any feelings of dizziness or nausea are typically resolved with the surgery for the second eye, but in rare cases the disruption can cause symptoms that may be hard to overcome. The real problem arises when the cataracts don't mature symmetrically, and one eye needs surgery well before the other eye.

Because of the technological advances of the

implantable lens that is used during cataract surgery, a patient now has many different options concerning the visual outcome they desire. There are options available today that allow a patient to see in the distance and up close without the aid of glasses, at least to some degree. The two most popular options are multifocal intraocular lenses and a monovision outcome. Multifocal intraocular lenses allow the patient to use both eyes to focus on objects up close and far away. Monovision purposely sets one eye to focus on distance objects, while the other eye focuses on near targets. Both visual experiences are far different (and less efficient) than normal human vision, and as such can be difficult for the brain to adjust to, especially for a patient with a vestibular disorder.

The key to success centers on communication between the doctor and the patient before surgery. Any pre-existing condition, especially a vestibular one, should be thoroughly explained with all options explored. For most patients the safest result is to choose to have both implants focused for distance, and to use glasses to see up close.

This is generally the safest option as it most closely mimics how our vision is naturally used, emphasizing symmetry between the two eyes and encouraging our brain to use both eyes together. This set-up should also provide the smallest amount of disruption to the visual-vestibular connection. Extra caution should be given to the patient who

is considering a multifocal implant or a monovision result, and the patient who is only having one eye operated on for the foreseeable future. Contact lens simulations before surgery can be used to mimic the multifocal and monovision outcomes, and should be considered, if possible.



Effects of Multiple Chemical Sensitivity on the Vestibular System

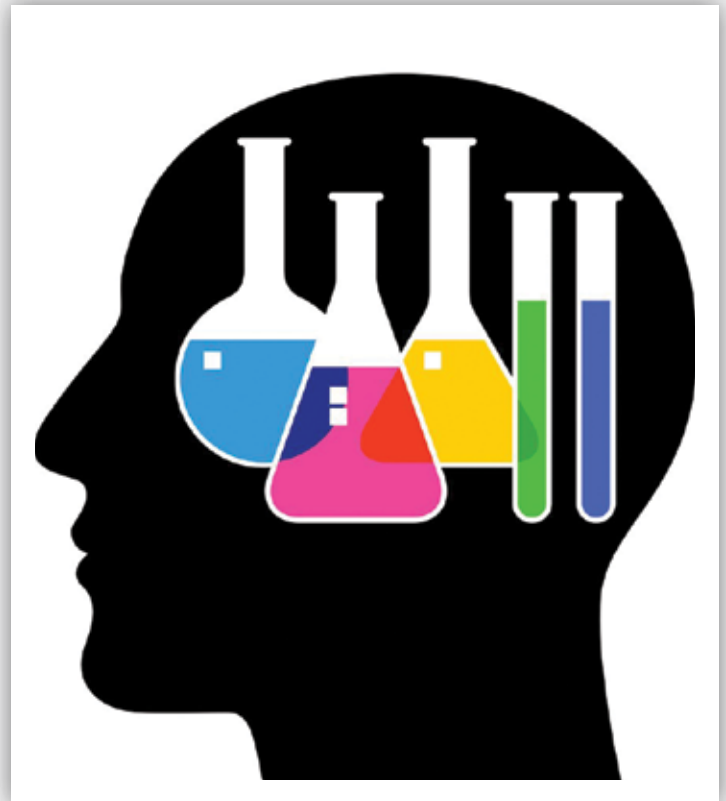
By Wendy Weizrbowski, PT

The Journal of Applied Science recently published a pilot study looking at the effects of multiple chemical sensitivity (MCS) on the vestibular system⁽¹⁾. MCS is a chronic condition characterized by susceptibility to multiple chemicals at low levels, which can cause a variety of central nervous system symptoms, including dizziness. Chemical compounds could include petrol, perfume or pesticides. Self-reported chemical sensitivity is a common complaint in western populations with a prevalence of 9% to 33%⁽²⁾.

The cause of MCS is unclear and a matter of debate^(2,5). Several studies in the past few years have shown cerebral blood flow changes in patients with MCS, especially while processing certain smells. The areas of the brain that show activation are connected with motivational, emotional and non-conscious processing of information^(6,7,8). Interestingly, these areas are also important in vestibular processing.

Central nervous system symptoms of neurotoxicity can include difficulty concentrating, memory problems, fatigue, depression, daytime sleepiness, "spaciness," irritability and dizziness^(2,3). Researchers studied 18 MCS and 20 healthy subjects using a variety of vestibular tests (static Posturography, video head impulse and several

others). Information was gathered from several questionnaires (Italian dizziness handicap inventory, environment exposure inventory)⁽¹⁾. After analyzing the data they concluded that dizziness symptoms and postural control abnormalities from chemical sensitivity could be related to a problem with the vestibular system.



REFERENCES

1. Micarelli, A.; Viziano, A.; Micarelli, E.; Genovesi, G.; Bruno, E.; Alessandrini, M. *Deranged Dimensionality of Vestibular Re-Weighting in Multiple Chemical Sensitivity*. *Appl. Sci.* 2016, 6(11), 330; doi:10.3390/app6110330
2. Alessandrini, M.; Micarelli, A.; Bruno, E.; Ottaviani, F.; Conetta, M.; Cormano, A.; Genovesi, G. *Intranasal administration of hyaluronan as a further resource in olfactory performance in multiple chemical sensitivity syndrome*. *Int. J. Immunopathol. Pharmacol.* 2013, 26, 1019–1025. [Google Scholar] [PubMed]
3. Miller, C.S.; Mitzel, H.C. *Chemical sensitivity attributed to pesticide exposure versus remodeling*. *Arch. Environ. Health* 1995, 50, 119–129. [Google Scholar] [CrossRef] [PubMed]
4. Cullen, M.R. *The worker with multiple chemical sensitivities: An overview*. *Occup. Med. State Art Rev.* 1987, 2, 655–661. [Google Scholar]
5. Das-Munshi, J.; Rubin, G.J.; Wessely, S. *Multiple chemical sensitivities: Review*. *Curr. Opin. Otolaryngol. Head Neck Surg.* 2007, 15, 274–280. [Google Scholar] [CrossRef] [PubMed]
6. Chiaravalloti, A.; Pagani, M.; Micarelli, A.; Di Pietro, B.; Genovesi, G.; Alessandrini, M.; Schillaci, O. *Cortical activity during olfactory stimulation in multiple chemical sensitivity: A (18)F-FDG PET/CT study*. *Eur. J. Nucl. Med. Mol. Imaging* 2015, 42, 733–740. [Google Scholar] [CrossRef] [PubMed]
7. Alessandrini, M.; Micarelli, A.; Chiaravalloti, A.; Bruno, E.; Danieli, R.; Pierantozzi, M.; Genovesi, G.; Öberg, J.; Pagani, M.; Schillaci, O. *Involvement of Subcortical Brain Structures During Olfactory Stimulation in Multiple Chemical Sensitivity*. *Brain Topogr.* 2016, 29, 243–252. [Google Scholar] [CrossRef] [PubMed]
8. Hillert, L.; Musabasic, V.; Berglund, H.; Ciumas, C.; Savic, I. *Odor processing in Multiple Chemical Sensitivity*. *Hum. Brain Mapp.* 2007, 28, 172–182. [Google Scholar] [CrossRef] [PubMed]

Documenting The Patient Perspective

By Cynthia Ryan, Executive Director



In 2014, VEDA asked members to assist in a research project by signing onto a patient registry and providing information on their diagnosis experience. We are grateful that over 500 members signed up and provided information, which has resulted in important insights. Data was initially collected from March 2014 through

October 2015. There were 521 respondents by the end of that period.

The patient registry was a collection point for data on vestibular patients' experience with healthcare providers as they searched for an accurate diagnosis and effective treatment. Data related to diagnostics, treatment, quality of life and healthcare costs was collected. In 2016, in collaboration with Dr. Michael Schubert from Johns Hopkins University, VEDA published a white paper on our findings in the *Journal of Otology and Neurotology*. The key findings are summarized here.

MOST COMMON DIAGNOSES

- The top four diagnoses reported by participants were Meniere's disease (25%), vestibular migraine (18%), vestibular neuritis (17%) and

BPPV (15%).


- Patients who reported having Meniere's also tended to report a concurrent vestibular diagnosis (e.g. vestibular migraine, vestibular neuritis and BPPV).¹
- 25% of respondents reported having Meniere's, which is higher than previous research studies have estimated (i.e. 14%).¹ This could indicate that the Meniere's diagnosis was disproportionately given (e.g. because of healthcare providers' familiarity with that disease versus other, less familiar, vestibular disorders), or that one diagnosis was originally given and later a different diagnosis was given, either because both occur concurrently or the first diagnosis was made in error.

PATIENTS CONCERNS ABOUT ACCURACY OF DIAGNOSIS

- A wide range of healthcare provider specialties were involved in diagnosing patients, yet only 20% of participants felt that they received an accurate and timely diagnosis.¹ This could indicate that patients were not referred to the appropriate specialist for their particular condition, and/or that testing and evaluations procedures are not followed consistently by the different specialists.
- 18% of participants felt that their healthcare



18% OF PARTICIPANTS
FELT THAT THEIR
HEALTHCARE PROVIDER
MISDIAGNOSED THEIR
CONDITION.



NEARLY HALF OF RESPONDENTS REPORTING BEING TREATED WITH CANALITH REPOSITIONING MANEUVERS, BUT ONLY 15% REPORTED HAVING BPPV.

provider misdiagnosed their condition.¹

- 17% of participants were told by their healthcare provider that their dizziness would go away on its own.¹ While we know that this does sometimes occur, we also know that unless the root cause is identified and treatment prescribed, the dizziness often returns.

OTHER OBSERVATIONS ABOUT TREATMENT AND TIMELINESS OF DIAGNOSIS

- Nearly half of the respondents reported being treated with canalith repositioning maneuvers, but only 15% reported having BPPV¹, indicating an overuse of these maneuvers as a treatment.
- 81% of BPPV patients reported being treated with canalith repositioning maneuvers, but only 52% said that it reduced their symptoms, indicating that they may have been misdiagnosed.
- Most participants reported seeing a healthcare provider within one month of their dizziness onset, but the time to reach a diagnosis was much longer (>50% required 5 months or

longer), confirming subjective reports that vestibular patients are not diagnosed in a timely manner.¹

- 45% of participants reported that they were currently receiving medications to treat either a specific diagnosis or relieve dizziness,¹ despite the fact that most medications only cover up symptoms and are most effective in acute cases but do not treat the underlying condition.
- 87% of Meniere's patients made dietary changes, with 50% reporting that their symptoms improved. 76% of vestibular migraine patients made dietary changes, with 41% reporting that they helped reduce symptoms.
- The average person visited their healthcare provider 3.5 times to treat their dizziness.¹
- 96% of Meniere's patients reported experiencing tinnitus, and 83% said they had hearing loss.
- Only 66% of vestibular migraine patients report having headaches.

KEY DIFFICULTIES OF DIAGNOSIS

- Dizziness is a difficult symptom to describe, which can confound doctors' efforts to evaluate patients and offer an accurate diagnosis. There is a need for standardized terminology that differentiates between different forms of dizziness – e.g. *vertigo*, *off balance*, *dizzy*, *lightheaded* - which has been identified in several previous research studies.
- Many vestibular patients suffer from concurrent cognitive disorders as a result of their condition. This can make it difficult to articulate their symptoms accurately.
- Subjective reports by vestibular patients indicate that they have a difficult time getting an accurate diagnosis that explains their symptoms; this data supports that claim. The data also suggests that many patients are not referred to the appropriate specialist, and that "common" vestibular diagnoses are generously given (e.g. Meniere's and BPPV), when in fact the patient may have a different underlying

condition.

IN SUMMARY

This study has demonstrated the value of the vestibular patient perspective, confirming many of your individual observations and highlighting important areas for improvement of the diagnostic process. Thank you to all who took the time to volunteer the details of your experience.

Note: VEDA continues to collect data through our patient registry so that we can document changes in vestibular diagnosis and treatment efficacy over time. You can participate by going to vestibular.org/registry.

RESOURCES

1. To-Alemanji, Jessica, Cynthia Ryan and Michael C. Schubert. "Experiences Engaging Healthcare When Dizzy." *Otology & Neurotology* 37.8 (2016): 1122-1127.

MOST COMMON VESTIBULAR DIAGNOSES REPORTED

Meniere's Disease	42%
Benign Paroxysmal Positional Vertigo (BPPV)	38%
Vestibular Migraine	33%
Labyrinthitis	23%
Vestibular Neuritis	18%
Still Seeking a Diagnosis	14%
Bilateral Vestibular Hypofunction	11%
Perilymph Fistula	5%
Chronic Subjective Dizziness	4%
Ototoxicity	4%
Superior Canal Dehiscence Syndrome	4%
Autoimmune Inner Ear Disorder	3%
Mal de Debarquement	3%
Central Vestibulopathy	3%

MOST COMMON DIAGNOSTIC TESTS REPORTED

Hearing Test	85%
MRI	75%
Blood Tests	61%
CT or CAT Scan	56%
Videonystagmography (VNG)	48%
Electronystagmography (ENG)	43%
Rotation Chair Test	39%
Vestibular Evoked Myogenic Potentials (VEMP)	33%
Computerized Dynamic Visual Acuity Test	24%
CDP (Posturography)	19%
Video Head Impulse Test (vHIT)	17%
Other	17%

Antivert (Meclizine): Miracle Drug or Myth?

By Dr. Dennis Fitzgerald, MD

In 1957, a new drug came on the market called Antivert (now known by its generic name, meclizine). Until this time, physicians had little in the way of medication to treat the symptoms of vertigo or dizziness.

(Note: vertigo and dizziness are symptoms of a disease, not diseases in and of themselves, despite the fact that many people, physicians included, use the terms that way. Vertigo is a sense of spinning, and dizziness is a general term that describes lightheadedness or imbalance.)

Antivert claims to be a treatment for the symptoms of vertigo and dizziness. However, a PubMed search resulted in little data on Antivert's claims to be effective against these awful symptoms. (Full disclosure: There is also no research disproving Antivert's efficacy to treat these symptoms.) Nevertheless, meclizine continues to be one of the most commonly prescribed medicines in the United States.



I am a neurotologist with over 35 years of experience dealing with patients who suffer from vertigo and dizziness. It is clear to me that a majority of physicians in this country do not understand the reason for these symptoms and would rather not take care of patients who come into their offices with these problems. When Pfizer first put Antivert on the market, physicians almost rejoiced that there was now a medication that they could give their patients to get them out the door. Antivert, with its catchy tradename, was an instant success. It rates as one of the best marketing and branding moves in U.S. advertising history.

What is Antivert? It is in a class of medicines known as a first-generation antihistamine. It is very similar to Dramamine, which had been used for motion

sickness for years before the arrival of Antivert. These medications have the negative side effect of drowsiness.

I have looked at many resources for the indications of the use of Antivert. Almost all of them say that its benefit is for the treatment of nausea from motion sickness, or the "dizziness of motion sickness." In my experience there is no such thing as the "dizziness of motion sickness," yet it is repeated over and over in resources such as the FDA, WebMD, etc. I cannot find credible scientific data to

support its effectiveness in the alleviation of the symptoms of vertigo and dizziness; the only two articles with any data at all suffer from a very small number of subjects being studied.

Let's be clear. In the short term, vestibular suppressants can be effective for management of the *acute* symptoms of vertigo and dizziness, namely nausea. And because they allow patients

to move with fewer symptoms, they may actually promote compensation. However, these medications should be discontinued within a short period of time so that the natural compensation process can continue. The problem is that it is often easier to cover up the symptoms than it is to treat them.

I have written this article with the experience of seeing and evaluating thousands of patients with the symptoms of vertigo and dizziness. Most had been seen after visits to their primary care physicians, urgent care centers, or the emergency room. Invariably, they have been given prescriptions for Antivert (meclizine) and their symptoms are unchanged. They are even prescribed this medicine to prevent vertigo and dizziness. If it really was effective, I would not have had a practice for the past 35 years!

Disclaimer: This article represents the opinions of Dr. Dennis Fitzgerald.

SPC Flakes Have Been Clinically Shown To Support Cellular Fluid Balance



spc-flakes are specially processed cereals that are made with a unique and patented production method.

SPC IS AN ABBREVIATION FOR
"SPECIALLY PROCESSED CEREALS."

spc-flakes may be used for the dietary management of vestibular disorders and Meniere's disease, among other conditions.

"I have had unilateral Meniere's disease for 10 years. I skeptically started on this product in July 2015. My disease is at the stage that my attacks are less frequent but the pulsating tinnitus is very uncomfortable and loud, and the duration may be up to 6-10 hours. I need to take benzodiazepine to cope.

I can honestly say that ingesting 1/4 cup spc-flakes three times each day has nearly alleviated the loud pulsating "gong" of my tinnitus. My head feels better and I have no vertigo, regardless of the direction in which I turn my head. This was after two weeks of using spc-flakes! I can only imagine how I will feel after a month. Best news is this is a medical food without any side effects."



VISIT

WWW.POAPHARMANA.COM

TO LEARN MORE, OR CALL

855-416-6826.



Contraindications: Not to be used by gluten intolerant individuals or those sensitive or allergic to oats.

Team Styx - A Story of Counterbalance

By Sherron Laurrell

INTRODUCING STYX

Styx is a 3-year-old Golden Retriever who is transforming the life of his human partner from one of uncertainty and limitation to one of renewed confidence and mobility.

Styx, you might say, is a Wonder Dog! That's what we all say about our beloved canine companions, right? Styx, however, is different. He is a medical service dog trained to provide balance assistance.

SUSAN'S STORY

Dr. Susan Hummel has dealt with imbalance and other difficulties associated with a traumatic injury for nearly 25 years. Now in her early 50s, she has been treated for superior canal dehiscence and perilymph fistula (dual surgeries in 2012), secondary endolymphatic hydrops and migraines.

Susan works full-time for the USDA Forest Service, based at a research station in Portland, Oregon. She and her husband, Rainer, have had to learn to manage her limitations as time has passed and her mobility has deteriorated.

Susan finally reached the point where she needed more help than a walking stick and sheer will could provide. When she read about a U.S. military veteran who dealt with balance problems aided



SUSAN AND STYX AT WORK IN THE FOREST

by his service dog, she began searching to learn more. She ultimately applied and was accepted by Brigadoon Service Dogs of Bellingham, WA, which matched Susan with 1-year-old Styx.

BECOMING A BALANCE ASSISTANCE DOG

Bringing a service dog into your life is not a simple thing. First you must apply. Then get accepted. Then be matched with the "right" dog (you don't choose the dog; the organization matches your needs with the dog's skills and capabilities). Then begins your team training.

It is very costly to raise a puppy into a highly skilled service dog, upwards of \$25,000. For non-veterans like Susan, fees associated with acquiring and maintaining a service dog like Styx are a quarter to half of the total cost it takes to get the dog fully certified. Expenses are tax-deductible. Veterans may qualify for all-expense-paid dogs.

Service dogs like Styx are trained according to Assistance Dog International (ADI) guidelines (see <http://www.assistedoginternational.org>)



SUSAN HUMMEL AND HER HUSBAND, RAINER

CONTINUED ON PAGE 14

beginning with "puppy raisers" and basic obedience training. Brigadoon uses both in-house trainers and a unique prison program where incarcerated men help with service dog training. Twelve months after the dog has been re-evaluated for basic soundness "matches" can begin.

MATCHING DOG AND HUMAN

After a careful evaluation of the human/canine connection (right size - Susan and Styx are both tall - right temperament, etc.) a match is made and several months of specialized training begin. Styx learned to accept wearing a harness, adapt his gait to any handler, brace and pick up dropped items like pencils, credit cards and books. Service dogs are also trained to potty on cue using the command "go hurry."

Once Susan was matched with Styx, she had to wait for his specialized training to be completed. It felt like a *long* wait! When the big day came for Susan and Styx to begin team training at Brigadoon, they started by spending three days together, 24/7, for integration and bonding (no classes) in nearby Bellingham. Then daily training with others who



TEAM STYX VISITING COLOGNE, GERMANY WITH FAMILY

were matched with Brigadoon dogs.

Their first big test? The PAT (public access test). Team Styx passed on the FIRST try! Then began a six-month probationary period, after which they were re-tested ... and passed again on the first try!

The PAT is conducted in busy, distracting public places like supermarkets and large department stores - a hellishly challenging environment for someone with sensory and vestibular disabilities.

Once the test is over, the teams are taken to a restaurant to celebrate (and to practice navigating the tricky world of entering and exiting a food establishment with a service dog). Team Styx has completed two PATs, with the third (and final) one scheduled for May 2017.

Teamwork is not an automatic thing, Susan explained, and the probationary period was a huge adjustment. Now, with one and a half years of history between them, Styx and Susan are a truly integrated team!



SUSAN AND STYX HIKING NEAR THEIR HOME IN THE COLUMBIA GORGE, WASHINGTON STATE

YES! I WANT TO HELP PEOPLE SUFFERING FROM VESTIBULAR DISORDERS.

**VEDA is entirely supported by donations and membership dues.
Your gift helps VEDA provide information on vestibular
disorders to millions of people every year. Thank you!**

You can make a gift to support VEDA's life-changing work online at vestibular.org/otl
or send your payment to 5018 NE 15th Ave, Portland, OR 97211 with the enclosed self-addressed envelope.

Donation:

\$250 \$200 \$150 \$100 \$50 \$25

Other \$ _____

**I would like to join the Sustaining Program
and contribute this amount every month**

Please make my donation anonymous

Method of Payment:

Check (payable to VEDA in US Dollars)

Visa MasterCard American Express

Options:

Please send me information about including
VEDA in my Will or Estate Planning.

My company will match my donation.

Company Name: _____

NAME _____

BILLING ADDRESS _____

CITY, STATE, ZIP _____

E-MAIL _____

PHONE _____

CREDIT CARD # _____

EXP. DATE _____ CSV CODE _____

Thank you for supporting the Vestibular Disorders Association! With your help we can reduce the time it takes to accurately diagnose vestibular disorders and improve treatment outcomes, helping patients live happy, productive lives.

Invest in VEDA

**DID YOU KNOW THAT YOU CAN DONATE
STOCKS, BONDS AND MUTUAL FUNDS TO VEDA?**

Benefits of donating security-based gifts:

- Avoid capital gains taxes
- Receive full fair market value for your tax receipt
- Give more than you might have been able to with cash

Talk to your tax and investment advisors to discuss how to maximize the value of your gift.

For more information, contact VEDA at veda@vestibular.org or call (800) 837-8428.



MEDICAL DECISIONS

Susan's journey, like most, has not been bump free. At first she dealt with physical pain and was determined to rehabilitate to her previous level of health. Then came the slow and humbling recognition that she would not return to an uninjured version of herself.

**SUSAN BEGAN
TO REALIZE THAT
HER COPING
STRATEGIES
WERE NO
LONGER
WORKING.**

She initially chose to avoid doctors and surgery and focus instead on people and activities that inspired her. Susan learned to substitute quiet and often solitary activities for those that triggered her symptoms.

By 2010, she began to realize that her coping methods were no longer working. Susan wrote to Sue Hickey, author of *Finding Balance - a vestibular memoir*, who is a former VEDA board member and lives in Portland, Oregon. Sue had undergone surgery for perilymph fistula, and as a retired business professional she knew the impact these conditions can have on your work and personal life. Finally, Susan decided that it was time for the surgeries.

I asked Susan how Styx has changed her life. She says he has expanded it, permitting her to continue working, meet people and have experiences that would otherwise have remained unknown. He has reduced Rainer's worry about her navigating the world apart from him. And he has helped with the feelings of isolation, frustration and resentment that can accompany chronic illness. His schedule is in sync with hers, he rarely makes her feel inadequate, and he keeps her safe.

YOU'RE QUITE A GIFT, STYX! THANKS FOR BEING SUCH A WONDER DOG!



VESTIBULAR
DISORDERS ASSOCIATION
5018 NE 15th Ave, Portland, OR 97211, USA
800.837.8428 | info@vestibular.org | vestibular.org
CHANGE SERVICE REQUESTED

NON-PROFIT ORG
U.S. POSTAGE
PAID
PONTIAC, IL
PERMIT NO. 592

STYX TURNS THREE AND TAKES A WELL-DESERVED ROLL

