

# ON THE LEVEL

A QUARTERLY NEWSLETTER OF THE VESTIBULAR DISORDERS ASSOCIATION



INFORMATION

SUPPORT

AWARENESS

ADVOCACY



## How My Life Changed

By Lori Perkins

My life before my vestibular issues was very different. I was a district manager for a large department store and had over 900 employees. I constantly traveled the state of Florida and was very active. I made a decision to leave that company and start another job. I took a two-week vacation to Europe in between jobs and came back with what I thought was a typical flu. I began the new job a few weeks later but still had mild symptoms. I went to my doctor three times and was put me on two different courses of antibiotics, but nothing helped.

I started my new job and had difficulties with simple tasks. I could not transfer numbers to spreadsheets and had difficulty walking on the large sales floors that were under my supervision. I was always a quick learner so this frustrated me. Driving became an issue, and I was

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LORI PERKINS USES WALKING POLES AND A WALKER TO GET AROUND, BUT GET AROUND SHE DOES!

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HOW MY LIFE CHANGES...CONTINUED FROM PAGE 1:

suddenly taking very long routes just to avoid any busy roads. Being new to the company, they did not know me or my work ethic, so I pushed through feeling sick every day. My boss paid me a visit one day and asked me to walk across the parking lot with him. I tried but found that I couldn't do it. I had to grab cars on the way and I'm certain he thought I had a drinking problem. I was told to go home and "sort myself out." I stayed in bed for a few days and decided to venture out and go shopping before returning to work.

I was in a large store and suddenly felt absolute panic. I could not find the floor with my feet and felt like I had just stepped off an amusement park ride. The store was packed with people and my journey to the front door was probably the most frightening experience I have ever had. I could barely walk, even leaning against a shopping cart. I was immediately driven to the hospital.

At the hospital I was seen by a cardiologist and neurologist. After spending the night I was told that I was fine. The next day at home I had to crawl to the bathroom, so I knew "fine" was not the correct diagnosis. I went to my family doctor that day and was immediately told to see an ENT. I was able to get in quickly and run through all the tests. I was told that I had vestibular neuritis and that it would clear up quickly. That was almost four years ago and 4 specialists and 6 months of vestibular therapy later, I still have not been able to lead a normal life. I have been diagnosed with chronic vestibular neuritis, hypoactive labyrinth (unilateral), chronic utricular dysfunction, and chronic BPPV.

I have been through all the vestibular testing, met with a rheumatologist to rule out immunosuppression, tried anti-virals for three months, six months of vestibular therapy, and several medications. My best results have come with time and movement. This has not been without injury to myself. I have fallen several times and on one occasion tore my TFCC (triangular fibrocartilage complex) on my wrist, requiring surgery, and also knocked a front tooth out on another fall. This has been a very frustrating journey and I am still unable to work.

After 4 years, I still use a walker to get around and

have difficulty tracking words and numbers. My visual issues have been my biggest challenge. I always looked forward to having the time to catch up reading all the books that I had purchased over my working years. I still have yet to make it through one. I have been to several eye doctors and find the adjustment to new glasses to be a huge challenge, even if the prescription hasn't changed. I have tried getting two pairs of glasses to split up a bi-focal but find that to be annoying.

My daily routine is very different. I prioritize cognitive tasks, talking to people, and telephone conversations to occur in the morning or early afternoon when I am at my sharpest. I rarely go out at night. Walking after sunset, different floor textures, and shadows are very challenging to me. I have learned to listen to my body and when I get the spins I know to stop what I am doing and sit quietly until it passes. I know that trying to fight it does not work and has caused many falls. Because of the person I was before, I need to be active in whatever way I can.

After all of this, I would still consider myself fortunate. I thought my life was over and could not imagine being like this forever. The important thing was for me to adapt to the new normal and the new normal is good. I still get around, just not to the degree I used to. I use a walker but my speed hasn't changed, so I whiz past people and they probably think I'm faking it! They just don't know that if I let go, I become a drunk and fall down. My

7-year old niece named my walker Zoom-Zoom because I walk so fast with it. I'm thinking of adding racing stripes!

I do have difficulties with reading, busy environments, brain fog, fatigue, and poor concentration. I drive but limit myself to short distances and quiet roads. But I have not given up! I just have a load of adaptive processes. I feel best when I move, so I use a Fitbit and make sure I get 10,000 SAFE steps daily. I may have to do this holding onto the back of my couch and walking in place, or using my walker to do them, but I get them every day. If I miss a day, I feel more brain fog than when I don't get them. I have done some traveling with this condition and use hiking sticks or a walker to get around, and while I am limited, I am not sitting at home and feeling sorry for myself any longer. I'm still seeing the world, just from a different view and at a different pace. So my advice to anyone with a similar condition: **move, Move, MOVE! SAFELY.**



# Helpful Tools for Your Recovery & Balance: Yoga & Meditation

By Sherron Laurrell

Like many of you, I live with chronic dizziness. When it started two and a half years ago, I was disoriented and scared. I had no idea what was going on. I went through the dance of diagnosis: multiple doctors, many tests, trial drugs, VRT, homeopathic alternatives, support groups. Some helped. Many didn't. I was left to contemplate the question "What Next?"

I am a long time journaler and meditator. I always have a journal going. It's like having a friend with you all the time. You can say anything you want. Capture everything you feel. No one will ever see it and you don't have to deal with unwanted advice from well-meaning family and friends. It's a form of meditating and it helps.

But I needed more. I wanted some way to diffuse the fear and anxiety of feeling off balance all the time. I had read a lot about yoga but didn't have the slightest idea how to begin. My friend Janet signed me up for an introductory yoga class. I was very skeptical but I decided I had to do something.



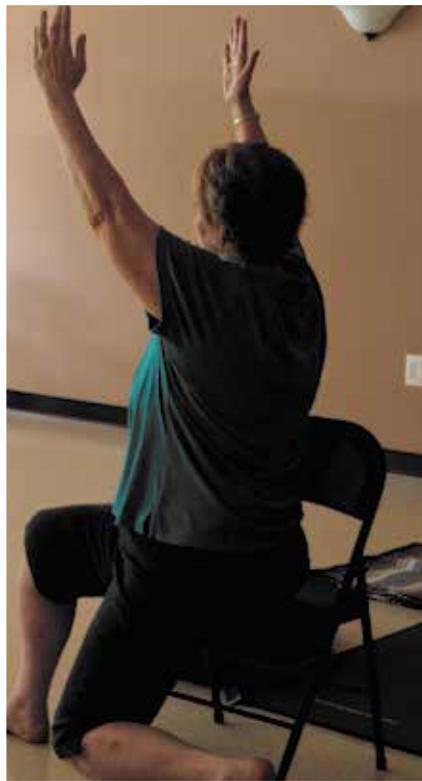
My first yoga class was in November, 2013. What I have learned over the past 2 years is that yoga is life changing. It's not easy. I am very inflexible. I always thought yoga required flexibility. Not true. What yoga requires is commitment. I go to class two times a week and practice at home. I'm not good at it, but it is good for me. It has dramatically improved my balance confidence and it has taught me how to center my thinking through my breath when I am feeling most vulnerable.



COLLEEN VERTON, AT MARIANNE WELL'S COSTA RICA YOGA RETREAT, WHERE SHE IS AN INSTRUCTOR.

Colleen Verton was the first person I met when yoga entered my life. She is the founder of Pink Lotus Yoga in Swedesboro, New Jersey. She is a Marianne Wells trained yoga instructor and has achieved the highest yoga certification, ERYT (Experienced Registered Yoga Teacher), indicating she has completed over 1,000 hours of yoga teaching. I asked Colleen about her experience in helping people with chronic illness who use yoga and meditation to cope with their challenges.

60+% of people who come to Colleen to begin or to continue the practice of yoga are dealing with a chronic illness either physical or emotional. She has a personal history of anxiety issues that she is able to manage through the practice of yoga and by meditating regularly. She is a mom of two and a wife and business owner, so it isn't like she has loads of free time. I asked her how she coaches her clients to begin meditating. "Take a task you do every day, like washing the dishes, and make it a time for meditation. Place items near your kitchen sink that make you happy, like a special photo or some pretty decorations. While you do the dishes, focus on breathing calmly, relax your muscles, and clear your mind. Do the dishes, breathe, relax. It will feel awkward at first. But the more you practice, the more it will give your mind a calming break from the chatter and worry that consumes you."



I know this to be true, because I do it regularly. Some people think that meditating requires setting aside 30 minutes, sitting somewhere quiet, and surrounding yourself with music and beauty. Nope. Meditating is a state of mind. A "practice" of slowing down your mind and focusing on your breath. It will change your life if you give it a chance.

There are thousands of resources online, at the library, and through community school programs that can help you learn how to meditate. The more often you practice, the more benefit you will get.

Yoga is the same. You do not have to be flexible or young or thin or athletic. You can start yoga sitting, standing, or laying down. The secret is to start. It's best not to start practicing yoga on your own. Colleen advises that you find a qualified yoga instructor to teach you techniques. You should look for someone who has at least 200 hours of certification. There are many types of yoga. Beginners find "Gentle or Restorative" yoga to be helpful. If money is a problem, don't give up looking for a teacher. The right instructor will not allow money issues to get in the way of helping you get started. Many local hospitals have low cost beginner yoga

programs. If you like to read, Colleen suggests Deborah Adele's *The Yamas & Niyamas: Exploring Yoga's Ethical Practice*.

Living with chronic illness is exhausting. When I have a dizzy spell, I have learned to use yoga and meditation to focus myself. I hope you try it. And most of all, I hope it helps you!



SPENCER LAURRELL MEDITATING NEXT TO HIS MOM'S YOGA MUSIC CD.

# Post Concussion Vision/Vestibular/Somatosensory Integration

By Dr. Neil Margolis, O.D., F.C.O.V.D., F.A.A.O.



It is my experience that many post-concussion patients can appreciate quicker relief from vision/vestibular disintegration related symptoms with the prescription of appropriate lenses, filters and

prisms. The proper lens prescription is able to resynchronize the visual system with the vestibular system. This serves to both decrease current post-concussion symptoms, and to facilitate recalibration of the two sensory systems for ongoing rehabilitation.

The lenses allow vestibular rehabilitation to be continued with fewer symptoms during therapy, and to also provide for faster recovery time post therapy. Most importantly, the lenses make it easier to carry out activities of daily living.

Appropriate testing allows for differential diagnosis and trial of select lenses, filters and prisms. The lenses are specifically prescribed to compensate for binocular

dysfunction, reduced focusing, or altered visual spatial coordinates. They can also be designed to alter the vestibular ocular reflex gain, or to decrease peripheral vision motion sensitivity through manipulation of the optical parameters.

Lenses do not treat the underlying visual or vestibular dysfunction directly, but rather provide compensation for many related symptoms, while facilitating longer term rehabilitation.

Improvements in headaches, dizziness, blurry vision, visual attention, light sensitivity, double vision, balance, and motion/clutter sensitivity are the symptoms and performance areas mostly affected.

It is especially gratifying as a practitioner to provide quicker relief and hope for many patients who have had their "normal world" suddenly changed. It allows them, even with trial lenses, to see what they can hope to achieve with appropriate interventions.

*Dr. Neil Margolis is a Developmental Optometrist in Arlington Heights, Illinois. He has specialized his practice towards the evaluation and treatment of functional vision problems: tracking, visual processing, visual sensory problems, post concussion.*

## YOU CAN JOIN VEDA'S TEAM!

WE ARE SEEKING PATIENTS & PROFESSIONALS LIKE YOU WITH FUNDRAISING, MARKETING, HEALTHCARE, OR POLICY EXPERIENCE TO FILL POSITIONS ON VEDA'S BOARD OF DIRECTORS.

CONTACT: [VEDA@VESTIBULAR.ORG](mailto:VEDA@VESTIBULAR.ORG)





# BALANCE AWARENESS WEEK to **DEFEAT** *DIZZINESS*™

SEPTEMBER 14-20, 2015



## \$71,187 RAISED

THANKS TO DONORS LIKE YOU!

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#### SUPERSTARS:

- SANDRA ROBERTS: \$4,800
- GARY BREITBORD: \$4,455
- JANIT GREENWOOD: \$3,752
- DR. DENNIS FITZGERALD: \$2,050
- MARY ZIEGLER: \$1,625
- LOUISE GEIB: \$1,335

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- GRAND VALLEY STATE UNIVERSITY'S DOCTORATE OF PHYSICAL THERAPY PROGRAM - GOLF TOURNAMENT: \$1,007
- T-SHIRT SALES: \$1,635 (207 SOLD)
- INDIAN BAZAAR: \$1,750
- DIZZY DASH: \$1,130

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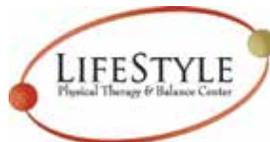
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# Spreading

## DIZZY DASH



DAVID



MONICA

## VIDEOS

### PATIENTS TELL THEIR STORIES



ANNE K.

### PROFESSIONAL TESTIMONIALS



STEVEN  
RAUCH, MD

# Awareness

BALANCE  
CHALLENGE



# Outreach

## FACEBOOK

|          |         |
|----------|---------|
| POSTS    | 49      |
| LIKES    | 1,137   |
| SHARES   | 2,609   |
| COMMENTS | 1,030   |
| REACH    | 245,761 |

## CELEBRITY TWEET



## PRESS RELEASE

VIEWED BY 227 NEWS AGENCIES  
WITH A TOTAL AUDIENCE OF  
183 MILLION

## E-BLASTS

|              | 2014   | 2015   |
|--------------|--------|--------|
| DELIVERED TO | 39,391 | 47,784 |
| OPENED BY    | 12,978 | 15,002 |

## NEWS

**Many VEDA partners - including non-profit organizations, corporate sponsors, members, and professional associations - raised awareness through press releases, articles, e-blasts, social media campaigns, and more!**

- › The American Academy of Audiology distributed a press release announcing Dr. Kristen Janky as the Balance Awareness Week Honorary Chair.
- › VEDA professional member, Vicki Seppell, was featured in an article in the Hudson Valley News Network highlighting a teenager she treated with vestibular symptoms following a concussion.
- › The University of Michigan Vestibular Testing Center published an article titled, "Dizziness is Not Normal."
- › Many physical therapy clinics announced free balance screenings in their local papers.
- › VEDA sponsor Otometrics sent an e-blast to their customers and employees announcing Balance Awareness Week and asking them to donate to their personal campaign page.
- › The Monterey Herald published an article about the inner ear's "balancing act."
- › The U.S. House of Representatives approved H.R. 418 designating September 15-21, 2015 Balance Awareness Week, and recognizing the importance of raising awareness about vestibular disorders.

**Tell us about your Balance Awareness Week event or outreach: [baw@vestibular.org](mailto:baw@vestibular.org).**

# Ambassadors

DAVID'S CAR DECAL



MARISSA'S T-SHIRTS



ETRILY'S INDIAN BAZAAR



TANIA'S LETTER TO DOCTORS

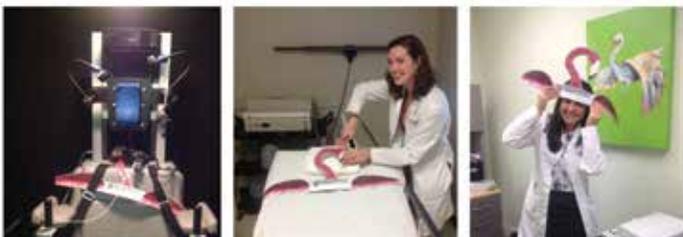


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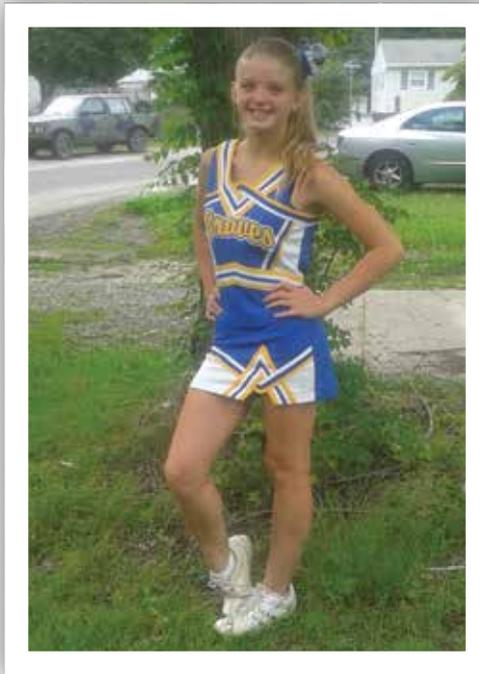
# A Parent's Nightmare: Teenage Concussion

By Dr. Jennifer Liss (with Sherron Laurrell)

Corinne Santana, age 13, is the picture of what makes a parent proud. Her parents, Jennifer MacDermott and Eric Santana, have watched with love and awe as their daughter has handled a medical emergency that introduced the family to the overwhelming topic of teenage concussion.

Corinne is an 8th grader and a cheerleader. On September 20, 2014, she was participating in a cheerleading stunt where she was in the second tier lifting another cheerleader to the top of a pyramid. The girl on the bottom lost her hold because of a weakened wrist that was wrapped in a brace. As the top girl fell, Corinne was clobbered in the back of the head. A few minutes later, Corinne hit her chin on another girl's forehead. Both Corinne's mom and her coach knew quickly that something was wrong. She was acting strangely and was unresponsive to questions. Her head was bobbing.

Her mom rushed her to the ER. After a CT scan, she was admitted to the hospital and eventually taken by ambulance to the Regional Trauma Center in Atlantic City, New Jersey. Suffering with intense head and neck pain, the doctors prescribed medications that required heart monitoring. For more than a week, Corinne zoned in and out. She remembers nothing of the accident or the days after. The on-call doctor at their family practice, although very sympathetic, did not



CHEERLEADER CORINNE SANTANA BEFORE HER CONCUSSION JOURNEY BEGAN

have much knowledge about concussion. She recommended Corinne be seen by a Sports Medicine Specialist.

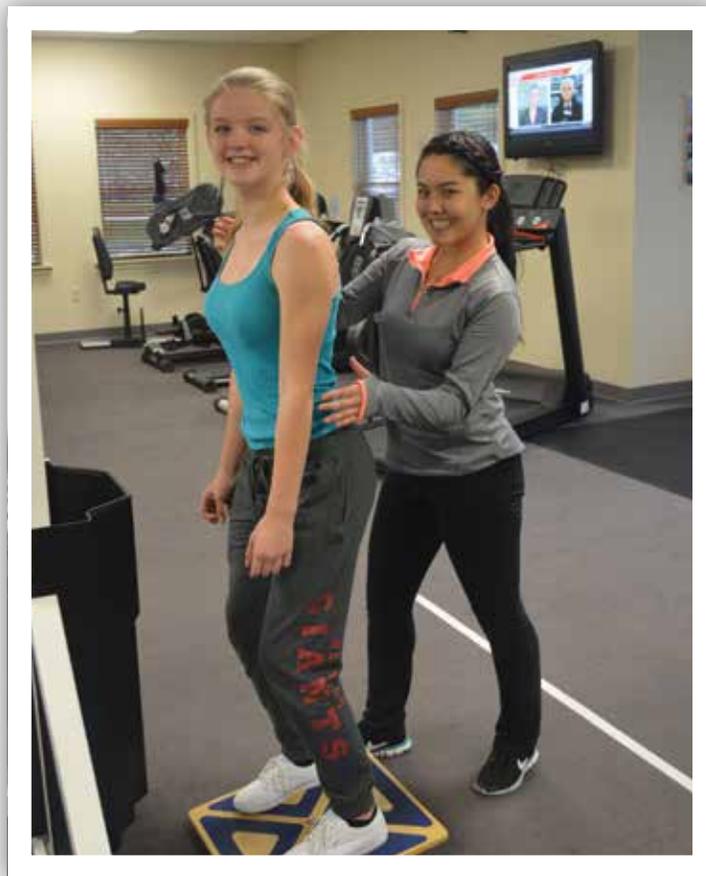
Corinne's school was even less informed about concussions than the family doctor. The middle school just didn't know what to do, including the school nurse. On October 2, 2014, Corinne was evaluated by a Rothman Institute Sports Medicine Specialist. Although Corinne's specialist gave her a 504 (academic) Accommodation Plan, some of her teachers would not cooperate. A few

were openly critical of her, saying that she was "exaggerating" and "faking" her symptoms. Corinne was depressed, full of anxiety, mentally confused, dizzy and in pain. She first came to see me on October 13th.

As a Certified Specialist in Vestibular Rehabilitation I had begun getting numerous referrals to treat post-concussive syndrome. When I initially started treating these patients four years ago I quickly realized they were different from the Traumatic Brain Injury (TBI)/neurological and vestibular populations. They often have a combination of central and peripheral abnormalities. VOR (vestibulo-ocular reflex) retraining, even with extensive modification, did not progress the way my vestibular patients progressed. Many times the patients seemed to have trouble focusing on a target even with their heads still.

After spending extensive amounts of time with concussion specialists, vision therapists, and attending as much continuing education in this area that I could find, I realized that in order to normalize impaired vestibular reflexes, concussion patients first had to be able to clearly focus on a target.

Corinne's main symptoms upon examination included headache, dizziness, fatigue, and neck pain. Her symptoms increased with reading, copying from the board, math class (always her hardest) and exertion. Instead of beginning my clinical concussion exam with the standard oculomotor exam, I began with monocular accommodative focus (the ability of an individual eye to focus clearly on a target) and found a significant difference between her two eyes. I then assessed for a convergence insufficiency (normal is 4-6 cm) and found that the same eye that had weaker accommodative focus had more difficulty moving medially and maintaining convergence on a target. This affected saccadic eye movement speed, and endurance strongly impacts reading ability. Copying from the board was even more difficult because it involves repetitive head movement combined with



CORINNE DOING BALANCE BOARD EXERCISES WITH STEPHANIE NGUYEN, THERASPORT PHYSICAL THERAPY AIDE.

visual accommodation between near and far targets.

I treated Corinne twice a week for five months. Her recovery was slow but consistent. 13-year old girls are the slowest youth population to recover from concussion due to their dramatic hormonal changes. However, thanks to Corinne's consistent efforts in therapy, she successfully graduated on February 5, 2015. She has returned to her middle school life and her cheerleading!

When Corinne's mom was asked what she has learned from this experience she was very clear. "Speak up if you see something that looks out of place." After the fact, she remembers seeing the wrist brace on the girl who was supporting her daughter in the



CORINNE WITH HER MOM JENNIFER MACDERMOTT (LEFT) AND PT AIDE STEPHANIE NGUYEN (RIGHT) AFTER HER GRADUATION FROM THERAPY!

pyramid and wondering why she was performing a cheerleading stunt if her wrist was injured. She also feels residual frustration about the lack of school system knowledge about concussions and how to treat patients. She tries hard to strike a balance between letting Corinne be independent and overprotecting her. This is an understandable reaction from a mom who has seen her daughter through such a powerful event. Corinne's mom

plans to educate those around them about the importance of treating teenage concussions seriously and immediately.

*Jennifer Liss is certified in Vestibular Rehabilitation. She is an Adjunct Professor of Kinesiology at Rowan University in Glassboro, NJ. TheraSport Physical Therapy offices are located in New Jersey, where she has practiced for 16 years. She can be reached at [JenLiss@Therasport.org](mailto:JenLiss@Therasport.org). Sherron Laurrell is a vestibular patient who has been treated by Dr.Liss. They now collaborate on case studies to educate and help others.*

## "I FEEL LIKE NO ONE UNDERSTANDS..."



Many vestibular patients feel alone and isolated and don't know where to turn. VEDA provides support: connections to patients who have been there before, and information to help patients understand their vestibular symptoms.

If your membership is up for renewal or expiring soon, you should have recently received VEDA's Fall Membership Campaign. We hope you will continue to support VEDA's patient education and advocacy efforts by returning the enclosed envelope or visiting us online at [vestibular.org/membership](http://vestibular.org/membership).

We hear every day from members who feel like no one understands. Many vestibular patients feel alone and isolated and don't know where to turn. Through our **Community of Support** VEDA connects vestibular patients to each other, to qualified healthcare professionals, and to information that helps them understand what they are going through. We provide a life-line to help patients on their road to recovery.

Thank you for being a VEDA member! We hope you will renew your membership.

**TOGETHER, WE CAN DEFEAT DIZZINESS™!**

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

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

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

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## **Method of Payment:**

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*"My name is Angel I have been suffering for the last year and a half with vertigo. My episodes usually last 3 to 8 hours. Lately it's been reoccurring every other day and the episodes last from 3-8 hours. Searching out of desperation I saw the advertisement for spc-flakes and Salovum on the VEDA website. I decided to give the spc-flakes a try. Yesterday I had a big episode and I took two packets of Salovum with orange juice. Within a half hour my episode had subsided and an hour later I was back to normal! I am thankful that I found you and your website. Thank you so much." ~Angel B.*

