# ON THE LEVEL A QUARTERLY NEWSLETTER OF THE VESTIBULAR DISORDERS ASSOCIATION

SUPPORT



#### INFORMATION

AWARENESS

#### ADVOCACY



## **Search For A Diagnosis**

By Jeanne Slauter

My symptoms began in February 2004. At first, dizziness and nausea were my major issues. Then, a few years later, I started having hemiplegic migraines (HM) 2-3 times a week on average.

Hemiplegic migraines are very disabling; they essentially took over my life. The symptoms are similar to having a stroke: slurred speech, extreme dizziness, inability to concentrate, and panic attacks. The left side of my body was numb from my head all the way down to my toes. Half the time my whole left side was paralyzed and I was unable to move. This would last for 4 to 5 hours per day, and I would be laid up for days afterward. I also had nonstop "regular" headaches daily, and occasional migraines. I was unable to commit to any kind of plans because of the inconsistency of my HM migraines.

Sometimes while driving I had to pull the car over and call someone to come get me because I became dizzy or was having an HM migraine. I couldn't go to church because the music would cause

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JEANNE & HER HUSBAND CELEBRATE THEIR 31ST WEDDING ANNIVERSARY WITH FAMILY

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#### SEARCH FOR A DIAGNOSIS...CONTINUED FROM PAGE 1:

dizziness, and at times trigger a HM.

My family has been severely affected by my disabilities. They could not rely on me to be there for them or do all the activities we use to do together. I was unable to take care of my grandbabies by myself because I was afraid of what could happen. My quality of life plummeted, and I figured that my health would only worsen as the years went by.



JEANNE'S DAUGHTER, TIFFANY, AND SON-IN-LAW, JUSTIN, TOOK CARE OF HER AFTER HER SURGERY

I've been to so many doctors over the past nine years that I've lost count. Every doctor I saw either treated me like I was crazy, didn't know what I was talking about, or thought I was a drug seeker. Basically they didn't believe me.

My daughter and I did our own research and discovered that I had all the symptoms of HM. Then I did more research to find a doctor who knew of and could treat HM. There were no doctors in my area that even knew what this was. Finally I found Dr. Dale Carter in Portland, Oregon. I told my primary care doctor about her and asked him for a referral. He said that he preferred to treat my symptoms with medications. I went to Portland anyway.

Dr. Carter is amazing. For the first time in nine years a doctor validated all my symptoms. She realized that there was something else wrong with me other than my HM's, so she sent me to Dr. Ashley Wackym. God bless his soul, Dr. Wackym was able to get me in within a couple of weeks.

Dr. Wackym asked me what all my symptoms were and then asked me specific questions about symptoms that I hadn't realized were symptoms at all. After a series of tests he diagnosed me with superior canal dehiscence syndrome (SCD). For the first time in many years I had hope.

Dr. Wackym is an outstanding doctor. He treated me with respect and compassion. He recognized my suffering and did everything he could to get me scheduled for surgery within a month of my first visit.

Surgery was the best thing to happen to me since I got sick. Immediately the static, heart beat, and ringing in my ears was gone. It came back for a little while but then went away within weeks of my surgery. My dizziness has gotten a little better every day.

It's been 14 weeks since my surgery. I had two mild HM migraines the first week and I have not had any since. My daily headaches are mostly gone, just an occasional one now and then. My life has improved tremendously, and now I can look forward to doing some of the things I used to do.

As the weeks have gone by, I find myself with more energy.



JEANNE AND HER GRANDBABIES

I am able to take care of my beautiful grandbabies and I started going back to church with joy. My memory is improving more and more every day. I am even able to drive at night without any dizziness. Just knowing that there was something wrong and that it could be fixed was the most amazing feeling I have had in a long, long time.

I know surgery is not for everyone, but for me it was a miracle. I am so grateful to Dr. Carter and Dr. Wackym, not only for their expertise and compassion, but for advocating for vestibular patients like me.

# **Community of Support Membership Program** ATTENTION BASIC/PATIENT MEMBERS!

Starting in April you will receive an invitation to join VEDA's "Community of Support" membership program.



#### OUR GOAL

VEDA aims to "Defeat Dizziness." As a member of our Community of Support, you help us achieve this goal.

VEDA relies solely on donations and membership dues. Your membership gift helps us educate and support vestibular patients while we advocate for better medical care.

Your membership benefits will stay the same. The only change will be that you will receive an invitation to join VEDA's Community of Support in the spring or fall, rather than 30-days before your scheduled expiration date.

#### **QUESTIONS?**

Call (800) 837-8428 or email membership coordinator, Christina Conner, at info@vestibular.org.

## **The Migraine Connection**

By Dr. P. Ashley Wackym, President, Ear and Skull Base Center, Vice President of Research, Legacy Health, Portland, Oregon, Chair, VEDA Medical Advisory Board



Vestibular migraine (VM) is becoming recognized as a distinct clinical entity that accounts for a high proportion of patients with vestibular symptoms (Furman et al.<sup>1</sup>). It is so common that VM should

be considered in any patient presenting with dizziness, vertigo, or disequilibrium.

An overlap between vestibular symptoms, such as vertigo and head-movement intolerance, and migraine symptoms, such as headache, photophobia, and phonophobia, is a requisite diagnostic criterion. Physical examination and laboratory testing are usually normal in VM but can be used to rule out other vestibular disorders with overlapping symptoms such as perilymph fistula (PLF) or superior canal dehiscence (SCD).

The physiology of VM is incompletely understood but could include neuroanatomical pathways to and from central vestibular structures and neurochemical modulation. Current treatment options for patients with VM largely mirror those for migraine headache, including: 1) antiseizure medications; 2) calcium channel blockers; 3) tricyclic antidepressants; or 4) beta-blockers. Approximately one-third of vestibular migraine patients have endolymphatic hydrops, which is typically bilateral.

VM patients do not have sound-induced dizziness and nausea or autophony. However, when these patients have endolymphatic hydrops, they can have sound sensitivity. For this reason, when a high-resolution temporal bone CT with color 3D volume rendering shows no evidence of SCD, I treat all patients suspected as having PLF as a VM patient since medical management, if successful, avoids unnecessary surgery.

Typically PLF patients will have some improvement with medical management, then regression as the

dose is increased, resulting in switching to another class of medication. Ultimately PLF patients never come under control and reassessment leads to the decision for surgical intervention.

VM is an example of the integral overlap between vestibular pathways and migraine circuit triggers and central mechanisms for premonitory symptom generation. Information transmitted by peripheral vestibular sensory organs and the vestibular nerve to the medulla and pons is an external trigger within the migraine circuit construct.<sup>1,2</sup>

I have observed that migraine headache is nearly always present in patients with disequilibrium caused by PLF or SCD, but infrequently with true rotational vertigo (e.g., benign positional vertigo or vestibular neuronitis).4-7 This is an important concept as PLF and SCD can induce migraine and the three variants of migraine - ocular migraine, hemiplegic migraine and vestibular migraine. This is why patients with PLF and SCD, who normally only have disequilibrium can have episodes of vestibular migraine and infrequent true rotational vertigo attacks. Surgical management of PLF and/ or SCD typically resolves the migraine. However, sometimes there is only a marked decrease in the frequency and intensity of the migraines, as migraine has a high incidence overall.<sup>1,4-7</sup> References

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2. TW, Edvinsson L, Goadsby PJ. CGRP and its receptors provide new insights into migraine pathophysiology. Nat Rev Neurol 2010;6:573–82.

3. Wackym PA. Ultrastructural organization of calcitonin gene-related peptide immunoreactive efferent axons and terminals in the rat vestibular periphery. Am J Otol 1993;14:41-50.

 Vestibular migraine. Patient video describing symptoms before and after treatment with Topamax. https://www.youtube.com/watch?v=Zy7YjCDnLYM (Accessed March 16, 2015). Copyright © Ear and Skull Base Center, used with permission.

5. Right perilymph fistula not superior canal dehiscence. Patient video describing symptoms before and after surgical repair. https://www.youtube.com/ watch?v=bDph0B0uLbg (Accessed March 16, 2015). Copyright © Ear and Skull Base

Center, used with permission. 6. Right perilymph fistula: dizziness, migraine headaches and cognitive dysfunction.

Patient video describing symptoms before and after surgical repair. https://www. youtube.com/watch?v=ETjsJocMBYk (Accessed March 16, 2015). Copyright © Ear and Skull Base Center, used with permission.

<sup>7.</sup> Perilymph fistula. Patient video describing symptoms before and after repair of traumatic perilymph fistulae. https://www.youtube.com/watch?v=jSAM6h-7Mwc (Accessed March 16, 2015). Copyright © Ear and Skull Base Center, used with permission.

## New Technologies to Help More Vestibular Patients

By Anders Lund, Project Manager, Otometrics

For many people who suffer from a vestibular disorder, the journey to a diagnosis and treatment can be long and frustrating. Fortunately, there are new advancements in balance assessment technologies that are helping practitioners reduce the time it takes to diagnose vestibular disorders, especially the most prevalent affliction, Benign Paroxysmal Positional Vertigo (BPPV).

Except for a few ear infections, 50-year-old Kirsten Nielsen – an active woman with children and grandchildren – had never been seriously ill. Yet, one morning two years ago, her life took a dramatic turn.

"I woke up and the whole room was spinning," says Kirsten. "At first I thought I was having a stroke. I tried to stand up and walk around, but I was so dizzy – it felt like I was on a sailboat in high seas – I couldn't keep my balance."

The dizziness returned later that day and on and off for two more weeks until Kirsten finally called her doctor. Still, even after several visits, Kirsten's physician was unable to find out what was causing her dizzy spells.

#### WAIT, WORRY AND HOPE

A long diagnosis time is typical for people suffering from balance disorders. According to the Vestibular Disorders Association, it can take between three to five years for a person with vestibular symptoms to receive a diagnosis. Even worse, a person with a vestibular disorder will see on average between four to five doctors or specialists before getting a diagnosis. That means long waiting time and lots of worry.

"It took two months from the time I woke up with dizziness until I found out exactly what was wrong with me," says Kirsten. "And during that time, I was worried. My family was worried, too. I couldn't do the things I was used to doing. I never knew when the dizziness would come, and when it did, all I could do was hold on to a table or something stable and wait until it was over." There are several reasons for the long diagnosis time. First, dizziness is a common symptom for many diseases and doctors want to rule out lifethreatening conditions first. Another reason is that not all physicians have the same level of training in vestibular assessment or the same exposure to patients with vestibular disorders. A general practitioner may only see a few patients per year reporting vestibular symptoms whereas a neuroophthalmologist in a balance clinic, for example, may see all patients with vestibular symptoms. Fortunately for Kirsten, after several visits with her physician, she was referred to a specialist who could help her within a relatively short time.

"I was very lucky," says Kirsten. "The specialist ruled out several diseases one by one using an MRI scan and conducting tests with video goggles. He could see that I had a very common balance disorder, BPPV."

# THE MOST COMMON VESTIBULAR DISORDER

Benign Paroxysmal Positional Vertigo or BPPV is the most prevalent vestibular disorder<sup>1</sup>. Approximately 40% of people with a vestibular disorder have BPPV. Moreover, if it occurs in the



ICS IMPULSE FROM OTOMETRICS IS A NEW BALANCE ASSESSMENT SOLUTION THAT ENABLES PHYSICIANS TO HELP VESTIBULAR PATIENTS

<sup>1</sup> Baloh RW, Honrubia V, Jacobson K (1987) Benign positional vertigo: clinical and oculographic features in 240 cases. Neurology 37:371-8.

NEW TECHNOLOGIES...CONTINUED FROM PAGE 5:



ACCURATE DATA COLLECTION IS KEY TO A CORRECT DIAGNOSIS. ICS IMPULSE PROVIDES TOOLS THAT ENSURE THE TESTS ARE PERFORMED ACCURATELY.

posterior canal – one of the three semi-circular canals in the inner ear – it can be treated easily using a repositioning maneuver.

Given that BPPV is so prevalent and because many physicians don't have the training, skills and equipment to properly assess the vestibular system, many patients are often told that they have BPPV, when in fact, they have another vestibular disorder. This results in a long and frustrating journey before the patient finally receives a diagnosis and treatment for their balance problem.

Proper diagnosis requires accurate data collection Luckily, things are changing. New technologies are emerging with functionality that helps physicians and clinicians collect the right data and information to make an accurate diagnosis quickly. One example of this is ICS Impulse from Otometrics, a manufacturer of hearing and balance assessment solutions. ICS Impulse has Head Position Feedback that guides the physician or clinician in positioning the patient in the right way during video head impulse and positional testing. The device also gives the tester immediate feedback during video head impulse testing so they know if they perform the test correctly.

"Accurate data collection is key to getting a proper diagnosis," says Wendy Crumley-Welsh,

Audiologist and Product Manager for Balance Solutions at Otometrics. "ICS Impulse enables physicians to collect the data they need quickly to make the correct diagnosis. And, the goggle solution is more comfortable and convenient for the patient and more accessible for the doctor than the traditional balance assessment equipment."

With health care changes and reduced reimbursement for physicians, many cannot afford the expensive equipment that state-of-the art hospitals can afford. Moreover, with budget cuts, many physicians who want to help patients with balance problems cannot afford yesterday's technology.

"We have been focusing our development on building quality hardware that is produced at an optimal cost so that we can offer equipment to a broader market whose budgets are smaller," says Crumley-Welsh. "We are offering modular solutions so the physician can purchase exactly what they need."

It is also increasingly important to streamline processes and triage patients more efficiently and accurately. With the release of ICS Impulse in 2011, Otometrics made it easier to assess patients at the bedside.

# AWARENESS, EDUCATION AND TRAINING

However, it is not enough to develop new solutions based on the latest technology. It is just as important to bring awareness of the new technology to physicians and clinicians and provide training so they become familiar with how they can use it to help more of their patients.

As part of Otometrics' ongoing commitment to vestibular assessment education and training, they offer training seminars, host informational webinars, sponsor lectures at conferences, and partner with the leading experts in the field of vestibular disorders.

"Our goal is two-fold – first we want to apply the latest technological advancements to develop practical and accessible solutions that can help shorten the patient journey for people suffering from vestibular disorders," says Crumley-Welsh. "And second, we want to increase the awareness of this technology – and how to use it – among as many practitioners and specialists as possible. Only through awareness, knowledge and education can we help make these new methods available to more doctors and, in turn, help more people with vestibular disorders obtain a timely diagnosis and proper treatment."

As for Kirsten Nielsen, she is healthy, active and enjoying life. She was fortunate in that the specialist she visited had the right diagnostic equipment. Her physician was able to use this



KIRSTEN NIELSEN IS FINE TODAY. HER SPECIALIST HAD THE RIGHT DIAGNOSTIC EQUIPMENT FOR A FAST AND PRECISE DIAGNOSIS.

equipment to help rule out other diseases, determine exactly what was wrong with her, and prescribe treatment relatively quickly.

"It was a relief when I found out what was wrong with me," says Kirsten. "And I was lucky that it was something that could be fixed."

VEDA's Provider Directory helps patients like Kirsten find a vestibular health care professional in their area.

For more information on the ICS Impulse from GN Otometrics, visit: www.icsimpulse.com



## Vestibular Neuritis: Navigating the Real World - A Case Study

*By Jennifer Liss, DPT (Editor: Sherron Laurrell, vestibular patient)* 

This case study outlines challenges facing clinicians when treating vestibular neuritis in patients who continue to work full-time in highly stimulating vestibular environments.

Jen Beasley, a 37-year old first grade teacher, was referred to me by her ENT in December, 2014. She had awakened a month earlier with severe dizziness and nausea. After attempting to push through, holding on to the walls at school as she went through her day, she was diagnosed with vertigo by her family doctor and sent home with anti-nausea medication. Two weeks later, Jen saw an Urgent Care doctor who saw fluid in her ears and attributed it to allergies. Jen eventually ended up in bed as the dizziness and nausea exhausted her. Her ENT referred her to me with a diagnosis of BPPV.

During our first meeting, we spent time talking about her symptoms and situation. I suspected Jen was not dealing with "simple" BPPV and was likely suffering with either vestibular neuritis or labyrinthitis.



DR. JENNIFER LISS EVALUATES JEN BEASLEY

The most important component of any patient evaluation is getting a good history.



DR. JENNIFER LISS & VESTIBULAR PATIENT, JEN BEASLEY

Key **subjective** elements a clinician should look for to differentially diagnose vestibular neuritis include:

- Onset 2 to 4 days extreme nausea, vertigo, and imbalance. By the time they see the physical therapist they should be SLOWLY improving. Episodes usually follow a cold/flu or sinus infection.
- Hearing loss distinguishes labyrinthitis from vestibular neuritis. Treatment plans from a PT perspective are the same. An ENT/ audiologist should be consulted about the hearing loss.
- Increased symptoms with movement in visual fields, such as computer use, crowded places, TV.
- Balance impaired stability with gait especially with un-level or darkened environments.
- Motion sensitivity increased symptoms with position changes, quick turns. THIS IS USUALLY THE ONLY SYMPTOM WITH A BPPV PATIENT.
- Dizziness Handicap Inventory (DHI) usually in the moderate disability range.

Key **objective** elements include:

• Most important tests are Head Thrust and Dynamic Visual Acuity (DVA). If these 2

tests are positive and you have normal oculomotor & neurological exams; this is usually a peripheral vestibular insult verses a central insult such as stroke.

- Frenzel goggles to rule out BPPV with Hallpike maneuver, performing the test at slow to medium speed. Hallpike test is negative if there is no sign of a torsional nystagmus.
- Dynamic Gait Index (DGI)

After a comprehensive work up we concluded that Jen's diagnosis was vestibular neuritis.



JEN BEASLEY DOING VESTIBULAR THERAPY WITH JUSTIN DATORRE, THERASPORT PHYSICAL THERAPY AIDE

As we put together the plan for her vestibular rehabilitation, the biggest challenge was limiting stimulation in her work environment. Jen's job responsibilities involve constant head movement, frequent turning and excessive visual & auditory stimulation.

Early on, she had to modify her work duties as much as possible. One of her "extra" responsibilities was supervising children during bus duty. A medical excuse note eliminated this from her daily schedule. Because her work environment was heavily loaded with vestibular stimulation, it was difficult to progressively load her vestibular system during therapy as I would normally recommend. I had to be careful with her home program. Visual retraining is essential to recovery of normal function but it has to be progressed more slowly for active patients like Jen than for patients who are retired or in less stimulating work environments. I taught Jen strategies such as limiting head movement and focusing her eyes when she felt "overloaded."

It is essential to teach patients that vestibular exercises should increase dizziness for 5-10 minutes but if the symptom increase lasts, they are overloading an impaired system.

Jen needed to accept that this would not be a smooth recovery because of her work environment. She hit her first setback at week 4, which is common. Many patients are driven to see steady weekly progress. At about week 4, they increase their home exercise program and try to do more at work because they are feeling better. Consequently, they will have a 2+ day spike in symptoms from doing too much. This is when we have "emotional chat" days for encouragement and counseling to accept that the road to recovery isn't always easy and modifications need to be made along the way.

Jen has learned to modify her activities while continuing her VRT exercises in my office and at home. She has seen overall improvements and is feeling hopeful. Although it may take longer than she would like, I expect Jen to make a full recovery of normal vestibular function.

I want to emphasize that patient education is essential for ALL vestibular patients. They need to know the reasoning behind what they are doing, be warned about pitfalls that may happen along the way, and most importantly, that compliance is key to vestibular success!

Editor's Note: Jennifer Liss is certified in vestibular rehabilitation by Susan Herdman's VRT certification course at Emory University. TheraSport Physical Therapy offices are located in New Jersey, where Jennifer has practiced for 16 years. Jennifer can be reached at JLiss@Therasport.org

# Annual Report 2014 - A YEAR IN REVIEW

## FINANCIAL REPORT



## OUTREACH





## 2014 Achievements

# EDUCATIONAL RESOURCES

- 10 EDUCATIONAL PUBLICATIONS UPDATED
- 5 NEW PUBLICATIONS WRITTEN
- "FEELING DIZZY" INFOGRAPHIC PRODUCED
- "AN INTRODUCTION TO BALANCE DISORDERS"
   PRESENTATION DEVELOPED
- MILITARY RESOURCES WEBPAGE LAUNCHED





## **BALANCE AWARENESS WEEK 2014**

- REVENUE INCREASED BY 54%
- 45 PERSONAL CAMPAIGNS RAISED \$29,192
- SPONSORS CONTRIBUTED \$23,500
- 3 NEW VIDEOS REACHED 3,203 PEOPLE
- 1ST ANNUAL PHOTO CONTEST
- 63 FACEBOOK POSTS REACHED
  253,982 PEOPLE

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### Your Legacy Can Help Defeat Dizziness

When you make a planned gift today, you're making a pledge to promote awareness for vestibular disorders now and into the future.

TO JOIN VEDA'S BALANCE SOCIETY VISIT VESTIBULAR.ORG/LEGACY

### BALANCE AWARENESS WEEK FUNDRAISERS

Thank you to those people who created a personal campaign page to help raise over \$100 in funds and awareness for vestibular disorders!

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# A Message From VEDA's Executive Director

By Cynthia Ryan



I was recently visiting my mother, Eileene, who has Meniere's disease. Mom had her first "drop attack" of vertigo around 1980. She has been losing her hearing for many years, and at this point, even with hearing aids, she can only hear you if you talk clearly, project your voice, and look right at her, and then only in a quiet space. This, along with her severe balance problems, greatly limits her social interaction, which is sad for a naturally gregarious woman.

I work with vestibular patients every day. I hear your stories, and intellectually I understand your struggles. But it is when I interact with my mother, who is so obviously challenged on a daily basis by her vestibular dysfunction, that I get a visceral sense of the true impact vestibular disorders have on the life of a vestibular patient.

These visits renew my commitment to improve the quality of life for vestibular patients everywhere. It is only through education and awareness that we will realize our vision of a global community where vestibular disorders are widely recognized, rapidly diagnosed, and effectively treated. And I am proud to say that, thanks to your support, we are

thanks to your support, we are making great progress.

Our small staff of four can only do so much, but our extended community of board members, medical advisors, ambassadors, volunteers, committee participants, and members at large (that's YOU!) all contribute to spreading the message that vestibular disorders are treatable illnesses, that they have a profound impact on the lives of patients and their families, and that healthcare providers need to be better prepared to diagnose and treat these conditions.



RIGHT TO LEFT: VEDA EXECUTIVE DIRECTOR, CYNTHIA RYAN, WITH MOTHER, EILEENE, AND SISTER, SUZETTE

Balance Awareness Week takes place in September, and VEDA is already preparing to spread the word about vestibular disorders so we can reach people who experience dizziness and disequilibrium but are not yet diagnosed. Please join us! In the coming months we will be sharing with you simple ways you can raise awareness about vestibular disorders. I invite you to make a commitment today to pay it forward. Please help us make "vestibular" a household word, so no one has to suffer with this terrible condition alone.

Thank you!

Cynthia Ryan

## Ménière's Goes Mainstream

Despite its prevalence, Ménière's disease was not represented in pop culture. Until now.

Recently celebrities such as Grammy-nominated singer-songwriter, Ryan Adams, and Tony and Emmy award-winning actress, Kristin Chenoweth, have begun to use their fame as a platform to spread awareness and educate their fan base about Ménière's.

# RYAN ADAMS: A MUSICIAN WITH MÉNIÈRE'S



Adams, who took a two-year hiatus from music after being diagnosed with Meniere's in 2008, is particularly outspoken about his condition and how it affects his life and career. In an interview with the popular music site, Stereogum, Adams described his diagnosis: "I had seen so many... people before anyone could figure out what...was wrong. How many people do you hear talk about Ménière's disease? Not many."

Flashing lights from stage setups and eager fan photography are particularly challenging for Adams. "If somebody flashes lights in front of my eyes...while I'm onstage...I'm going to have a Ménière's attack," Adams said. "My knees are going to get weak and I'm going to get really freaked out until I'm going to want to throw up or pass out." In an effort to prevent his episodes from occurring, Adams is often seen sporting sunglasses during his shows and at events such as the Grammy's. He also politely requests that fans disable flash photography if they are going to take photos during his shows. At a recent show in London, Adams handed out fliers with educational information about Ménière's disease and the importance of stable lighting for people with inner ear disorders.

#### KRISTIN CHENOWETH: A PERFORMER THROWN OFF BALANCE



Kristin Chenoweth, best known for her Broadway role of Glinda the Good in Wicked, as well as TV appearances on Pushing Daisies and Glee, was diagnosed with Ménière's disease in 2007 and has been very public about the disorder's impact on her life. Chenoweth has discussed her diagnosis with outlets such as the Los Angeles Times, sharing that a low-sodium diet helps her cope, and that she is most bothered by the choreographychallenging vertigo and the tinnitus. When asked about the disorder on the Joy Behar Show she replied, "I'm so glad that you brought that up. I want to bring more information and knowledge about this disease."

## **Attention: Meniere's Disease Patients**



# SPC-FLAKES HAVE BEEN CLINICALLY SHOWN TO SUPPORT CELLULAR FLUID BALANCE.

About 10 years ago, Elisabeth woke up and found the room spinning, which caused her to start vomiting. A week later she had another episode of dizziness while on a walk. The dizziness increased and after a period of chronic dizziness she was diagnosed with Ménière's disease. Elisabeth's physician offered



"A LITTLE SPC-FLAKES AT BREAKFAST RELIEVES ME OF MY DIZZINESS!"

several treatments - diuretics, anti-anxiety medication and motion sickness medication, but nothing seemed to help. Since these options did not provide the relief Elisabeth was seeking, she found herself hesitant to leave her home for fear that another spell of dizziness would occur. The symptoms were exacerbated by her decline in social activities and took a toll on her emotional well-being.

In the spring she connected with a professor at the Sahlgrenska University Hospital. She was informed about a study with a specially processed cereal called SPC-Flakes®. She gladly agreed to participate in the study and found relief within several weeks. Within a few more weeks, her symptoms were nearly gone and she found herself returning back to the life she led before her attacks began.

Elisabeth uses 1 gram of SPC-Flakes® per kilogram of body weight daily. Ménière's damaged one of Elisabeth's ears and she battles with tinnitus, however, she is relieved of the challenges of being dizzy.

# THE AF PROTEIN – A CLINICAL INNOVATION OF ENDOGENOUS ORIGIN

20 years of Swedish research has led to the discovery of the Anti-secretory Factor (AF), an endogenous protein with the ability to regulate cellular fluid and ion transport over the cellular membranes in various organs in the body.

The effect of the AF protein on different types of secretion is very pronounced. Diseases where the transport of fluid is disturbed - for instance, in gastrointestinal diseases, diarrhea, and Ménière's disease - have been studied to assess the clinical significant of AF protein. AF has also shown marked antiinflammatory properties that have been proven in studies of Irritable Bowel Disease (IBD), rheumatic diseases, and mastitis (inflammation of the breast). American studies describe that the AF protein might even have an important role in regulating our immune system.



# 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 or send your payment to 5018 NE 15th Ave, Portland, OR 97211 with the enclosed self-addressed envelope.

#### **Donation:**

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#### **Method of Payment:**

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- □ 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: \_\_\_\_\_\_

#### SPC-FLAKES...CONTINUED FROM PAGE 18:

The research has resulted in two medical food products for clinical use: SPC-Flakes® (Endogenous stimulation of AF) and Salovum® (Exogenous supply of AF). Both have significance in secretory and inflammatory diseases. They were classified as the first medical food based on AF protein in Europe.

Published clinical studies: Mb Ménière's, short bowel syndrome, IBD, Mb Crohn og Colitis Ulcerosa, Secretory diarrheas (carcinoids), Prophylactic treatment of mastitis, Rheumatoid arthritis, Endocrine induced Diarrhea, Child diarrhea Lahore.

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FOR MORE INFORMATION, CALL 855-416-6826 OR EMAIL SALES@NOVAM-NUTRITION.COM. MENTION "VEDA" TO RECEIVE A 15% DISCOUNT.

3. Antisecretory Factor–Inducing Therapy Improves Patient-Reported Functional Levels in Ménière's Disease - Samuel C. Leong, MPhil, FRCS(ORL-HNS);Surya Narayan, MS, DLO, FRCS(ORL-HNS); Tristram H. J. Lesser, MS, FRCS Annals of Otology, Rhinology & Laryngology. 122 © 2013 Annals Publishing Company.

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<sup>1.</sup> AntisecretoryFactor: A Clinical Innovation in Ménière's Disease? - Per Hanner', Eva Jennische^ and Stefan Lange^'Taylor&Francis health sciences From the Departments of' Audiology, ^Anatomy and Cell Biology and ^Clinical Bacteriotogy, Sahlgrenska University Hospital, Gothenborg University, Gothenborg, Sweden.

<sup>2.</sup> Antisecretory factor-inducing therapy improves the clinical outcome in patients with Ménière's disease Per Hanner a; Helge Rask-Andersen b; Stefan Lange c; Eva Jennische c - a Department of Audiology, Sahlgrenska University Hospital, Gothenburg b Department of Otolaryngology, Uppsala University Hospital, Uppsala, Sweden c Institute of Biomedicine, Departments of Medical Chemistry and Cell Biology, Gothenburg University, Acta Oto-Laryngologica 2009.

MENIERE'S GOES MAINSTREAM...CONTINUED FROM PAGE 17:

# ADDITIONAL VESTIBULAR DISORDERS IN THE SPOTLIGHT



Another extremely common vestibular disorder, tinnitus (ringing of the ears), which affects roughly 10 percent of the adult population in the U.S., has also made its way onto the TV screen recently. In Netflix's House of Cards, a lead character seems to have developed debilitating tinnitus that interferes with their ability to work, and in FX's cartoon comedy Archer, a popular episode centers on the lead character having tinnitus (Season 2, Episode 7 "Movie Star").

Discussing vestibular disorders in the media and pop culture is extremely important for raising awareness of these diseases. We look forward to seeing more mentions of vestibular disorders in the media in the year ahead!



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

CHANGE SERVICE REQUESTED



### COMING THIS JUNE: BALANCE & AGING WEBINAR



Dr. Kimberley Bell will discuss the assessment and treatment of dizziness, vertigo and disequilibrium in older adults.

Registration instructions will be sent via email.

Space is limited. However, a recording of the webinar will be available for those unable to attend.