On the Level

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Summer & Fall 2011
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Quarterly Newsletter of the Vestibular Disorders Association

VEDA Produces Benchmark Study to Help Reduce Suffering

By
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Portland, Oregon

The recent "Vestibular Disorders Association 2011 Advocacy Survey" produced valuable information about the degree to which vestibular disorders impact lives, how long it takes to diagnose a vestibular disorder, factors that extend diagnosis times, and the perceived consequences of long diagnosis times. This information will help us build an advocacy plan with benchmarks and can help medical and insurance industries make choices. The results are also beneficial right now because they validate the true challenges of having a vestibular disorder.

Between mid-June and mid-August, more than 1,000 people filled out the printed or online survey produced by the Vestibular Disorders Association (VEDA). We have only just begun to analyze the results but thought you'd like to see the following preview of what the survey substantiates.

Advocacy priorities

Three clear priorities emerged as areas in which people would like VEDA to dedicate increased efforts to advocate for them:

1. Help shorten the time it takes to diagnose a vestibular disorder. An essential strategy identified for accomplishing this is to educate primary-care and emergency-room doctors so that they recognize vestibular system involvement and promptly refer to specialists when appropriate.
2. Support solid, evidence-based research about vestibular disorders.
3. Help improve understanding about emotional and cognitive impacts of vestibular disorders.

Survey participants included VEDA members and nonmembers who provided input from these perspectives:

- Individuals who'd consulted a doctor for symptoms of a vestibular disorder
- Family members or friends of someone with vestibular disorder symptoms
- Medical and health professionals who diagnose/treat vestibular disorders

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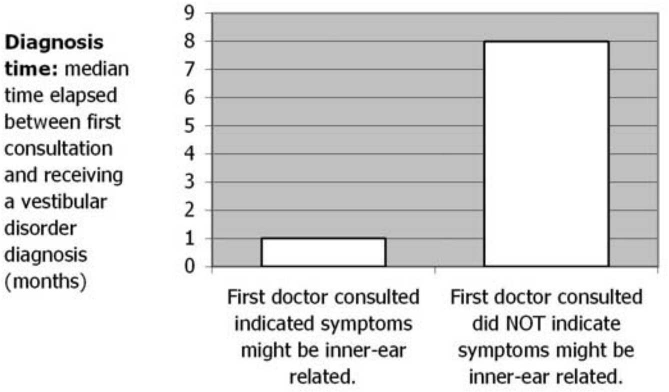
People with symptoms

(1019 survey participants)

Diagnosis specificity

For individuals with a confirmed vestibular disorder, 29% were given a general diagnosis (e.g., vestibular weakness or vestibulopathy) and 71% were given a specific diagnosis (e.g., labyrinthitis, vestibular neuritis, benign paroxysmal positional vertigo, or Ménière's disease). This information is important because treatment for vestibular disorders varies according to the specific diagnosis; it may consist of head maneuvers, diet changes, physical therapy (vestibular rehabilitation therapy), prescribed drugs or equipment, or in some cases surgery. An effective treatment for one type of vestibular disorder is not necessarily effective for a different type. An unspecified diagnosis can lead to poor treatment outcomes.

Figure 1. Diagnosis Time and Early Recognition

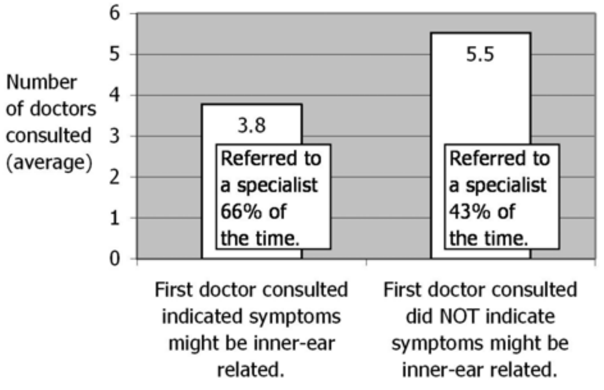


Diagnosis time

Forty-nine percent of persons with a vestibular disorder thought that their ability to eventually get better was affected by the length of time it took to get a diagnosis. This is consistent with the opinions expressed by medical and health professionals (see page 7).

The median time between when a person first consults a doctor for vestibular symptoms and receives a diagnosis is 2.6 months. Figure 1 shows that if the first doctor consulted recognizes that symptoms are possibly inner-ear related ("early recognition"), diagnosis time is one month. For the 35% of those who are not initially told that their symptoms might be related to the inner ear, the median diagnosis time is eight months. (See the Appendix on page 8 for a more detailed version of the distribution of diagnosis times with respect to physicians' ability to recognize vestibular disorder symptoms.)

Figure 2. Number of Doctors Consulted Leading to a Confirmed Diagnosis of Vestibular Disorder



Number of doctors consulted

A person sees an average of 4.4 doctors for vestibular disorder symptoms before receiving a confirmed diagnosis. This number is 3.8 with early recognition and 5.5 without early recognition (Figure 2) and is also associated with whether a person is promptly referred to a specialist.

Referral to specialists
With early recognition, a doctor is more likely to refer a person to a specialist, which can also shorten diagnosis time (Figure 3). The type of specialist to which a person is referred appears to differ according to recognition of the vestibular symptoms (Figure 4).

Figure 3. Diagnosis Time and Referral to a Specialist

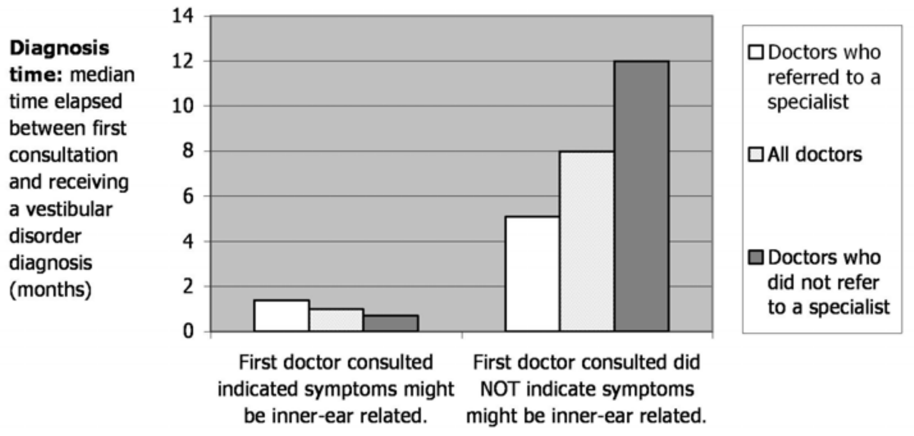
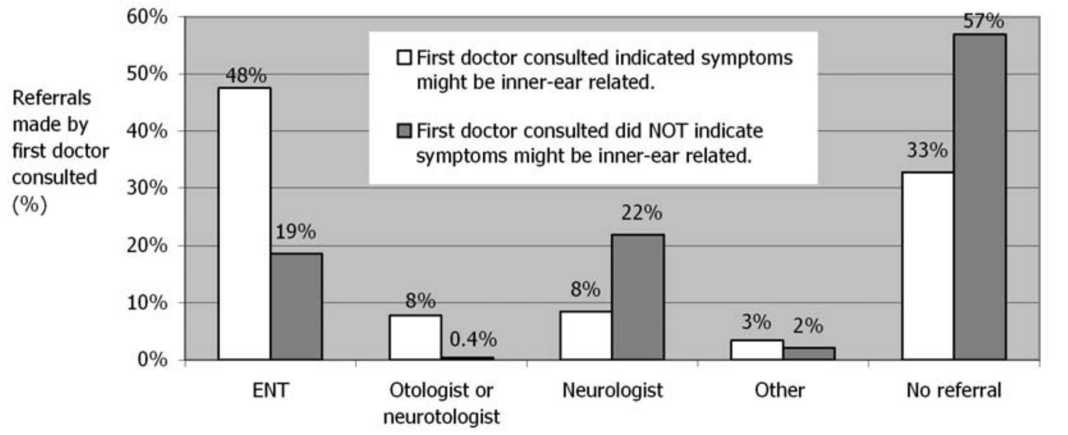


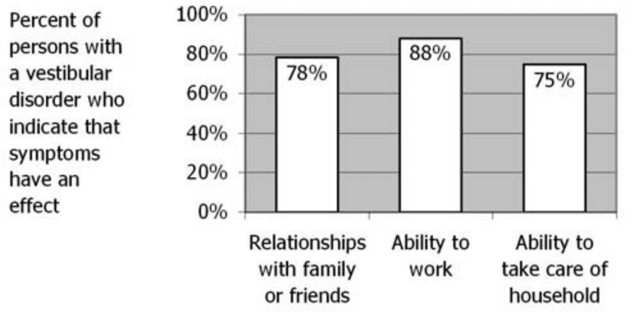
Figure 4. Specialist Referrals by First Doctor Consulted



Effect of vestibular symptoms
Vestibular disorder symptoms affect a person's relationships and ability to work and take care of the household (Figure 5).

Frustrating assumptions
Comments submitted by participants provide striking validation about the experiences of having a vestibular disorder, including the powerful secondary effects on general social wellness. Uncertainties about spatial awareness, coupled with a lack of understanding by others, can create inner turmoil fed by assumptions

Figure 5. Vestibular Symptoms Affect Relationships and Basic Functioning



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VEDA Produces Benchmark Study to Help Reduce Suffering (continued from page 3)

that undermine a person's self-confidence, self-esteem, and self-worth. The table below summarizes responses we received when we asked the question "When you are having difficulty managing your vestibular disorder symptoms, what is the most frustrating thing that people assume about you that is not true?" Even though almost 1,000 independent comments poured in for this question, they were remarkably similar. Frequently reported assumptions included faking, laziness, unrealistic expectations, psychological motivations, intoxication, and willful anti-social behavior.

Most Frustrating False Assumptions by Others
Perceived by Persons Struggling with Symptoms

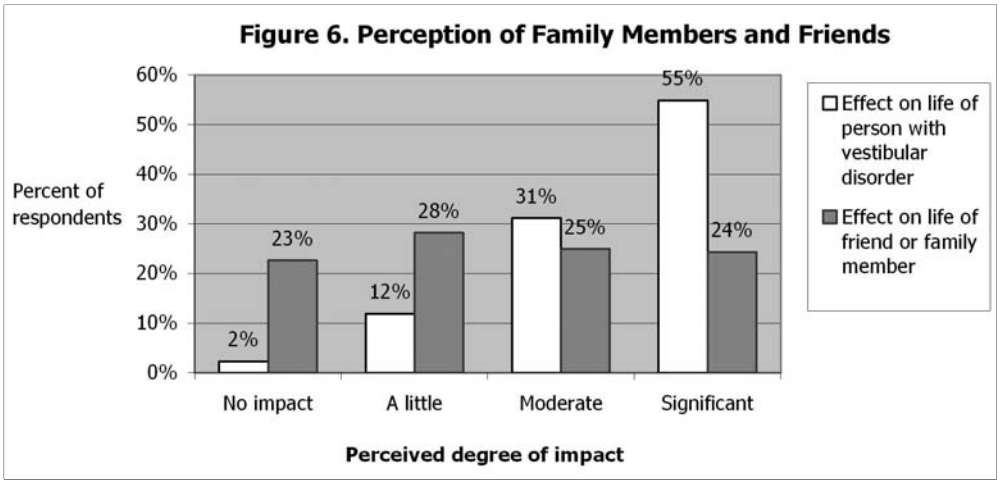
Percent of occurrence	Perceived assumption	Often paired with	Concepts and examples
32%	Faking	Laziness	You're pretending, exaggerating, over-dramatizing. This problem is trivial compared with your complaining.
22%	Laziness	Faking and/or unrealistic expectations	You're not trying hard enough. You don't work fast enough. You could do so much more. You just don't want to work. You could control, cure, or forge through this if you wanted to. You're malingering. You're using this as an excuse, as a "disease of convenience."
22%	Unrealistic expectations	Laziness	You look OK so you must feel OK. You did stuff yesterday so you can do it again today. Being dizzy is no big deal—we've all been dizzy. Just stop complaining and move on. You aren't complaining so it can't be that bad. Since you see doctors you should be getting better. This is fleeting, it'll be over soon.
17%	Psychological	Faking	It's all in your head. You're crazy, stressed, anxious—just relax. You're a hypochondriac; you dwell on it too much. Your attention-seeking behavior and self-pity are out of control. You don't want to get better.
12%	Intoxicated		You are drunk, tipsy, on drugs.
7%	Anti-social	Faking	You're grouchy, angry, self-absorbed, aloof, boring, shy, rude, a party-pooper, not a team player, unreliable, unpredictable, inconsiderate. You are being a Diva.
5%	General declining health	Helplessness	You're just old, weak, clumsy, have dementia. We just need to speak louder to you.
3%	Stupidity		You are a dimwit, foolish, confused, indecisive, forgetful, ditsy, inattentive, not thinking straight.
2%	Helplessness		We should coddle you. You can't do anything for yourself; you're fragile, brave. We need to help you even if you don't want help. Since you crash after we do something, you should not do anything at all.
2%	Other		It is your fault, you are causing it, you can avoid it. It's a stroke, multiple sclerosis, menopause. It's contagious. Those bruises can't be from falling–who beat you up?

Family members and friends

(188 survey participants)

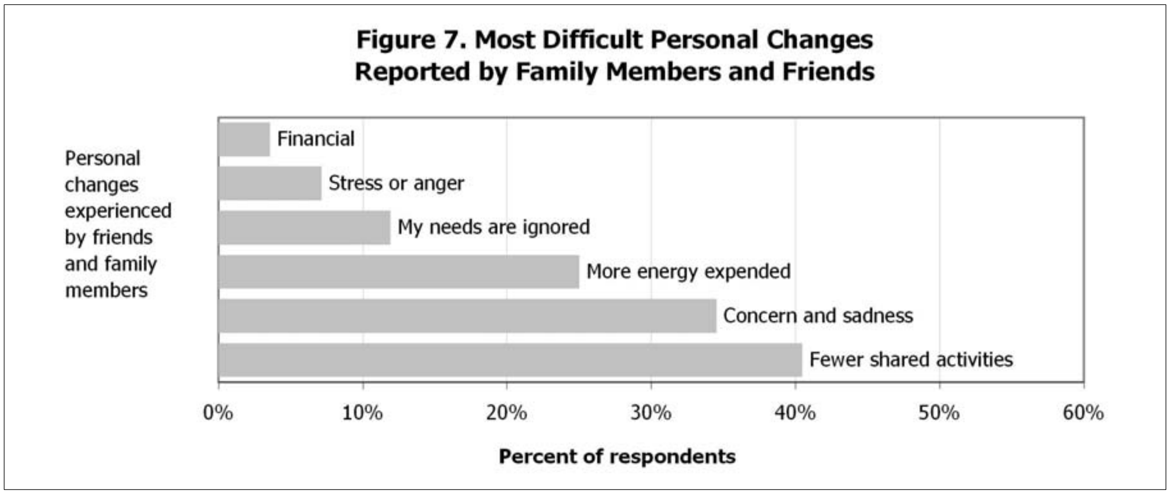
Perceptions

Most family members and friends perceive that the vestibular disorder has significantly affected life for the person with symptoms and has affected the family members and friends to varying degrees (Figure 6).



Difficult changes

A decrease in shared activities is the most difficult change reported by family members and friends, followed by experiencing deep concern or sadness for the symptomatic person's loss of independence and joy (Figure 7). Friends and family members report the need to summon more energy to communicate, get things done, and manage false expectations. They admit to elevated anger and stress, and difficulty adjusting to increased medical expenses and decreased income. In addition, some indicate that their own needs are ignored by the person with the vestibular disorder.



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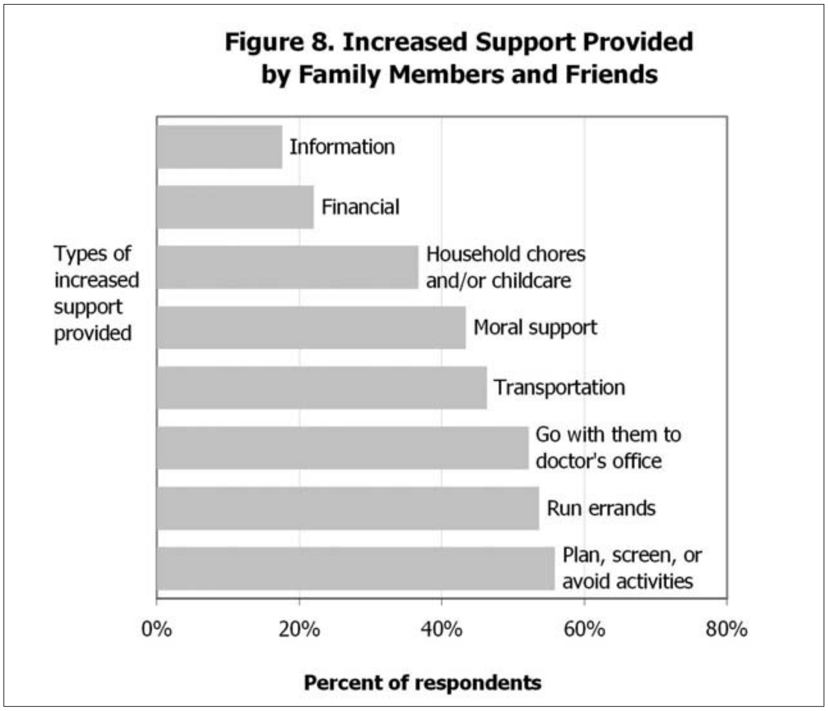
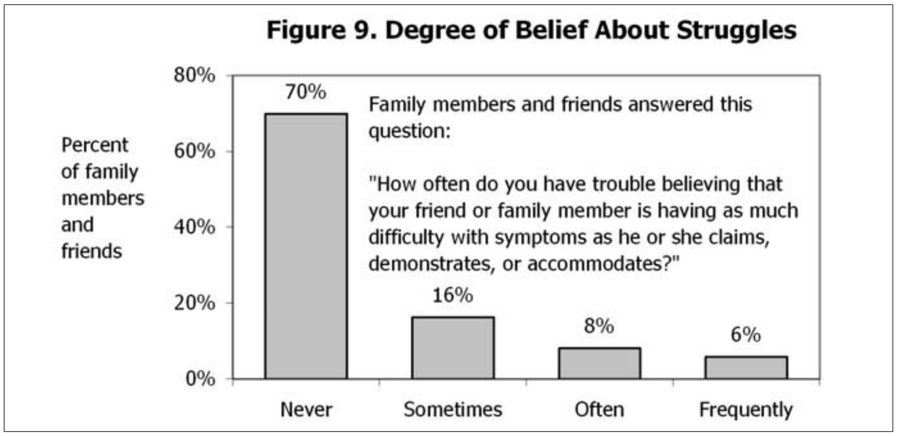
Increased forms of support provided

The most common type of support offered by friends and family members centers on planning, screening, or avoiding certain activities. Sometimes this includes gracefully accepting or pretending that it is "no big deal" to cancel a treasured activity. Other frequent forms of support include running errands, attending doctor's appointments, providing transportation, and giving moral support (Figure 8).



Assumptions about faking and laziness

Most family members and friends never have trouble believing that the person with symptoms is having as much difficulty as he or she claims, demonstrates, or accommodates (Figure 9). Understandably, family members or friends who themselves have a vestibular disorder are 26% more likely to believe that the other person is having as much difficulty as claimed, and they are also twice as likely to feel that their own life is significantly affected by the illness of their friend or family member.



Medical and health professionals who diagnose and/or treat vestibular disorders

(65 survey participants)

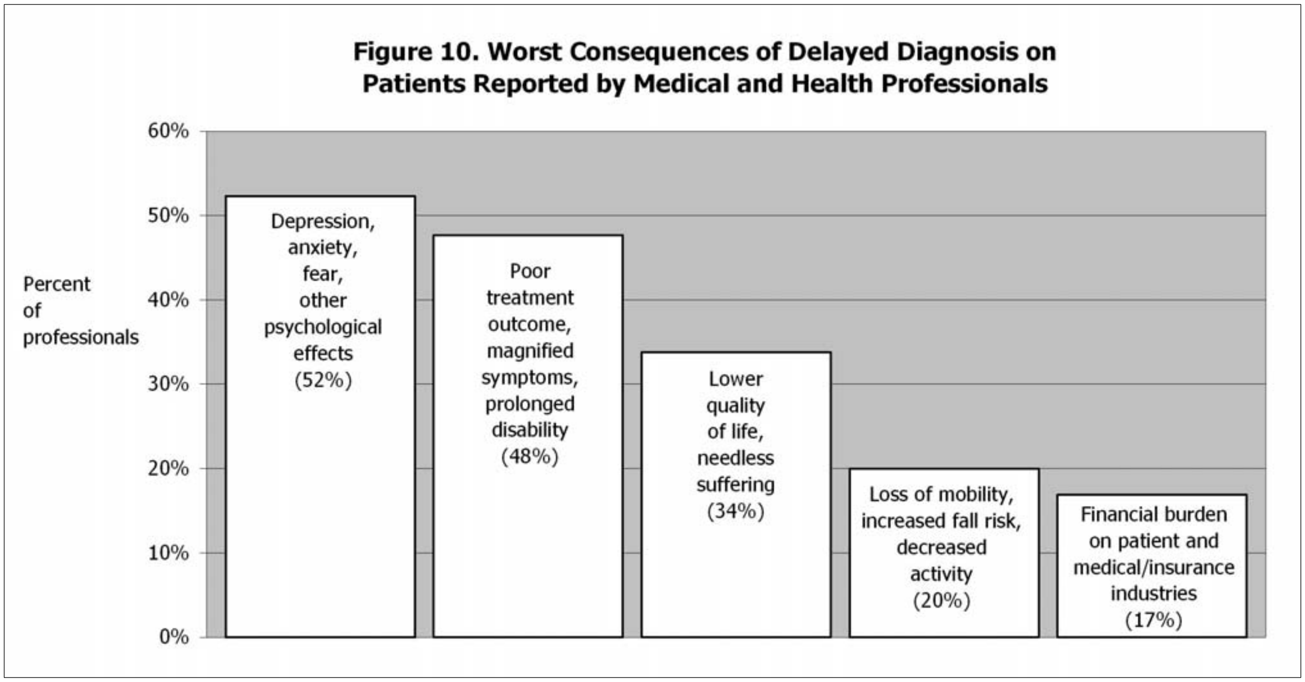
Strategies for shortening diagnosis time

Using information provided in advance by VEDA's Board of Medical and Scientific Advisors, we prepared a list of strategies for decreasing diagnosis time and asked medical and health professionals to select what they consider to be the five most effective strategies. Their ranking of strategies follows:

1. Improve education about dizziness/vestibular disorders for primary-care providers (92%).
2. Promote development of a standardized plan/systematic protocols for diagnosing dizziness (60%).
3. Develop formal certification and re-certification requirements for competency in diagnosing and treating vestibular disorders (54%).
4. Emphasize the importance of trained diagnosticians above diagnostic equipment (51%).
5. Improve access to high-quality continuing education coursework (49%).
6. Increase exposure to the subject in medical school (48%).
7. Increase research (40%).
8. Promote creation of physician specialty groups dedicated to vestibular disorders (39%).
9. Improve diagnostic tools (35%).
10. Improve consistency and appropriateness of coding guidelines for vestibular-function diagnostic testing (32%).

Worst consequences of a delayed diagnosis on patients

Professionals believe that the worst consequences of a delayed diagnosis on their patients are psychological impacts such as depression, anxiety, and fear (Figure 10). Poor treatment outcome



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and prolonged disability are also significant, are congruent with what patients observe (see pages 2–4), and were often mentioned in combination with psychological consequences. In fact, many comments submitted included a combination of the consequences appearing in Figure 10.

About the survey and benchmarks

By collecting, analyzing, and reporting about this information, we strengthen VEDA's ability to widely broadcast the true impacts of vestibular disorders and to effect changes with defined benchmarks. The Vestibular Disorders Association 2011 Advocacy Survey produced a wealth of information, some of which has been presented here using simple descriptive statistics. More elaborate analysis may be useful to further illustrate these key points:

1. Vestibular disorders significantly affect a person's functioning and well-being.
2. We need to learn more about—and address—the psychological and cognitive effects.
3. It takes too long to diagnose a vestibular disorder.
4. A long diagnosis time leads to secondary problems that prolong disability and that financially burden patients, the medical community, and the insurance industry.
5. We can reduce diagnosis time and the number of doctors consulted if primary-care and emergency-room doctors recognize and acknowledge inner-ear involvement and promptly refer to a specialist when appropriate.
6. We can reduce suffering.

Appendix

The following expanded version of Figure 1 (see page 2) details the distribution of diagnosis times relative to whether the first doctor consulted recognized and acknowledged possible inner-ear involvement.

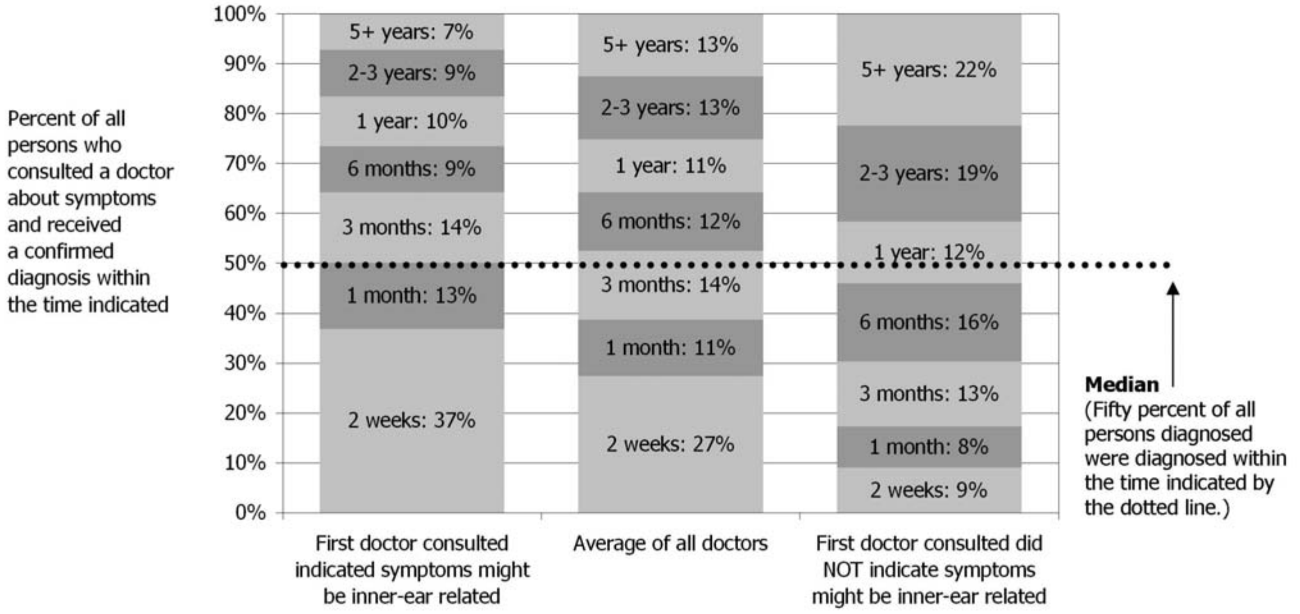


Figure 11. Diagnosis Time and Early Recognition (detail)

News About VEDA

Changes in VEDA's Board of Directors during 2011

VEDA's Board of Directors is dedicated to building VEDA's advocacy efforts. This year our Board bade good-bye to three long-time members and welcomed three new ones. Departing members are Al Bowman, DPT (Hayward, WI), Gaye Cronin, OTD, OTR (Atlanta, GA), and Steve Johnson (Lakewood, CO). For six years they devoted their time and skills to help VEDA grow. We are extremely grateful for their service, and we hope they'll stay in touch. New Board members added in 2011 are Alan Butchman (Seattle, WA), Nancy Devine (Bend, OR), and most recently otologist Fred Arrigg, Jr., MD (Lawrence, MA). They join midterm members Deanne Bonnar, PhD (Acton, MA), Claire Haddad, CFA (Cohasset, MA), and Sue Hickey (Portland, OR).

VEDA seeks new executive director

VEDA's Board of Directors has been doing some long-range planning and has made a strategic decision to hire a new executive director to build partnerships and focus on advocacy. This will help VEDA find better ways to serve its community and will give current Executive Director Lisa Haven, PhD, the opportunity to focus more in other areas, such as research. The job announcement will be posted soon online, and the Board wants your help in suggesting names and ideas for getting the word out to great people who might be a good fit for this opportunity. Please visit www.vestibular.org/about-veda.php after September 12 for more information.

Combined newsletter issue

In order to provide members with such an extensive report about the survey results and other news about VEDA's recent accomplishments in improving advocacy, expanding public awareness, and raising funds to support our efforts, we've produced an unprecedented expanded issue of *On the Level.* To make this feasible, we've combined the last two issues of 2011 into this one very special Summer–Fall issue.

Bequest received from VEDA's first chairperson

One year ago, we announced to members that we'd received notice about a bequest made to us by one of VEDA's champions, Jeanette Ann Welch. We recently received more than $30,000 from Jeanette's estate, and we wanted to share the news about this extraordinary gift with members. As we've reported before, Jeanette was VEDA's first chairperson, a volunteer, who during the 1980s made it a priority to provide members with three assurances:

> "You must educate yourself."
> "You aren't alone."
> "You aren't crazy."

Jeanette was committed to helping VEDA help others. After finishing each week teaching high school mathematics in Seaside, OR, she would drive over the Coast Range to VEDA's office in Portland and put herself up in a local hotel so she could make the most of her working weekend. "People asked us for help," she declared, "and we gave it!" Long after retiring, Jeanette continued to support VEDA as a dedicated member and donor for almost 30 years. Although she is no longer with us, her remarkable commitment to VEDA's work will carry on through her thoughtful bequest.

Star Athlete Dedicates Exhibition Event to VEDA During Balance Awareness Week

VEDA is the charity beneficiary for Jimmer Fredette's two-game exhibition showcase, Jimmer's All-Stars Presented by Zions Bank. Fredette's family has been affected by a vestibular illness and understands the importance of raising awareness for these disorders. Part of the proceeds from the games will go to fund VEDA's 2012 awareness campaign.

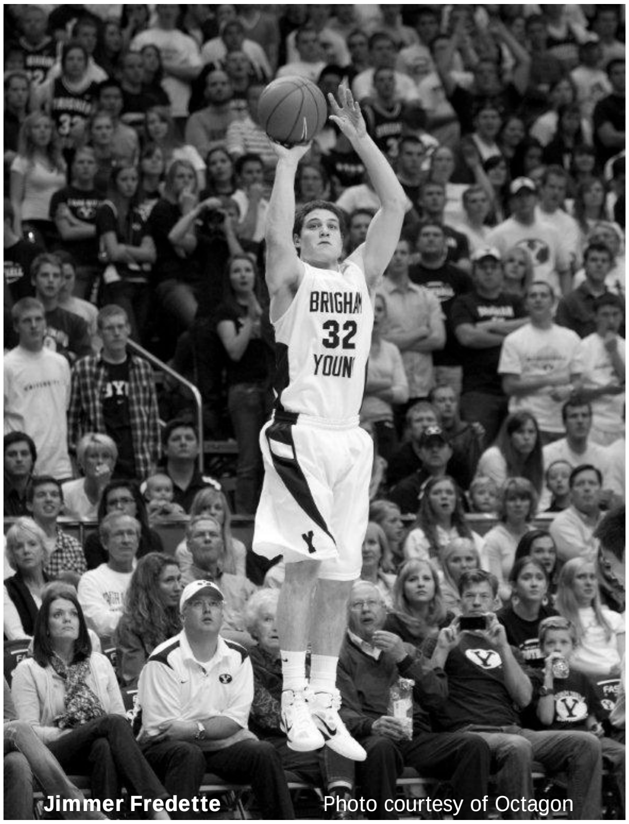
Vestibular disorders are "really near to my heart and to my family's heart because we have a family member that's gone through it," Fredette reports. "So it would be a great cause, and we hope to get awareness out there and have people know what it is all about."

The first benefit game will be held Sept. 21 at the Maverik Center in Salt Lake City. Tip-off is at 7 p.m., and tickets are available at www.maverikcenter.com or via (800) 745-3000. The second game is at the Marriott Center in Provo on Sept. 22, at 7 p.m. Tickets are available at www.byutickets.com or via (801) 422-BYU1. Both games will be broadcast by KSL News radio, 102.7 FM/1160 AM.

Fredette is the 10th overall pick in the 2011 NBA Draft by the Sacramento Kings. He finished his career at Brigham Young University (BYU) as the most decorated player in school history, including winning the AP Player of the Year Award. A first-team All-American, Fredette received nationwide acclaim last season as he led the country in scoring at 28.9 points per game and guided BYU to the NCAA Sweet 16.

VEDA was selected as the beneficiary of Fredette's philanthropy because our work shined above all others as being most professional and clearly dedicated to serving people with vestibular disorders. Said VEDA's Executive Director, Lisa Haven, "I'm extremely pleased that our work has drawn such attention. We've given a strong voice to members' concerns to draw attention to vestibular disorders, and we're very grateful for the support of our work by Jimmer and the Fredette family, including the confidence they have in our ability to help those who suffer from vestibular disorders."

Questions about this event may be directed to alyssa.romano@octagon.com.



Jimmer Fredette Photo courtesy of Octagon

Letter from the Executive Director

I’ve enjoyed standing up for you!

Dear Members: VEDA will soon have a new executive director, and I want to take this opportunity to tell you what a privilege it has been to stand up for you during the past nine years.

Together with VEDA’s small and dedicated staff, I’ve fielded your descriptions of struggles with concentration and other disconcerting symptoms that seem so difficult to define. Fruitless consultations with physicians trouble you. Burgeoning self-doubt and devastating assaults on your character produce unnecessary complications.

Such hardship is the most important reason that I find VEDA’s work to be so important.

During my tenure as executive director, and as VEDA’s only full-time staff member for much of that time, I’ve aimed to create useful educational documents about vestibular disorders that bring forward the often unspoken and indirect effects of having a chronic vestibular disorder. The subtlety and “invisibility” of those effects belie the magnitude of their impact on a person. It is a distortion that I’ve worked to unbend by publishing straightforward information.

The distortion is also what has motivated the scientist in me to produce member surveys about such things as disability determination, support services, and the recent amazing information featured in this newsletter about diagnosis time, referral to specialists, character assumptions, recommended approaches to improving diagnosis time, effects on family and friends, and more. As members, you’ve avidly wanted to help us move forward—so it seemed natural to compile your collected input as the data we need to substantiate these issues.

As a result of this work, I’ve not just collected, analyzed, publicized, and testified about your concerns, but together we’ve also actually advanced public understanding and produced evidence not to be ignored!

Our 2011 Advocacy Survey concluded with this note: “Thank you for providing VEDA with your valuable insights.” On surveys mailed back to us, some members wrote in “Thank you for asking.” This was such a rewarding message to me. You deserve to be heard—and I’ve been so very pleased to listen to you and find ways to broadcast your concerns.

Together we’ve built a solid and rich platform for the new executive director to use in advocating for you, side by side with VEDA’s staff. I’m excited about VEDA’s next steps and will watch for the furthering of our steadfast commitment to integrity and representation.

It’s been a pleasure working for you!

Lisa Haven, PhD
VEDA Executive Director
LH@vestibular.org

Thank You

We thank the following individuals and organizations for their generous donations and pledges to VEDA received January 1 through August 1, 2011.

Balance Society

Planned Giving

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David Beal MD *and* Alaska Dizziness and Balance Center
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Margaret Schultz
Cheri Smith *in honor of my vertigo*
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Sociometrics Corporation *with* Tamara Kuhn *in recognition of VEDA's outstanding contribution to our community*
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You Want Me to Do What?

Letter from a member

Dear VEDA: I just started vestibular rehab therapy (VRT) and I'm not happy. Don't get me wrong—I'm glad a treatment is available. I also know that in order for me to manage my vestibular disorder, I need to unclench my hands from the chair arms, lift my head off the back of the chair, and open my eyes. Oh, if there were only another way!

VRT is supposed to stimulate the vestibular system in a way that coordinates signals coming from my vision, vestibular, and proprioceptive systems. I've done my research—VRT is effective for a lot of folks, and I gather that it involves provoking the dizziness and desensitizing me to it. Ah, there's the rub: right now it seems like the "T" in VRT stands for "torture." Needless to say, I'm having difficulty complying with the prescribed treatment regime. I'm not proud.

I'm going to go out on a limb (only figuratively, due to my balance problem) and suppose that each of you is saying "tut-tut" at my resistance while shaking your head and rolling your eyes (only figuratively if you're dizzy, of course). But really, many of you reading this can also appreciate why it's hard to sacrifice those rare "good" days for some long-term progress out beyond the horizon.

Clinging to some semblance of my old self is a respite vital to my sanity. It's a veritable life preserver in the swirling vortex of an apparently altered gravitational constant. So on these better days, it doesn't seem unreasonable to resist embarking on VRT exercises that sometimes make me feel worse, even momentarily. Alas, this is fodder for internal

(continued on page 14)

You Want Me to Do What? (continued from page 13)

guilt and external pressure from friends who think I'm not trying hard enough. To that I want to shout "Hey! When you see me clinging to a life preserver, do not confuse my desire to avoid drowning with a preference to stay in the water!"

It's natural to crave stillness over movement when I'm dizzy. Look at how animals cope with injury. I once saw a friendly neighborhood dog slink off into cover in nearby bushes after being grazed by a car. When his beloved owners chased him down, he growled and nipped at them. His fight-or-flight reflex compelled him to find a protected place so that he could isolate himself from all other stimuli in order to manage the intense pain of his dislocated hip. Procuring necessary treatment for the injury required finding a way to override that fight-or-flight reflex.

> When you see me clinging to a life preserver, do not confuse my desire to avoid drowning with a preference to stay in the water!

Well, managing dizziness seems to involve a similar dilemma. Without a firm grasp on where you exist in space, your core survival is threatened and every minute feels like an emergency. It explains why I'm always wiped out and why I do what I can to maintain balance and disallow anything that increases vertigo. My physical therapist says I balance by swinging my hips so my head stays steady. I'm also not above closing my eyes and anchoring my head in a pillow or lurching around with a stiff neck and shoulders in order to fastidiously avoid moving my head.

The bad news is that such strategies undermine my brain's ability to register and coordinate signals from my vestibular system. The good news is, unlike an injured animal, I'm capable of understanding intellectually what I need to do to reduce experiencing the chronic emergency.

And so, enough with the indulgence! But I also think I deserve credit, too. Developing a steely resistance to succumbing to total disability could not have occurred without the admirable fortitude that's helped me cope with the vestibular symptoms in the first place. Hmmm, perhaps there is some way I can use that strength to get creative about tricking myself into doing VRT. Any suggestions?

—Anonymous member

Wounded Warrior Honored

This year, Bret DiFrancesco received the AbilityOne Award for Veterans with Disabilities. The AbilityOne Program is a federal initiative to help employ persons with significant disabilities within a national network of agencies contracting with the U.S. government. Bret has permanent vestibular-system damage from a 2006 blast injury in Iraq. The vestibular injury wasn't diagnosed until 2007 when he noticed he kept losing his balance and was angry and always hypervigilant. Family members told him he was "just no longer the same person." After retiring from the military on disability, he found it difficult to make ends meet. Eventually he found employment through the AbilityOne Program. To view a short video of Bret DiFrancesco talking about his injuries and involvement in AbilityOne, visit: www.youtube.com/watch?v=ZsS1EGff0dc.

JOIN THE CELEBRATION!

Balance Awareness Week XV

The fifteenth annual Balance Awareness Week (BAW) takes place September 18–24, 2011. VEDA established BAW in 1997 to raise awareness about the importance of balance and inner-ear health to general well-being and quality of life. Millions of people are affected by inner-ear balance disorders. However, getting effective treatment is frequently complicated by the challenge of diagnosing the specific source of the problem. The impact on an individual's work, family, and personal life is often made worse by the disorder's invisibility to others.

VEDA keeps expanding how we celebrate BAW so that it reaches into all arenas. This year we are thrilled to have the help of Jimmer Fredette, who on August 22 announced a charitable basketball event, Jimmer's All-Stars Presented by Zions Bank, and designated a portion of the proceeds to go to VEDA to help fund our nationwide awareness campaign. (See the story on page 10.)

In addition, many clinics and support groups around the U.S. and the world participate by offering free balance screenings, providing public Q&A sessions, and hosting presentations by medical specialists. VEDA promotes the wonderful work of these clinics online so that as many people as possible know about these great opportunities. If you work for a clinic or support group and you would like us to advertise your 2011 Balance Awareness Week event, please send an e-mail with details to kcdenner@vestibular.org.

Board member Sue Hickey also urges us to advertise the BAW special-event pricing of her book *Finding Balance: Healing from a Decade of Vestibular Disorders*. During BAW, purchasers receive 30% off the $19.95 price (shipping and handling charges are additional) when buying it from her publisher at demoshealth.com and entering code SSVEDA30 at check-out. This code only works for purchases made at the publisher's site, not elsewhere (such as at amazon.com). To learn about pricing on bulk orders, e-mail rsantana@demosmedpub.com. [Editor's note: VEDA does not benefit financially in any way by the sales of Sue's book, and Sue has relinquished her royalties to her publisher for all books sold with the pricing advertised here.]

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