

# VEDA

## ADVOCACY PLAN



A GRASSROOTS PUBLIC POLICY PLAN TO REDUCE DIAGNOSIS TIMES  
AND IMPROVE TREATMENT OUTCOMES FOR VESTIBULAR PATIENTS

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WE ENVISION A WORLD WHERE  
VESTIBULAR DISORDERS ARE WIDELY  
UNDERSTOOD, RAPIDLY DIAGNOSED, AND  
EFFECTIVELY TREATED  
SO PATIENTS CAN  
RESTORE BALANCE AND REGAIN LIFE.

# MESSAGE FROM THE DIRECTOR



Balance is easily taken for granted. However, when the fragile vestibular organs of the inner ear and brain are damaged by illness or injury, anyone can lose the ability to balance – the demands of school, work, family, and independent living become trying at best, impossible most often. These profound impacts are often made worse by the disorder's invisibility to others and the extended amount of time it takes to get an accurate diagnosis.

According to the National Institutes of Health (NIH), 40% of the US population age 40 or older will experience a balance disorder in their lifetime. Dizziness is the 3rd most common major medical symptom reported, yet the majority of cases remain unexplained.

More than 12 million people over 65 experience a dizziness or balance problem that significantly interferes with their life. In addition, falls are the leading cause of injury or death for people over 65. According to the Centers for Disease Control (CDC), an estimated \$19 billion is spent annually to treat fall related injuries.

A complication for vestibular patients is the difficulty of getting an accurate diagnosis, often searching six months or more with referrals to 3.5 specialists on average (“Experiences Engaging Healthcare When Dizzy”: 2016). Once patients do receive a diagnosis, treatment is frequently not effective.

VEDA's goal is to reduce the time it takes for vestibular patients to receive an accurate diagnosis and improve their treatment outcomes. To achieve these goals, we must:

- Increase the amount of funding allocated toward research into the diagnosis and treatment of vestibular disorders.
- Improve diagnostic criteria for the many different types of inner ear and brain balance disorders.
- Create systematic protocols for the triage, diagnosis and treatment of vestibular patients.
- Ensure that necessary diagnostic tests and treatments are covered by insurance.
- Make it easier for vestibular patients who can no longer work to receive disability insurance.

VEDA looks forward to working with legislators and patient advocates to bring awareness to the devastating impact vestibular disorders have on the lives of so many patients and their loved ones, bringing us closer to a day when vestibular disorders are widely recognized, rapidly diagnosed, and effectively treated.

Thank you.

Sincerely,

A handwritten signature in black ink, appearing to read 'Cynthia Ryan'.

Cynthia Ryan, MBA

# ORGANIZATIONAL OVERVIEW

## VEDA - A HISTORY

In 1983 a group of vestibular patients and professional providers from Good Samaritan Hospital in Portland, Oregon, established a support group named the "Dizziness and Balance Disorders Association of America" (DBDAA). The organizers adopted the following goals:

- To collect and disseminate information about vestibular disorders and related topics.
- To educate the public and health professionals about vestibular disorders and their effects.
- To establish and nurture a support network for people and families affected by dizziness and balance disorders.

In 1989, a team from The Today Show conducted interviews with DBDAA board members, staff, and others in Portland. After discussion of vestibular disorders aired on the Dr. Art Ulene segment of Today, DBDAA received about 2,000 requests for information. At that point, the board hired a full-time director and decided to change the organization's name to the Vestibular Disorders Association (VEDA) as part of its effort to make "vestibular" a household word.

## MISSION

To support and empower vestibular patients on their journey back to balance.

## VISION

We envision a world where vestibular patients are rapidly diagnosed and effectively treated so they can restore balance and regain life.

## PROGRAMS

VEDA leads and educates. VEDA is trusted as the leading international organization that people turn to for help with vestibular (inner ear balance) disorders. We are an authoritative source of information, publishing information that is clear, reliable, and scientifically objective.

Our publications about vestibular disorders include information about diagnosis and treatment, social and work impacts, and practical advice for coping with symptoms. Our member newsletter, On the Level, features up-to-date articles, information about current research, other news, and personal stories from people with vestibular disorders.

## VEDA SUPPORTS PEOPLE SO THAT THEY AREN'T STRUGGLING ALONE

- VEDA helps vestibular patients understand their condition so they can become effective advocates for their own healthcare.
- VEDA refers patients to vestibular healthcare specialists so they can get quickly and accurately diagnosed, and receive effective treatment.
- VEDA connects vestibular patients with support networks, where they receive validation and share coping strategies.
- VEDA raises awareness about vestibular disorders among the greater public, within the medical community, and in all levels of government through events, testimony, presentations, and grassroots advocacy efforts.

# PUBLIC POLICY ADVOCACY GOALS

## GOALS:

- Cultivate relationships with policy makers with the goal of improving vestibular patient diagnosis, treatment and support.
  - » Metric: Send outreach letters to a minimum of five elected officials per year.
- Raise political awareness around vestibular disorders through grassroots advocacy (e.g. VEDA Ambassadors reach out to their legislators).
  - » Metric: Share VEDA Ambassador Toolkit with stakeholders.
  - » Metric: A minimum of 10 Ambassadors reach out to their elected representatives per year.
- Stay updated on current legislation affecting vestibular patients by fostering reciprocal relationships with elected officials and government agencies.
  - » Metric: Sign up for key legislators' mailing lists.
  - » Metric: Create and maintain a spreadsheet of relevant legislation.
- Employ reciprocal relationships to launch outreach campaigns that generate targeted policy outcomes to advance VEDA's organizational mission.
  - » Metric: Monitor and track VEDA Ambassador outreach attempts and responses.
  - » Metric: Create and maintain a spreadsheet of VEDA's outreach to specific elected officials and government agencies, and any results of said outreach.
- Create a policy advocacy program that is both accessible to stakeholders and can be improved over time to meet VEDA's changing organizational goals.
  - » Metric: Update Public Policy Advocacy Plan annually.
  - » Metric: Maintain a Public Policy Advocacy page on VEDA's website.
  - » Metric: Survey VEDA Members & Ambassadors annually to solicit input on the public policy advocacy plan.
  - » Metric: Report on VEDA's advocacy efforts in our quarterly newsletter.

**VEDA'S #1 PUBLIC POLICY OBJECTIVE IS TO EDUCATE POLICY MAKERS ABOUT ISSUES AFFECTING VESTIBULAR DIAGNOSIS AND TREATMENT.**

## SAMPLE RESULTS:

- Relationships with policy makers established.
- Increased funding for vestibular research.
- Better Medicare coverage for vestibular testing and treatment.

**Public policy**

Public policy is generally the principled guide to action taken by the administrative or executive branches of the state with regard to a matter in a manner consistent with national customs. In

# PUBLIC POLICY ADVOCACY COMPONENTS

## ENGAGEMENT

Our goal is to develop substantive relationships with elected officials and policy makers to help them understand what vestibular disorders are, and advocate for increased funding for research and insurance coverage for testing and treatment.

- Connect with elected officials: Send letters to elected officials, and guide and encourage Ambassadors to do the same.
- Engage with interested stakeholders: Attend relevant meetings and schedule in-person meetings with stakeholders who are directly involved in legislation that impacts research, insurance coverage, and other relevant public policy.



## RESEARCH

Stay up to date on policy decisions impacting vestibular disorders to facilitate more substantive dialogue with political actors. The research component of the political advocacy plan provides a framework for efficiently collecting and contextualizing relevant health policy.

- Track outreach: By recording outreach efforts and coordinating with elected officials, VEDA staff will gain perspective on where VEDA fits into the national health policy conversation. With this information, VEDA can promote a targeted national advocacy program that will introduce VEDA to policy makers across the country.
  - » Create a spreadsheet to track outreach from VEDA and other stakeholders to elected officials and government agencies.
- Research Key Health Policy Agencies: Health policy often changes. To be involved in the national health policy conversation, VEDA needs develop a strong understanding of how agencies create policies that impacts members of the vestibular community.
  - » See information sheet on key health policy agencies.
- Develop Health Policy Knowledge: Building on a strong understanding of health agencies, VEDA staff can stay updated on policy proposals coming from relevant agencies by signing up for email updates.
  - » Sign up for relevant mailing lists.
- Report on Health Policy Activities: VEDA can leverage health policy knowledge to keep Ambassadors updated and engaged by reporting on key health policy issues and actions in their quarterly newsletter.



## SUSTAINABILITY

To continuously grow relationships with government officials and maintain our position as an influential stakeholder, VEDA must develop a sustainable advocacy program with best practices to pass on to interested stakeholders so that they can successfully advocate on behalf of VEDA for many years to come.

- Customized Advocacy Kits: Distribute a toolkit to empower Ambassadors to effectively highlight the great work VEDA does and advance its organizational mission. Ambassadors can follow a step-by-step road map to setting up a meeting with an elected official and sharing the importance of raising awareness about vestibular disorders. Toolkit includes:
  - » Step-by-step guide on how to engage with elected officials.
  - » Sample letter to your elected official.
  - » Sample talking points for phone conversation.
- Survey Stakeholders on How to Best Advocate For VEDA: To constantly improve VEDA's public policy advocacy program, we will track and monitor those aspects of our advocacy program that are working and the parts that are not. By tracking feedback, VEDA will be able to create a more sustainable policy advocacy program.
  - » Include questions about advocacy program in annual member survey.
  - » Survey engaged stakeholders bi-annually on more specific advocacy campaigns.
- Highlight Ambassador Best Practices: Advocates will be highlighted in VEDA's member newsletter and through e-blasts and social media to reinforce advocacy best practices and demonstrate the impact of public policy advocacy on the vestibular community.



PROGRAMS  
+  
ADVOCACY

WHEN NONPROFITS COMBINE  
DIRECT SERVICE PROGRAMS  
AND ADVOCACY THEY  
ENHANCE THEIR IMPACT OVER  
TIME. ADVOCACY AND SERVICE  
REINFORCE EACH OTHER.

- STANFORD SOCIAL  
INNOVATION REVIEW



# TARGETED ELECTED OFFICIALS

## SENATOR PATTY MURRAY (D-WA)

Senate Health Labor and Pensions Committee(Ranking Member)

Senate Appropriations Committee

Contact Information

- <https://www.murray.senate.gov/public/index.cfm/contactme>
- DC Office Phone: (202) 224-2621

## SENATOR JEFF MERKLEY (D-OR)

Senate Appropriations Committee

Contact Information

- <https://www.merkley.senate.gov/connect>
- DC Office Phone: (202) 224-3753

## SENATOR BERNIE SANDERS (I-VT)

Senate Health Labor and Pensions Committee

Contact Information

- <https://www.sanders.senate.gov/contact>
- DC Office Phone: (202) 224-5141

## CONGRESSWOMAN NITA LOWEY (D-NY)

House Appropriations Committee

Contact Information

- <https://lowey.house.gov/contact>
- DC Office Phone: 202-225-6506

## CONGRESSWOMAN SUZANNE BONAMICI (D-OR)

House Committee on Science, Space, and Technology

Contact Information

- <https://bonamici.house.gov/contact-me>
- DC Office Phone: (202) 225-0855

## CONGRESSMAN EARL BLUMENAUER (D-OR)

House Neuroscience Caucus

Contact Information

- <https://blumenauerforms.house.gov/forms/writeyourrep/>
- DC Office Phone: (202) 225-4811

## STATE SENATOR LEW FREDERICK

VEDA's State Senator

Contact Information

- <http://www.oregonlegislature.gov/frederick>
- Office Phone: 503-986-1722

## STATE REPRESENTATIVE CHRIS GORSEK

VEDA's State Representative

Contact Information

- <http://www.oregonlegislature.gov/Gorsek>
- Office Phone: 503-986-1449



# OUTREACH LETTER TEMPLATE

Month, Day 2017

The Office of Senator XXXXXX  
Senate Office Building Room XXXX  
Washington, DC 20001

Dear Senator/Congressman XXXXXXX,

On behalf of the Vestibular Disorders Association (VEDA) and the approximately 69 million Americans who have experienced some form of vestibular dysfunction, we invite you to learn more about our mission to inform, support and advocate for the vestibular community. We hope you and your staff will connect with us to help raise awareness around vestibular disorders on a national stage.

VEDA is trusted as the leading international organization that people turn to for help with vestibular (inner ear balance) disorders. We are an expert resource, publishing information that is clear, reliable, and scientifically objective. Our publications about vestibular disorders include information about diagnosis and treatment, social and work impacts, and practical advice for coping with symptoms. VEDA connects doctors and other health care specialists with patients through its popular provider directory of professional members. VEDA connects people with vestibular disorders to communicate about their experience through support groups and social networking opportunities as part of basic membership services. VEDA connects the greater public with vestibular disorder awareness through testimony and advocacy, such as presentations to community and government groups.

VEDA's medical and scientific advisors represent the best and most well-respected professionals in the vestibular community. Our board of directors includes both vestibular patients and healthcare professionals, providing a balanced and informed view on the needs of the vestibular community. We have a small but highly qualified staff who engage all interested stakeholders in achieving our goals.

The Vestibular Disorders Association can best be reached at [vestibular.org](http://vestibular.org). We would be pleased to meet in whatever format is most convenient for your office. We are also excited to relate to other health policy advocates you may recommend. Thank you in advance for your support.

Sincerely,

Cynthia Ryan, MBA  
Executive Director  
Vestibular Disorders Association (VEDA)  
Phone: 503.294.9085  
E-Mail: [Cynthia.Ryan@vestibular.org](mailto:Cynthia.Ryan@vestibular.org)  
Website: <https://vestibular.org>  
Facebook: <https://www.facebook.com/vestibulardisorders/>



# FEDERAL HEALTH POLICY MAKERS & RESEARCH FUNDING AVENUES

## CENTERS FOR MEDICARE & MEDICAID SERVICES

The Centers for Medicare & Medicaid Services (CMS) is part of the Department of Health and Human Services (HHS). CMS administers the Medicare program and works in partnership with state governments to administer Medicaid. Additionally, CMS has other responsibilities, including the administration of HIPAA (the Health Insurance Portability and Accountability Act), overseeing quality standards in long-term care facilities, ensuring clinical laboratory quality standards, and oversight of HealthCare.gov.



## NATIONAL INSTITUTE ON DEAFNESS & OTHER COMMUNICATION DISORDERS

The National Institute on Deafness and Other Communication Disorders (NIDCD), a member of the National Institutes of Health (NIH), is mandated to conduct and support biomedical and behavioral research and research training in the normal and disordered processes of hearing, balance, smell, taste, voice, speech, and language. The Institute also conducts and supports research and research training related to disease prevention and health promotion; addresses special biomedical and behavioral problems associated with people who have communication impairments or disorders; and supports efforts to create devices that substitute for lost and impaired sensory and communication function.



## ADMINISTRATION FOR COMMUNITY LIVING

Within HHS is there is the Administration for Community Living (ACL) which deals with health issues directly impacting seniors, a key demographic VEDA hopes to advocate for. The ACL leads policy development by analyzing trends in demographics, service needs, public policy and program development, and translating those trends into new policies, programs, and technical assistance related to long-term services and supports and health care for people with disabilities and older adults. The office leads and participates in departmental and interdepartmental activities that concern health and long-term care, reviews and comments on departmental regulations and policies regarding health programs, institutional and non-institutional long-term services and supports, and provides technical and policy development input on legislative and budget activities. The Office also conducts relevant policy research, conducts periodic reviews of needs and resources in the fields of aging, and develops policy reports based on the needs of the aging population. Additionally, the Office develops and coordinates initiatives with other federal agencies, national aging and disability organizations, universities, non-profit organizations and private corporations to fill gaps in information in the field of aging.

