

# VEDA

LIFE REBALANCED

## STRATEGIC PLAN

2017-2021

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# INTRODUCTION

## ABOUT VESTIBULAR DISORDERS

The vestibular system includes the parts of the inner ear and brain that process the sensory information involved with controlling balance and eye movements. If disease or injury damages these processing areas, vestibular disorders can result. Vestibular disorders can also result from or be worsened by genetic or environmental conditions, or occur for unknown reasons.

Although vestibular disorders are not widely recognized, they are surprisingly common. Recent medical research has shown that almost 40% of the US population over 40 will experience a vestibular disorder in their lifetime. More than 12 million people over 65 experience a dizziness or balance problem that significantly interferes with their life. Behind these statistics lie real people with real problems. Individuals with vestibular disorders lose significant work time as a result of their disability. Anxiety and depression are common among vestibular patients. Patients are also impacted by decreased ability to participate in family and social activities, resulting in social isolation. Societal costs - such as disability, lost productivity and hospital time due to falls - have been largely overlooked.

A further complication for vestibular patients is the difficulty of diagnosing vestibular disorders. As a result vestibular patients often spend three to five years seeking a diagnosis, and it is not uncommon to see seven to nine doctors in different specialties before receiving a diagnosis. Once patients do receive a diagnosis, treatment is frequently not effective.

There is an urgent need to address the needs of vestibular patients for information and improvement in diagnosis and treatment. VeDA is responding to this need by creating a community of support, promoting legislative advocacy, leveraging partnerships, and increasing public awareness. We are committed to growing so we can improve and increase the services we provide to the vestibular community.

## COMMUNITY

VeDA is building a community of vestibular patients and professionals to become dedicated activists for our cause.

## ADVOCACY & RESEARCH

VeDA is developing a grassroots advocacy program designed to engage our community in raising awareness about vestibular disorders at a legislative level with the goal of increasing research funding and improving insurance coverage for vestibular diagnostics and treatments.

## PARTNERSHIPS

VeDA is building mutually beneficial partnerships with other organizations to enhance our community and increase our impact.

## PUBLIC AWARENESS

VeDA is engaged in multi-channel marketing campaigns aimed at increasing awareness about what vestibular disorders are and how they impact patients and their loved ones. Our goal is to make "vestibular" a household name and increase empathy and compassion for the struggles faced by patients with these chronic invisible illnesses.

## INFRASTRUCTURE

VeDA is committed to increasing our capacity to achieve our goals by engaging dedicated volunteers and Ambassadors, cultivating a diverse Board of Directors, maintaining a qualified Medical and Scientific Advisory Board, and growing a well-trained staff.

## FUND DEVELOPMENT

We will maintain adequate funding to support our programs and services. We take member and donor stewardship seriously, keeping all stakeholders informed about our progress. We are clear and transparent to assure that donor funds are used wisely.



# OVERVIEW

## OUR HISTORY

VeDA was founded in 1983, filling an urgent need for vestibular information by providing scientifically-based books, articles, and support for patients, many of whom had been dismissed by the medical system. We quickly became the leading source of patient-friendly information on vestibular disorders worldwide, and remain so to this day.

## VEDA ADAPTS TO CHANGE

The demand for printed publications diminished as the demand for online information grew. VeDA adapted by offering the largest library of educational resources about vestibular disorders through our website, which receives 5 million visitors per year. VeDA has also developed an engaged community on Facebook, with over 21,000 followers and an average monthly reach of 160,000.

## OUR COMMUNITY

VeDA has shifted our focus from providing static information on vestibular disorders to creating a dynamic interactive vestibular community that captures the enthusiasm and leverages the unique skills and experience of our patient and professional healthcare members. We have introduced an Ambassador program where patients raise awareness about vestibular disorders in their local communities and through their social networks. Our volunteer committees have a real impact on improving our patient education, advocacy and outreach programs. While we remain a small organization, we have a large reach thanks to the contributions of our members, donors and volunteers.

## PROVIDING SUPPORT

VeDA started as a support group for patients. We continue to facilitate a network of in-person support groups. However, the need for support is so great, a new model is needed. To address the needs of rural communities and individuals who cannot travel due to their vestibular symptoms, we are initiating online support groups that meet in real-time using video conference technology.

## DOCUMENTING THE PATIENT EXPERIENCE

Recognizing the value of vestibular patients' experience with the healthcare system, we created a patient registry

to collect this data. In 2016 we shared the initial results in a paper published in the Journal of Otology and Neurotology.



## RESEARCH

VeDA partners with organizations and healthcare professionals involved in research aimed at improving vestibular diagnostics and treatment. Our goal is to get more involved in actively promoting research by providing seed grants to help investigators define objectives and test hypotheses in preparation for major grant applications to governmental agencies.

## VEDA LEADS THE WAY

VeDA has lead worldwide efforts to raise awareness about vestibular disorders through our signature event, Balance Awareness Week. Our goal is help people discover a Life Rebalanced, whether they are still seeking a diagnosis, are newly diagnosed, or have learned to manage their symptoms. By engaging patients as activists for our common cause we have greatly expanded the reach of this event, which grows annually.

## WORKING TOGETHER

VeDA's relationships with vestibular patients, healthcare professionals, researchers, and other organizations involved in developing diagnostic and treatment tools has put us in a unique position to foster collaborations that advance our mutual interests - reducing diagnosis times and improving treatment outcomes for vestibular patients.

## BE THE CHANGE

We recognize a need for systemic change, in the medical community, insurance coverage, and research funding availability, and we are working to identify ways we can make a difference. Our strength is in numbers, and the passion of our community to make sure future vestibular patients receive the care they need. We are working on a grassroots advocacy plan that will leverage our core competencies by engaging patients and professionals around issues that will have a direct impact.

# MISSION, VISION & VALUES

## MISSION

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



## VISION

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

## VALUES

VeDA recognizes our responsibility to be a champion for the vestibular community and to achieve measurable results.

In valuing all members of the vestibular community:

- VeDA serves all people with vestibular disorders with dedication, understanding and compassion.
- VeDA engages vestibular professionals with respect and appreciation for their service.
- VeDA values its donors and is committed to ethical and responsible stewardship of donor's funds.
- In conducting our business, VeDA operates with transparency and credibility and is always trustworthy.

In valuing our staff, Board, Medical Advisers and volunteers, VeDA actively promotes integrity, respect for different perspectives, innovation and accountability.

# CORE FOCUS

REDUCE DIAGNOSIS TIMES  
IMPROVE TREATMENT OUTCOMES

## VESTIBULAR COMMUNITY:

- Patients
- Medical Specialists
- Corporate Partners
- Government
- Insurance
- Other Non-Profits

VEDA

COLLABORATION



COMMUNITY

ADVOCACY

AWARENESS

RESEARCH



RAPID DIAGNOSIS

EFFECTIVE TREATMENT

# GOALS & OBJECTIVES

## GOAL I: COMMUNITY

Build a large & influential community of patient and professional members, family and caregivers, who are engaged and motivated to remove barriers to reducing diagnosis times and increasing treatment effectiveness.

### Objectives

1. Patient Education: Remain the trusted source of information on vestibular disorders and treatment alternatives by providing up-to-date content on relevant topics.
2. Increase general awareness of vestibular disorders through outreach to people with vestibular dysfunction.
3. Attract and motivate ambassadors who are activists for the cause.
4. Support professional members in serving vestibular patients through tools and information that connect providers to patients, colleagues, research, and training opportunities.



### Measures of Success

10% annual growth rate (E-mail mailing list, Ambassadors, event participants, social media followers, etc.).

## GOAL II: ADVOCACY & RESEARCH

Become an influential advocate for improved vestibular patient diagnosis and treatment.

### Objectives

1. Continue to collect data on key patient experience measures through polls, surveys, and the Patient Registry.
2. Directly support vestibular research through seed grants.
3. Facilitate patient referrals from PCP to specialists through the development and promotion of vestibular triage protocols.
4. Engage vestibular healthcare specialists in training non-vestibular healthcare providers.
5. Engage in grassroots legislative advocacy to increase funding for vestibular research and insurance coverage for vestibular diagnostic tests and treatments.



### Measures of Success

Increased research funding and medical training, expanded diagnostic and treatment protocols, and increased insurance & disability coverage for vestibular disorders.

## GOAL III: PARTNERSHIPS

Form alliances with a range of organizations to increase VeDA's impact, speed results & expand resources.

### Objectives

1. Act as a key facilitator of interested parties (patient & practitioner organizations, as well as other nonprofits) in addressing vestibular challenges and increasing awareness.
2. Foster reciprocal relationships with government, regulatory & educational/academic agencies and institutions to increase awareness of vestibular disorders and improve policies affecting vestibular patients and healthcare professionals.
3. Secure and leverage marketing alliances and corporate partnerships.



### Measures of Success

Increased impact on societal support for vestibular patients. Coordinated efforts that directly impact the vestibular community

## GOAL IV: FUNDRAISING

Increase and diversify funding to support VeDA's programs & operations.

### Objectives

1. Increase revenue through active marketing to potential new members/donors.
2. Cultivate current members/donors through improved communications and targeted campaigns, resulting in continued giving and larger gifts.
3. Increase the number of sustaining members/donors (monthly giving).
4. Increase the frequency of donor gifts (e.g. >1x/year).
5. Continue to develop grassroots fundraising through events like Balance Awareness Week and the Dizzy Dash.
6. Cultivate new and current corporate partners and sponsors.
7. Explore grants and other sources of funding.

### Measures of Success

10-20% annual growth in revenue.



## GOAL V: INFRASTRUCTURE

Align board and staff capabilities to VeDA needs.  
Anticipate growth with expanded business systems.

### Objectives

1. Have sufficient staff to support current and new programs.
2. Have an enthusiastic and well-trained board with diverse skills and sufficient resources to meet VeDA's needs through board recruitment and training.
3. Automate and update business systems.
4. Tap into the skills within the vestibular community through an active volunteer program.
5. Continue to grow committee participation among volunteers.
6. Support all stakeholders through communication that is timely and relevant.



### Measures of Success

Infrastructure supports being able to effectively implement programs and achieve stated goals.

## GOAL VI: MARKETING

Implement marketing strategies that support and accomplish VeDA's goals and objectives.

### Objectives

1. Generate awareness of VeDA and vestibular disorders to a national audience through on and off-line media outlets.
2. Grow social media interactions & followers by providing relevant and engaging content.
3. Increase user visits to the VeDA website through email outreach, social media referrals, and improved SEO.
4. Improve printed collateral design and sponsorship/grant/donor materials.
5. Continue to identify and grow the VeDA brand through consistent and powerful messaging.
6. Advertise in targeted print publications.
7. Secure & leverage marketing partnerships.

### Measures of Success

Media hits, website visitors, social media followers - leads to increased awareness of VeDA and vestibular disorders.





# SWOT ANALYSIS

INTERNAL

## STRENGTHS

- Well-qualified staff works well as a team and accomplishes a lot for our size.
- Diversified Board of Directors represents patient and healthcare provider perspectives.
- Well-respected Medical and Scientific Advisory Board.
- Wealth of credible patient education articles.
- Passionate and committed community of supporters and Ambassadors.
- Participation from multiple specialties adds value to our provider directory.
- Long history engenders trust among patients and healthcare professionals.
- Personal connection with many of our supporters.
- Significant Facebook following and engagement.
- Robust newsletter content and stories.

## WEAKNESSES

- “Vestibular” has low public awareness.
- Invisible conditions don’t tug at people’s heartstrings.
- “Dizziness” and “balance” are universal symptoms, used by many conditions.
- There are many vestibular disorders that manifest symptoms differently.
- Most patients just want to get better and move on - low “vestibular identity.”
- Many healthcare providers don’t want to deal with “dizzy” patients.
- Limited funding and capacity to grow.
- Fundraising programs are not well developed.
- Most of our content is text heavy.
- Website has lots of information, but it’s difficult to navigate.

EXTERNAL

## OPPORTUNITIES

- Demand for our services, based on potential audience of vestibular patients.
- Leadership vacuum in the vestibular area.
- No other “umbrella” vestibular organizations nationally.
- Partnerships with healthcare professionals and nonprofits.
- Aging population is prone to vestibular and balance disorders.
- Increased public attention around head injuries (sports, military).
- Digital age increases access to prospective members; more people are using the Internet to find healthcare solutions.

## THREATS

- Rising fixed costs (e.g. staff, rent).
- Funding base is not diversified, e.g. limited number of major donors/sponsors that we rely heavily on.
- Lack of public awareness of vestibular disorders as a serious illness; impacts are dismissed.
- Lack of medical cohesion and integration of vestibular efforts amongst the various specialties.
- No control over the quality of care provided by professionals on our provider directory.

# LONG-TERM MILESTONES

## BY 2020 VEDA ENVISIONS THE FOLLOWING MILESTONES FOR THE VESTIBULAR COMMUNITY:

- Vestibular disorders are routinely covered in the popular press and there is a high level of public awareness about what “vestibular” means and what symptoms indicate a vestibular disorder.
- There are widely accepted clinical practice guidelines in place for the diagnosis and treatment of a broad range of vestibular disorders. Primary care providers and emergency room doctors routinely triage vestibular patients appropriately and refer to qualified specialists as needed.
- VeDA has a robust patient registry with data that informs our understanding of the vestibular patient experience, and contributes to policy decisions.
- Funds for vestibular research have increased proportionate to funds already allocated for hearing research. VeDA is a leader in vestibular advocacy and has established relationships with policy makers.
- Key vestibular testing and treatment is covered by Medicare and major insurance companies.
- Vestibular patients are rapidly diagnosed and effectively treated. Helpful information and support are available for patients and their families, validating the patient experience and engendering compassion and understanding for their struggles.

## BY 2020 VEDA ENVISIONS THE FOLLOWING MILESTONES FOR ITSELF AS AN ORGANIZATION:

- VeDA designs and implements programs that consistently achieve results for the vestibular community.
- VeDA’s donor base has doubled and is growing at over 10% per year.
- VeDA revenues have doubled and staff has grown to meet the needs of expanding national programs such as advocacy, volunteer management, and support groups.
- VeDA has strategic alliances with key leaders in areas such as clinical practice, research, regulatory policy, and education.
- VeDA’s Board of Directors has grown to 15 members, and is engaged in thought leadership and donor stewardship.
- VeDA’s committees are well staffed with qualified volunteers who are active in planning and implementing VeDA’s programs.

# ACTION PLAN

## GOAL I: COMMUNITY

Build a large & influential community of patient and professional members, family and caregivers, who are engaged and motivated to remove barriers to reducing diagnosis times and increasing treatment effectiveness.

### Objectives I

Patient Education: Remain the trusted source of information on vestibular disorders and treatment alternatives by providing up-to-date content on relevant topics.

#### ACTIONS:

- Website articles should be reviewed and updated every five years.
- New articles on relevant topics are written as needed.
- Multi-media collateral is developed for all primary topics, including one-page fliers, infographics and videos.

### Objectives II

Increase general awareness of vestibular disorders through outreach to people with vestibular dysfunction.

#### ACTIONS:

- Continue to grow Balance Awareness Week.
- Be responsive to media inquiries.
- Look for opportunities to partner with other organizations to reach a targeted audience.
- Promote sharing on social media.

### Objectives III

Attract and motivate ambassadors who are activists for the cause

#### ACTIONS:

- Promote Ambassador program through website, social media, and newsletters.
- Invite vestibular bloggers to become Ambassadors.
- Steward current Ambassadors to keep them engaged.

### Objectives IV

Support professional members in serving vestibular patients through tools and information that connect providers to patients, colleagues, research, and training opportunities.

#### ACTIONS:

- Educate professional members on VeDA resources through targeted e-blasts.
- Communicate directly with professional members annually.
- Continue to grow our professional member toolkit.
- Continue to provide a list of relevant trainings and conferences for vestibular professionals.

### Measures of Success

10% annual growth rate (E-mail mailing list, Ambassadors, event participants, social media followers, etc.).



## GOAL II: ADVOCACY & RESEARCH

Become an influential advocate for improved vestibular patient diagnosis and treatment.

### Objective I

Continue to collect data on key patient experience measures through polls, surveys, and the a Patient Registry.

#### ACTIONS:

- Promote the patient registry through the website, social media, newsletters, and other outlets.
- Create new surveys to distribute to registry participants.
- Send reminder to patient registry participants annually, asking them to update their information.
- Distribute annual patient survey to members/ mailing list.
- Update website poll quarterly.

### Objective II

Directly support vestibular research through seed grants.

#### ACTIONS:

- Develop grant guidelines.
- Establish a grant review committee.
- Ensure sufficient funds for program implementation (see "Fundraising").

### Objective III

Facilitate patient referrals from PCP to specialists through the development and promotion of vestibular triage protocols.

#### ACTIONS:

- Publish systematic review paper in primary care journal comparing VeDA triage protocols to other diagnostic tools for dizzy patients.
- Engage in clinical trial of triage protocols to demonstrate their efficacy in reducing diagnosis times and patient costs and improving patient quality of life.
- Distribute triage protocols to PCP and insurance companies.

### Objective IV

Engage vestibular healthcare specialists in training non-vestibular healthcare providers.

#### ACTIONS:

- Develop training materials.
- Develop action plan to help vestibular specialists implement a training program in their community.
- Distribute train-the-trainer package to VeDA professional members.

### Objective V

Engage in legislative advocacy to increase funding for vestibular research and insurance coverage for diagnostic tests and treatments.

#### ACTIONS:

- Recruit volunteers for a legislative advocacy committee.
- Participate in advocacy by writing letters to local, state and federal legislators.
- Provide materials to VeDA Ambassadors, members, and the general public to facilitate grassroots adocacy efforts.
- Respond to relevant legislative and regulatory actions by gathering feedback from interested parties and issuing a position statement.

## Measures of Success

Increased research funding and medical training, expanded diagnostic and treatment protocols, and increased insurance & disability coverage for vestibular disorders.

## GOAL III: PARTNERSHIPS

Form alliances with a range of organizations to increase VeDA's impact, speed results & expand resources.

### Objective I

Act as a key facilitator of interested parties (patient & practitioner organizations, as well as other nonprofits) in addressing vestibular challenges and increasing awareness.

#### ACTIONS:

- Coordinate Balance Awareness Week efforts globally by distributing branded materials to partner organizations.
- Respond to initiatives proposed by partner groups as appropriate.



### Objective II

Foster reciprocal relationships with government, regulatory & educational/academic agencies & institutions to increase awareness of vestibular disorders and improve policies affecting vestibular patients and healthcare professionals.

#### ACTIONS:

- Seek out opportunities to participate in relevant working groups (e.g. FDA panels).
- Recruit vestibular patients and healthcare professionals to serve on clinical practice guideline committees.

### Objective III

Secure and leverage marketing alliances and corporate partnerships.

#### ACTIONS:

- Pursue relationships with companies engaged in the vestibular arena.
- Establish guidelines for reciprocal marketing partnerships.
- Respond to corporate partnership opportunities with customized sponsorship package.

## Measures of Success

Increased impact on societal support for vestibular patients. Coordinated efforts that directly impact the vestibular community



## GOAL IV: FUNDRAISING

Increase and diversify funding to support VeDA's programs & operations.

### Objective I

Increase revenue through active marketing to potential new members/donors.

#### ACTIONS:

- Provide excellent patient support services to engender goodwill and encourage membership.
- Improve membership value message.
- Develop a culture of philanthropy.
- Distribute professional membership offers through trainers and professional associations.
- Actively identify vestibular healthcare providers and invite them to join.

### Objective II

Cultivate current members/donors through improved communications and targeted campaigns, resulting in continued giving and larger gifts.

#### ACTIONS:

- Continue and expand/improve member communications, including newsletters, direct mail, eblasts, and personal outreach.
- Continue and improve major donor stewardship program.
- Segment donors/members and customize communications.
- Identify opportunities for in-person meetings with board and staff.
- Organize member-only events.



### Objective III

Increase the number of sustaining members/donors (monthly giving).

#### ACTIONS:

- Increase awareness of the sustaining member program through newsletters and the website.
- Target long-time small donors and invite them to join the sustaining circle program.
- Provide custom benefits and communications to sustaining donors/members.

### Objective IV

Increase the frequency of donor gifts (e.g. >1x/year).

#### ACTIONS:

- Invite donors to give to a specific program in addition to their annual gift.
- Invite patient members to make an additional gift above and beyond their membership donation.



## Objective V

Continue to develop grassroots fundraising through events like Balance Awareness Week and the Dizzy Dash.

### ACTIONS:

- Grow DD & BAW committees by inviting engaged stakeholders to join.
- Begin planning at least 6 months prior to event date.
- Continue to improve event collateral, including sponsorship and public outreach materials.
- Continue to include technology, including Personal Campaign Pages (PCP) and photo contest entry.

## Objective VI

Cultivate new and current corporate partners and sponsors.

### ACTIONS:

- Develop sponsor stewardship parameters.
- Provide ROI packet showing benefits and impacts.
- Continue to prospect new sponsors and partners through industry research and surveying primary stakeholders.
- Solicit feedback from current sponsors and partners.

## Objective VII

Explore grants and other sources of funding.

### ACTIONS:

- Identify programs that might be attractive to foundations.
- Research relevant foundation giving priorities and processes.
- Develop relationships with key funders.
- If a strong connection exists and the funders indicate interest in a program, submit grant proposal.

## Measures of Success

10-20% annual growth in revenue.







## Objective IV

Tap into the skills within the vestibular community through an active volunteer program.

### ACTIONS:

- Improve volunteer management systems.
- Allocate sufficient staff resources to support volunteer efforts.
- Recognize volunteers through newsletters, social media, and on the website.
- Solicit volunteer input.
- Place volunteers in positions that fit their skills and interests.

## Objective V

Continue to grow committee participation

### ACTIONS:

- Promote committee participation through newsletters, social media, and on the website.
- Board and staff actively recruit committee members from patient and professional members and personal associates.
- Cultivate and steward committee members by soliciting input and providing program reports.

## Objective VI

Support all stakeholders through communication that is timely and relevant.

### ACTIONS:

- Continue to generate timely and relevant articles in the newsletters by developing relationships and soliciting content from vestibular patients and professionals, and other relevant sources.
- Improve and expand Annual Report.
- Send relevant program updates to major donors and medical advisors.

## Measures of Success

Infrastructure supports being able to effectively implement programs and achieve stated goals.



## GOAL VI: MARKETING

Implement marketing strategies that support and accomplish VeDA's goals and objectives.

### Objective I

Generate awareness of VeDA and vestibular disorders to a national audience through on and off-line media outlets.

#### ACTIONS:

- Respond to media inquiries in a timely manner.
- Create/maintain current and relevant communication templates.
- Pursue relationships with relevant media sources.
- Distribute Balance Awareness Week press release.
- Seek out opportunities for board and staff to speak to local media.

### Objective II

Grow social media interactions & followers by providing relevant and engaging content.

#### ACTIONS:

- Continue to generate engaging Facebook content by sharing relevant posts from various internal and external sources.
- Stay up-to-date on social media trends.
- Collect and analyze social media statistics/insights.
- Improve Twitter and Pinterest presence with customized content.
- Engage with other social media users.



### Objective III

Increase user visits to the VeDA website through email outreach, social media referrals, and improved SEO.

#### ACTIONS:

- Direct users back to the VeDA website with new and engaging content.
- Promote website content through V-News and social media.
- Track website user trends through Google Analytics.
- Improve Google AdWords campaigns and implement strategies to drive users to relevant search content.

### Objective IV

Improve printed collateral design and sponsorship/grant/donor materials.

#### ACTIONS:

- Re-brand all collateral with new logo and brand standards.
- Re-design key collateral (e.g. brochure, newsletter, sponsor and membership materials).

### Objective V

Continue to identify and grow the VeDA brand through consistent and powerful messaging.

#### ACTIONS:

- Update communication templates with new brand/tagline (Life Rebalanced) and messaging focused more on patient support and less on VeDA programs.
- Use A/B testing to evaluate the success of different messages/communication strategies.

## Objective VI

Advertise in targeted print publications.

### ACTIONS:

- Identify publications that share VeDA's target audience.
- Solicit for in-kind sponsorship.

## Objective VII

Secure & leverage marketing partnerships.

### ACTIONS:

- Develop reciprocal marketing partnership guidelines.
- Identify organizations with mutual interests/audiences.

## Measures of Success

Media hits, website visitors, social media followers - leads to increased awareness of VeDA and vestibular disorders.

