



AWARENESS DAY

Partner Toolkit



WELCOME

Heart valve disease (HVD) involves damage to one or more of the heart's valves, which disrupts blood flow by not opening or closing properly. While some types are not serious, others can lead to major complications—including death. HVD becomes more common with age, and one in eight people age 75 and older are estimated to have moderate to severe HVD. Fortunately, HVD can be successfully treated with valve repair or replacement in patients of all ages.

Despite the fact that more than five million Americans are affected by HVD, public awareness of the disease is shockingly low. A recent survey of more than 2,000 adults found that close to 50 percent of people have never heard of HVD, and only one in four know somewhat or a great deal about the disease.

The seriousness of the disease, combined with the fact that symptoms are often difficult to detect or dismissed as a normal part of aging, makes this lack of awareness dangerous. This is why the Alliance for Aging Research partnered with 29 national organizations to call on the U.S. Department of Health and Human Services to include National Heart Valve Disease Awareness Day, beginning annually on February 22, 2017, on its National Health Observances Calendar.

The goal of an annual National Heart Valve Disease Awareness Day on February 22 is to increase recognition of the specific risks and symptoms of HVD, improve detection and treatment, and ultimately save lives. The good news is that while HVD can be serious, innovative treatment saves lives and enables most patients to enjoy significant improvements in their quality of life.

Education and awareness have the potential to make a tremendous difference, which is why we need you—the advocates, educators, and health care professionals—to help us spread the word about this initiative. We thank you for your support and encourage you to use this kit and the additional materials at www.ValveDiseaseDay.org as you plan your outreach, educate your audience, and encourage others to join.

Sue Peschin, MHS
President and CEO
Alliance for Aging Research



ABOUT VALVE DISEASE



What is Heart Valve Disease?

As many as five million Americans have been diagnosed with heart valve disease (HVD). HVD involves damage to one or more of the heart's valves and while some types are not serious, others can lead to major complications—including death.

Most types of HVD involve a damaged valve that disrupts blood flow by not opening or closing properly. Regurgitation is when a valve does not fully close and allows blood to leak backwards. It is also commonly called insufficiency, or a leaky valve. Stenosis is when a valve does not fully open to allow enough blood to flow through. It is also commonly called a sticky, narrowed, or stiff valve. Each of four valves can have regurgitation or stenosis (sometimes both), although the aortic and mitral valves are most likely to be damaged.

Survey Data

A 2016 national omnibus survey of 2,018 adults revealed that, while over half of respondents say they have heard of heart valve disease (HVD), less than one in four know somewhat or a great deal about HVD. Although awareness increases with age, 30 percent of respondents over the age of 65 say they know nothing about HVD.

The surveying was done in collaboration with Belden Russonello Strategists, who put questions on Telephone CARAVAN, a national omnibus survey of adults randomly selected via landlines and cell phones.

The Alliance also worked with Belden Russonello Strategists to conduct an in-depth analysis to learn more about awareness levels and the experiences of HVD patients as they are diagnosed and seek treatment. A survey group of more than 400

When valve damage reduces blood flow, the heart has to work harder and the body gets less oxygen—leading to a number of symptoms. However, people with valve disease do not always have symptoms, even if their disease is severe. For these people, a heart murmur is the most important clue. For those who experience symptoms, they may be dismissed as a “normal” part of aging.

HVD can be there at birth or develop from damage later in life from calcification, other cardiovascular diseases and conditions, or infection. Fortunately, HVD can usually be successfully treated with valve repair and replacement in patients of all ages.

individuals diagnosed with HVD was recruited through the Harris Panel—including members of its third party panel providers. The panel provides a robust representative sample of the general U.S. population. Additionally, patient focus groups in Chicago and New York provided a qualitative look at the patient experience.

Key findings from the survey include:

- More than two thirds of the survey respondents knew a limited amount or nothing about HVD prior to their diagnosis.
- Six in 10 respondents were diagnosed with heart valve disease only because they went to see a health care professional for a regular check-up or some other issue.

Complete survey results can be found at www.agingresearch.org/heartvalvediseasesurveys.

BACKGROUND INFORMATION

What is Valve Disease Awareness Day?

National Heart Valve Disease Awareness Day is an annual day dedicated to raising awareness about heart valve disease—its risk factors, symptoms, detection, and treatment—in order to reduce the burden of the disease. With education and advocacy, we can reduce the number of people who lose their independence and ability to fully participate in their lives; experience heart attacks, arrhythmias, congestive heart failure, and other heart disease; suffer from strokes; and even die from the disease.

When is Valve Disease Awareness Day?

National Heart Valve Disease Awareness Day is every February 22—during American Heart Month. While we hope that partners will educate about heart valve disease awareness throughout the year, a dedicated day gives us the opportunity to collaborate and amplify each other's messages.

Who is the Target Audience?

The primary targets of the National Heart Valve Disease Awareness Day Campaign are:

- Older adults
- Family caregivers
- Health care professionals
- Other advocates & public health educators

HOW YOU CAN MAKE A DIFFERENCE

If you are not already an official partner of the Awareness Day Campaign, email Lindsay Clarke, vice president of health programs at the Alliance for Aging Research at lclarke@agingresearch.org, and join the movement.

- **Share information about heart valve disease with your audience** through your various channels like websites, blogs, newsletters, Facebook pages, Twitter accounts, and more. See below for tips, shareable graphics, and language you can use in your outreach.
- **Talk to other advocates, public health educators, and health care professionals about the campaign** and encourage them to join the movement.
- **Organize an event to educate your audience about heart valve disease** and the importance of early detection and treatment.

HOW YOU CAN STAY INFORMED

Even if you are not able to join us as a partner, you can still get regular updates about the awareness day campaign from Lindsay Clarke, vice president of health programs at the Alliance for Aging Research. Contact Lindsay to join our distribution list at lclarke@agingresearch.org.

You should also visit the campaign website at www.ValveDiseaseDay.org regularly for new materials, updates, news, and more.



HOW YOU CAN HELP SPREAD THE WORD



This toolkit contains ideas and resources to help you take action today—including suggested tweets and blog posts, content to plug into newsletters, graphics to use in your outreach, and more.

Core Messages to Use

Our goal is to provide easy-to-understand language that you can use in your outreach efforts. By using consistent language and messaging, we can leverage each other's outreach and maximize impact:

- As many as 5 million Americans have been diagnosed with heart valve disease (HVD).
- HVD involves damages to one or more of the heart's valves which disrupts blood flow by not opening or closing properly.
- HVD becomes more common with age—1 in 8 people ages 75+ are estimated to have moderate to severe heart valve disease.
- While some types of HVD are not serious, others can lead to major complications—including death.
- After the onset of symptoms, patients with severe aortic stenosis, one of the types of HVD, have a survival rate as low as 50% at 2 years and 20% at 5 years—without valve replacement.
- Each year, an estimated 22,000 people in the U.S. die from their HVD.
- HVD can usually be successfully treated with valve repair or replacement in patients of all ages.
- The survival rate for valve surgery is estimated at 97%.
- People with HVD do not always have symptoms, and those who do may be told or believe that they are a normal part of aging. This makes detection of HVD critical.
- Unfortunately, awareness about HVD is low. A recent survey found that close to 50% of adults have never heard of HVD, and only 1 in 4 know somewhat or a great deal about HVD.
- The goal of this annual National Heart Valve Disease Awareness Day is to increase recognition of the specific risks and symptoms of HVD, improve detection and treatment, and ultimately save lives.
- Learn more about National Heart Valve Disease Awareness Day at www.ValveDiseaseDay.org and share with your audiences.
- Use social media to spread the word. Follow on Twitter @ValveDiseaseDay and use #ValveDiseaseDay in your Tweets.

HOW YOU CAN HELP SPREAD THE WORD (CONT.)

Post to Your Website

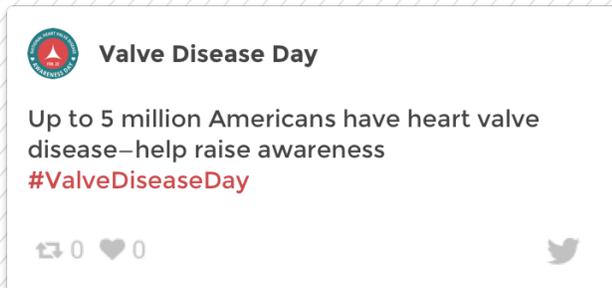
Consider featuring the Heart Valve Disease Awareness Day on your organization's website. You can incorporate the logo, web badge, other campaign materials, and more. Please make sure that whatever you feature links to www.ValveDiseaseDay.org.

Tweet

Twitter is a great place to connect with other Heart Valve Disease Awareness Day partners, leverage outreach, and build momentum in the lead-up to and on February 22. Use Twitter to:

- Follow other awareness day partners if you don't already (note that the Alliance for Aging Research will tweet out frequent information about the awareness day from @valvediseaseday),
- Share partner content,
- Promote your own heart valve disease materials and connect them to the Awareness Day Campaign,
- Use campaign graphics to give your posts visual interest,
- Use the logo as your profile or background image in the weeks leading up to, and on Heart Valve Disease Awareness Day,
- Link your posts to www.ValveDiseaseDay.org,
- Host a Twitter chat about heart valve disease and mention the Awareness Day Campaign,
- Use the official hashtag in your Tweets - #ValveDiseaseDay, and
- Encourage your audiences and connections to also spread the word.

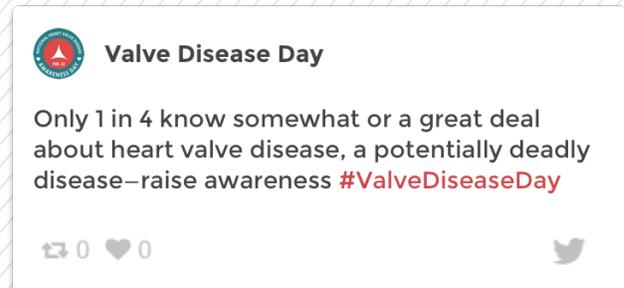
Sample Tweets



 **Valve Disease Day**

Up to 5 million Americans have heart valve disease—help raise awareness
[#ValveDiseaseDay](https://www.ValveDiseaseDay.org)

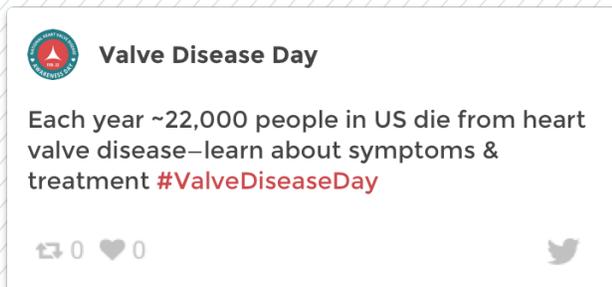
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 **Valve Disease Day**

Only 1 in 4 know somewhat or a great deal about heart valve disease, a potentially deadly disease—raise awareness [#ValveDiseaseDay](https://www.ValveDiseaseDay.org)

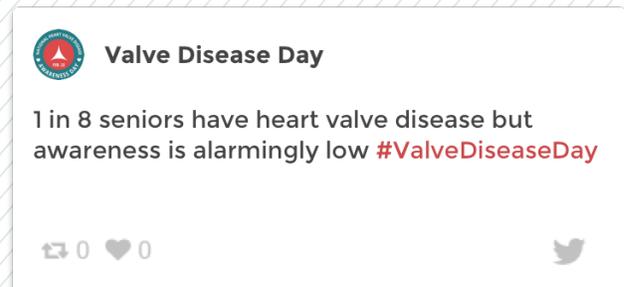
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 **Valve Disease Day**

Each year ~22,000 people in US die from heart valve disease—learn about symptoms & treatment [#ValveDiseaseDay](https://www.ValveDiseaseDay.org)

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 **Valve Disease Day**

1 in 8 seniors have heart valve disease but awareness is alarmingly low [#ValveDiseaseDay](https://www.ValveDiseaseDay.org)

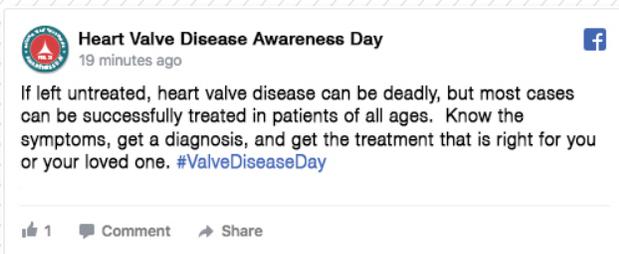
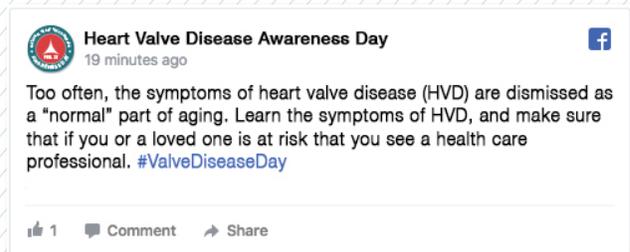
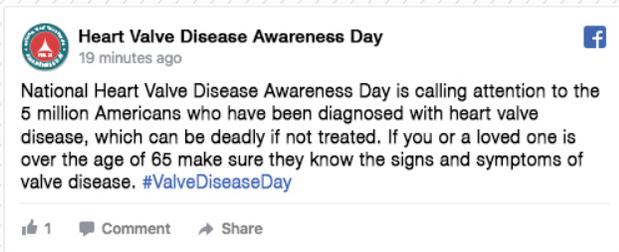
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HOW YOU CAN HELP SPREAD THE WORD (CONT.)

Post to Facebook

- Be sure to like us @AllianceforAgingResearch and get regular updates on the Awareness Day Campaign;
- Include posts of your own on your Facebook pages and use the campaign graphics, logo, video, and whatever else will resonate with your audience;
- Ask your followers to help you spread the word.

Sample Facebook Posts



Write a Blog Post or Newsletter Article

Consider featuring the Heart Valve Disease Awareness Day on your organization's website. You can incorporate the logo, web badge, other campaign materials, and more. Please make sure that whatever you feature links to www.ValveDiseaseDay.org.

Sample Article/Post

This February 22nd, [insert your organization] is proud to participate in National Heart Valve Disease Awareness Day. More than 5 million Americans have heart valve disease (HVD); which can cause heart attacks, arrhythmia, congestive heart failure, and other heart disease—significantly impacting quality of life and even leading to death. The good news is that most HVD can be successfully treated in patients of all ages. Unfortunately, awareness of HVD is alarmingly low, with close to half of respondents to a national survey reporting that they have not heard of HVD. This is why an awareness day dedicated to heart valve disease is so important.

Learn more about valve disease, the Awareness Day Campaign, and how you can join the movement at www.ValveDiseaseDay.org.



HOW YOU CAN HELP SPREAD THE WORD (CONT.)

Put out a Press Release

Consider putting out a press release the week before Heart Valve Disease Awareness Day on February 22nd to announce your partnership and efforts to raise awareness about heart valve disease (HVD). If you can, emphasize the impact of HVD on your community, share quotes and stories from patients and experts if you have them, make the case for why more awareness is critical, provide action steps for people or loved ones who are at risk for HVD or who have a diagnosis, and focus on what your organization is doing to support the Awareness Day Campaign.

Write an Op-Ed

Op-eds are a great way to raise the visibility of both the issue and your organization. Include any personal stories or expert perspectives that will help bring HVD, and the impact of low awareness about the disease, to life. Include a call-to-action that directs readers to the Awareness Day Campaign if possible.

Post Flyers

Print out the Awareness Day Campaign flyer and post it at your events and in places where seniors and their caregivers gather—health fairs, senior centers, libraries, coffee shops, etc.

CAMPAIGN MATERIALS



Graphic Elements

The Valve Disease Awareness Day logo is the official logo of the Awareness Day campaign, and is designed to be used by partners in their awareness day outreach. We hope that you will use it on your website, in social media, on handouts, and more.

Please note that:

- The logo should not be altered in any way.
- It should not be associated with any brand logos or used for commercial purposes.
- The logo should only be used for education and advocacy that follows the spirit of the campaign as outlined in this document.
- The name National Heart Valve Disease Awareness Day and the supporting logo are registered trademarks of the Alliance for Aging Research, and can only be used as outlined in this document.
- The materials produced for this campaign are also subject to copyright laws and terms of use.



Web Badge

Feature the web badge on your website and link it to www.ValveDiseaseDay.org.



Social Media Graphics

These ready-to-use graphics can easily be used in social media channels like Facebook and Twitter. Make sure that the images link to www.ValveDiseaseDay.org.

HEART VALVE DISEASE IN THE U.S.

Heart valve disease (HVD) involves damage to one or more of the heart's valves. This can reduce blood flow and lead to major complications—including death.



HEART VALVE DISEASE (HVD) CAN BE SERIOUS AND DEADLY

➤ MORE THAN...
...5 MILLION PEOPLE IN THE UNITED STATES ARE ESTIMATED TO HAVE HVD¹

...ONE IN EIGHT PEOPLE AGE 75+ ARE ESTIMATED TO HAVE MODERATE TO SEVERE HVD²

...22,000 AMERICANS DIE FROM HVD EVERY YEAR³

¹Nemoto et al. 2006, Burden of Valvular Heart Diseases: A Population-Based Study. *Lancet* 368(9542):1005-11
²Idib
³Go et al. 2013, Heart Disease and Stroke Statistics—2013 Update. *Circ* 127(1)



HEART VALVE DISEASE IN THE U.S.

AWARENESS OF HEART VALVE DISEASE IS LOW

60% OF PEOPLE HAVE HEARD OF HVD...
BUT ONLY **9%** KNOW A GREAT DEAL ABOUT IT



AND **15%** KNOW SOMEWHAT ABOUT IT

OF THOSE 65+, **30%** KNOW NOTHING ABOUT HVD



Based on results from a national omnibus survey of 2,018 adults via randomly selected landlines and cell phones conducted by the Alliance for Aging Research and Beiden Russonello Strategists



HEART VALVE DISEASE IN THE U.S.

IN THOSE WITH HEART VALVE DISEASE

➤ MORE THAN...
...2/3 KNEW NOTHING ABOUT HVD PRIOR TO THEIR DIAGNOSIS

60% WERE DIAGNOSED AFTER A REGULAR CHECK-UP OR VISIT FOR SOMETHING ELSE



HVD CAN USUALLY BE SUCCESSFULLY TREATED IN PATIENTS OF ALL AGES

RESPONDENTS WHO HAVE RECEIVED TREATMENT EXPRESS **HIGH LEVELS OF SATISFACTION** WITH IT



Stats from an online survey of more than 400 individuals diagnosed with heart valve disease, conducted by the Alliance for Aging Research and Beiden Russonello Strategists



CAMPAIGN MATERIALS (CONT.)

Infographic

This infographic lays out the burden of valve disease, the awareness rates from recent public opinion polls, and information on the Awareness Day Campaign. The infographic and individual statistics and visuals can be downloaded and used in outreach. The individual statistics are especially well-suited for social media.

Flyer

We encourage you to print out copies of the flyer and post them anywhere that seniors in your community gather. Hard copies can also be ordered by contacting the Alliance for Aging Research at info@agingresearch.org.

HEART VALVE DISEASE IN THE U.S.

Heart valve disease (HVD) involves damage to one or more of the heart's valves. This can reduce blood flow and lead to major complications—including death.



Close to **50%** of people have never heard of heart valve disease—and only **1 in 4** know somewhat or a great deal about the disease.



Yet more than **5 million** people in the U.S. are estimated to have HVD, and more than **22,000** Americans die from HVD every year.




1 in 8 people age 75+ are estimated to have **moderate to severe** HVD.

Symptoms can be difficult to detect and are too often dismissed as a "normal" part of aging. **This makes raising awareness about the disease critical.**



February 22nd is National Heart Valve Disease Awareness Day—a day where national groups, advocates, and patients come together to reduce the number of people who lose their independence and their lives to heart valve disease.

Follow the campaign on Twitter
@ValveDiseaseDay with #ValveDiseaseDay



Learn more about the disease and the awareness day, and find out how to become a partner at ValveDiseaseDay.org.



HEART VALVE DISEASE IN THE U.S.

Heart valve disease (HVD) involves damage to one or more of the heart's valves. This can reduce blood flow and lead to major complications—including death.



HEART VALVE DISEASE CAN BE SERIOUS AND DEADLY

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IN THOSE WITH HEART VALVE DISEASE

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Stats from an online survey of more than 400 individuals diagnosed with heart valve disease, conducted by the Alliance for Aging Research and Belden Russonello Strategists

HVD CAN USUALLY BE SUCCESSFULLY TREATED IN PATIENTS OF ALL AGES

RESPONDENTS WHO HAVE RECEIVED TREATMENT EXPRESS HIGH LEVELS OF SATISFACTION WITH IT




Learn more about a public awareness campaign to increase recognition of symptoms, improve detection and treatment, and ultimately save lives



ValveDiseaseDay.org



For more information about heart valve disease visit: LivingWithValveDisease.org





HOSTING AN EVENT

Consider partnering with other organizations to host an event. This is a great way to raise awareness about heart valve disease, mobilize advocates, and connect to your related programs and resources. Use the campaign tools above to spread the word.

CREATING PARTNERSHIPS

There is strength in numbers so for all of the above outreach consider joining forces with other organizations, companies, etc. who are interested in raising awareness about heart valve disease and its burden. This could include other health advocates, medical and health professional societies, hospitals and healthcare systems, caregivers, public health organizations, cardiovascular disease advocacy groups, leadership groups of at-risk populations, local universities and research institutions, community and civic groups, local and national government agencies, and health insurance companies.

Check the [list of current partners](#) to see if they would like to join forces for a specific effort or event.

Encourage all of your partners to amplify your message, join the campaign, co-host an event, and more.

TRACKING SUCCESS

However you are able to help spread the word, please share your outreach and successes with us so we can highlight it on www.ValveDiseaseDay.org, use it as examples for other partners looking for inspiration, and track the success of this Awareness Day Campaign.

Please let us know the:

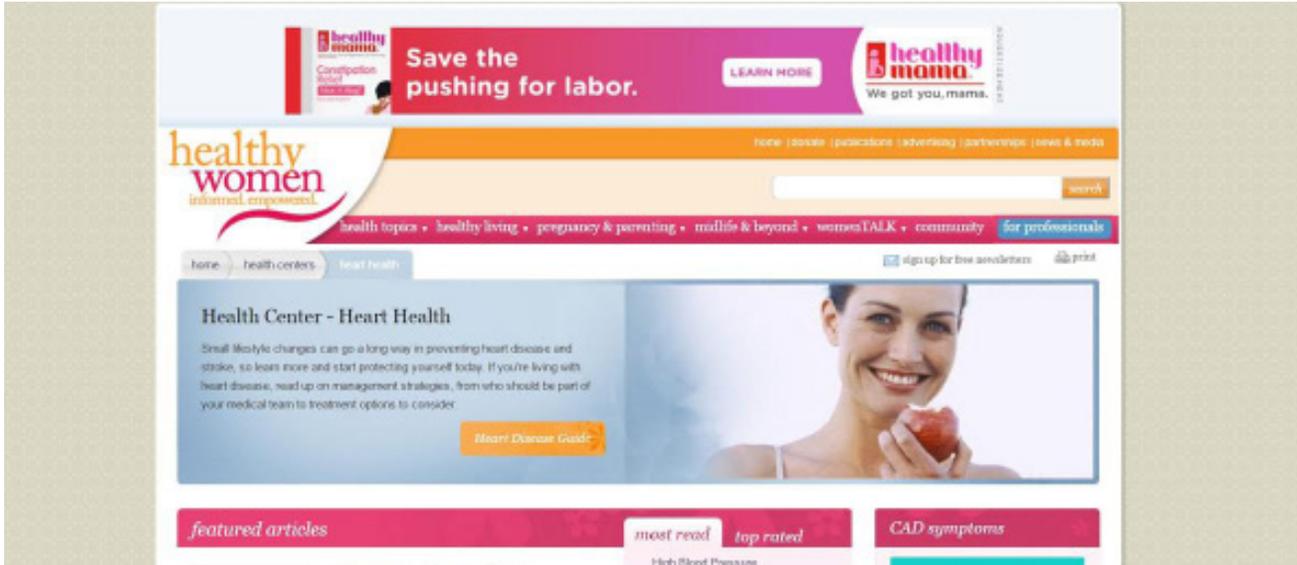
- Channels of communication that you used;
- What you said and when;
- Campaign assets that you used like graphics and logos; and
- Any engagement you were able to measure like views, downloads, likes, shares, etc.

ADDITIONAL RESOURCES



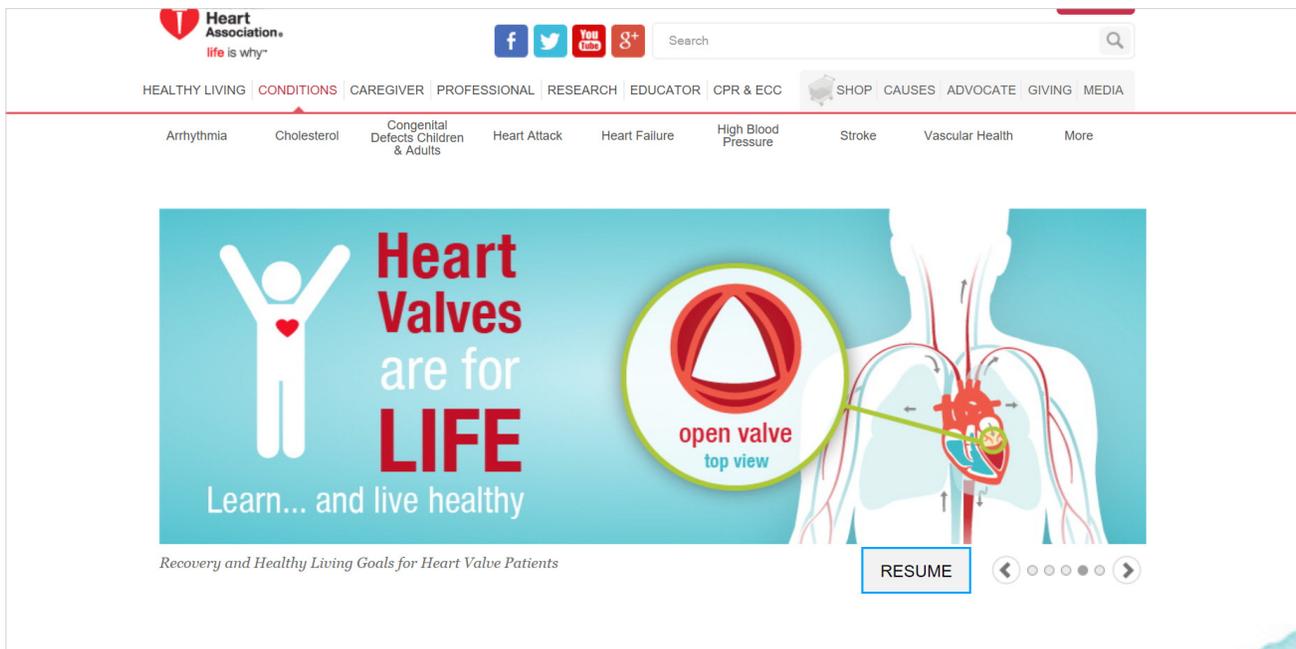
HealthyWomen.org

The nation's leading independent health information source for women, Health Women's heart health page shares information on managing heart disease.



Heart.org

The American Heart Association is the nation's oldest and largest voluntary organization that is dedicated to fighting heart disease and stroke. Its overall mission is to provide individuals with public health educational tools and help them understand the importance of healthy living.



CAMPAIGN MATERIALS (CONT.)

Heart-Valve-Surgery.com

Created by Adam Pick, a heart valve patient, HeartValveSurgery.com features the largest heart valve disease-centered community where patients can share their experiences and learn from others, discover top-of-the line heart valve surgeons and hospitals, and gain knowledge through Adam's personal blog.

The screenshot shows the website's header with the logo, a search bar, and navigation links: Home, Community, Learning Center, Surgeon Finder, Heart Hospitals, Videos, Adam's Blog, Book, and About Us. The main content area features a headline: "Let Adam Pick Guide You Through Heart Valve Surgery". Below this is a welcome message: "Welcome to the #1 doctor recommended website for patients created by Adam Pick, a heart valve patient." and a sub-headline: "Get prepared, learn what to expect, avoid stress, and enhance recovery using resources designed for you." There are three buttons: "Meet Patients Like You", "Learn About Your Valves", and "Find Surgeons & Hospitals". To the right is a photo of Adam Pick with a patient in a hospital bed, accompanied by a badge that says "OVER 5 MILLION WEBSITE VISITS" and a quote: "I created this website to help you or your loved one!" -- Adam Pick, Patient, Author & Website Founder. A link "Watch Adam's Story" is also present.

HeartValveVoice-us.org

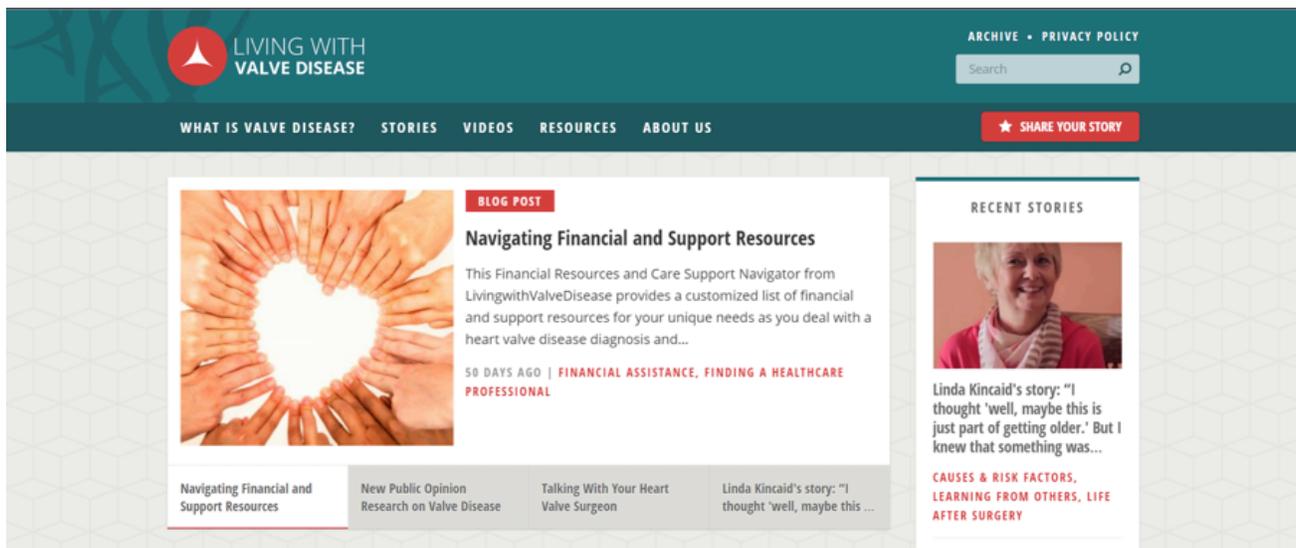
This patient advocacy, nonprofit organization provides patients with a unique voice to improve health for people living with HVD by advocating for early detection, meaningful support, and timely access to appropriate treatment for all people affected by HVD.

The screenshot shows the website's header with the logo and the tagline: "Giving a voice to people with heart valve disease." The navigation menu includes: Home, About Us, What Is Heart Valve Disease?, News, Resources, and Add Your Voice. The main content area features a large illustration of a heart and text: "A healthy heart beats up to 100,000 times a day and pumps about 2,000 gallons of blood." and "Valve disease affects how well the heart works. Aortic and mitral valve diseases are the most common." A red button at the bottom says "CLICK HERE TO LEARN MORE ABOUT HEART VALVE DISEASE".

CAMPAIGN MATERIALS (CONT.)

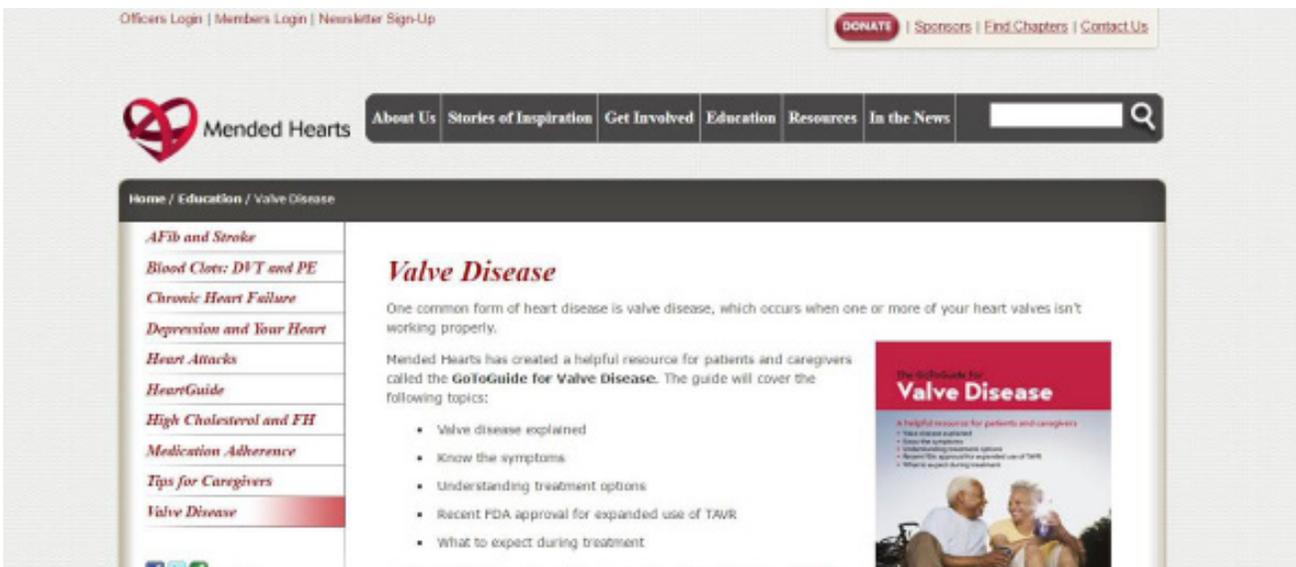
LivingWithValveDisease.org

This website from the Alliance for Aging Research, provides curated resources from leading organizations on the types of valve disease, symptoms, causes & risk factors, diagnosis, finding a healthcare professional, heart basics, treatment options, preparing for surgery, recovering from surgery, life after surgery, and patient & healthcare professional communication. It also shares stories from other patients who have been diagnosed with valve disease, and a financial and support navigator that provides a customized list of resources for the unique needs of heart valve disease patients.



MendedHearts.org

This national and community-based non-profit offers the gift of hope to heart patients, and through its GoToGuide for Valve Disease, provides important information for patients and caregivers on the basics of valve disease, treatment options, what to expect during treatment, and more.



PARTNERS



Adult Congenital Heart Association
Alliance for Aging Research
American Association for Cardiovascular and
Pulmonary Rehabilitation
American Geriatrics Society
American Heart Association/ American
Stroke Association
Association of Black Cardiologists, Inc.
Healthy Women
Heart Valve Voice
HeartValveSurgery.com
Lipoprotein(a) Foundation
Men's Health Network
Mended Hearts
National Forum for Heart Disease and
Stroke Prevention
Nurse Practitioners in Women's Health
OWL- The Voice of Women 40+
Preventive Cardiovascular Nurses Association
Society for Cardiovascular Angiography &
Interventions

CONTACT

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