

NATIONAL HEART VALVE DISEASE AWARENESS DAY

Outreach Toolkit



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 at least 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 40 percent of people have never heard of heart valve disease, and only one in four know somewhat or a great deal about the disease.



Around **40%** of people know nothing about heart valve disease—and only **1 in 4** 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 launched National Heart Valve Disease Awareness Day—beginning annually on February 22, 2017. Recognized by the U.S. Department of Health and Human Services on its National Health Observances Calendar, and by a Congressional Resolution in the 114th U.S. Congress, the goal of National Heart Valve Disease Awareness Day (Valve Disease Day) on February 22 is to increase recognition of the specific risks and symptoms of heart valve disease, improve detection and treatment, and ultimately save lives.



The Alliance for Aging Research is joined by 28 well-respected national groups including cardiovascular and aging non-profits, professional societies, and health systems. 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 <u>www.ValveDiseaseDay.org</u> as you plan your outreach, educate your audiences, and encourage others to join.

Susan Rocki

Susan Peschin, MHS President and CEO Alliance for Aging Research



ABOUT VALVE DISEASE



At least five million Americans have 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 the four valves can have regurgitation or stenosis (sometimes both), although the aortic and mitral valves are most likely to be damaged.

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 HVD 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, infection, or radiation to the chest. Fortunately, HVD can usually be successfully treated with valve repair or replacement in patients of all ages.

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, 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 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 HVD 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 <u>www.agingresearch.org/heartvalvediseasesurveys</u>.

BACKGROUND INFORMATION

WHAT IS HEART 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 HVD 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 Campaign are:

- Older adults and others at risk of HVD
- 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, e-mail Lindsay Clarke, vice president of health programs at the Alliance for Aging Research at <u>lclarke@agingresearch.org</u>, 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 <u>lclarke@agingresearch.org</u>. You should also visit the campaign website at <u>www.ValveDiseaseDay.org</u> 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:

- At least five million Americans have heart valve disease (HVD).
- HVD involves damage 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 most common types of HVD, have a survival rate as low as 50% at 2 years and 20% at 5 years—without valve repair or 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 40% 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 <u>www.ValveDiseaseDay.org</u> and share with your audiences.
- Use your social media to spread the word.
 Follow on Twitter <u>@ValveDiseaseDay</u> and use #ValveDiseaseDay in your tweets.

POST TO YOUR WEBSITE

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

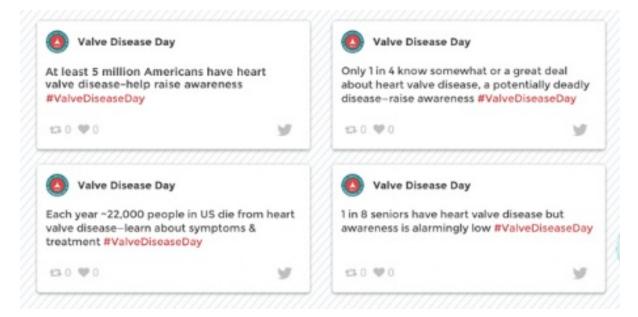
TWEET

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 <u>www.ValveDiseaseDay.org</u>,
- 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.

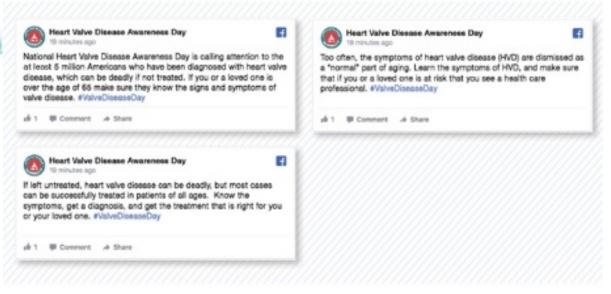
Sample Tweets



POST TO FACEBOOK

- Be sure to like us at @ValveDiseaseDay 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 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 logos, web badges, other campaign materials, and more. Please make sure that whatever you feature links to www.ValveDiseaseDay.org.

Sample Article/Post

This February 22, [insert your organization] is proud to participate in National Heart Valve Disease Awareness Day. At least five million Americans have heart valve disease (HVD); which can cause heart attacks, arrhythmia, congestive heart failure, and other disease—significantly impacting quality of life and even leading to death. Every year, an estimated 22,000 people in the U.S. die from HVD.

HVD can be there at birth, or develop due to damage from previous heart conditions or infections. Age is the greatest risk factor for heart valve disease—one out of every eight people ages 75+ have it.

Symptoms of HVD can include shortness of breath; weakness or dizziness; pain, tightness, or discomfort in the chest; fainting or feeling faint; fatigue; rapid or irregular heartbeat; lightheadedness; decrease in exercise capacity; and swollen abdomen or ankles and feet. However, people with HVD do not always have symptoms, even if their disease is severe. For these people, a heart murmur is an important clue.

The good news is that most HVD can be successfully treated with valve repair or replacement in patients of all ages. Unfortunately, awareness of heart valve disease is alarmingly low, with 40 percent of respondents to a national survey reporting that they have not heard of heart valve disease. This is why an awareness day dedicated to HVD is so important.

Learn more about HVD, the Awareness Day Campaign, and how you can join the movement at <u>www.ValveDiseaseDay.org</u>.

PUT OUT A PRESS RELEASE

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

For a sample press release, please go to <u>www.ValveDiseaseDay.org/campaign</u>.

WRITE A LETTER TO THE EDITOR OR OP-ED

Op-eds are a great way to raise visibility of the issue. Include patient stories and expert perspectives that will help bring heart valve disease, and the impact of low awareness about the disease, to life. Include a call-to-action that directs readers to the Awareness Day Campaign.

Examples of Valve Disease Day op-eds are here and here.

POST FLYERS & DISTRIBUTE POSTCARDS

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. The postcards can also be printed and distributed with your audiences.

CAMPAIGN MATERIALS

All graphic elements can be found at <u>www.ValveDiseaseDay.org/campaign</u>.

GRAPHIC ELEMENTS

The National Heart 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. The "Listen to Your Heart" logo represents the 2018 awareness day theme and is also designed for partner outreach. We hope that you will use both on your website, in social media, on event materials, in press outreach, and more.



Please note that:

- The logos should not be altered in any way.
- They should not be associated with any brand logos or used for commercial purposes, but you may use with your hospital or organizational logo for Awareness Day Campaign purposes.
- The logos 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 logos 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

You can feature the web badges on your website and link to it on <u>www.ValveDiseaseDay.org</u>.

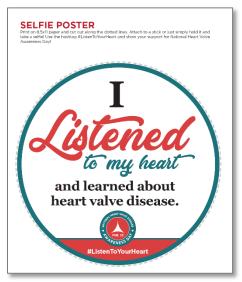


CLICK TO VISIT National Heart Valve Disease Awareness Day Website



SELFIE BOOTH

Create a "selfie booth" by printing this sign and encouraging your audiences at in-person gatherings to take a selfie showing that they *Listened to their Heart.* Encourage them to post the selfie on social media—using the hashtag #ValveDiseaseDay. With their permission, you could also take a picture of them with the selfie booth sign and share it through your social media, newsletters, and more.



POSTCARD

Print and share the National Heart Valve Disease Awareness Day postcard with your audiences.

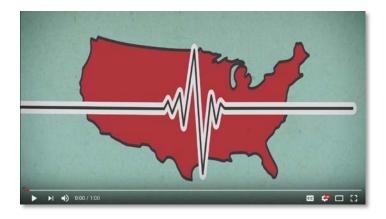




VIDEO

Embed or download the Valve Disease Day video and share it on your website, Facebook, waiting room TVs, patient tablets, and more.

30-second PSA on YouTube 60-second PSA on YouTube 30-second PSA on Vimeo (for download and use off-line) 60-second PSA on Vimeo (for download and use off-line)



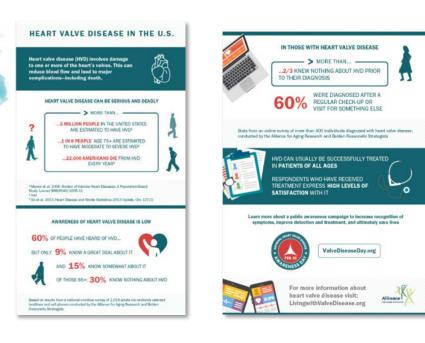
SOCIAL MEDIA GRAPHICS

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



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.



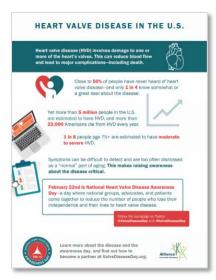
FACEBOOK FRAME

Change your profile picture for Facebook for National Heart Valve Disease Awareness Day, and encourage your followers to do the same.



FLYER

We encourage you to print out copies of the flyer and post them anywhere that seniors in your community gather.



HOST AN EVENT IN FEBRUARY 2018

You can observe National Heart Valve Disease Awareness Day on February 22, or on another day during American Heart Month in February. Whether you already have events planned, or are looking for new opportunities to engage the community and press, National Heart Valve Disease Awareness Day can easily be incorporated into your plans. See the Community/Press Event Toolkit for details, graphics, and more at <u>www.ValveDiseaseDay.org/campaign</u>.

CREATING PARTNERSHIPS

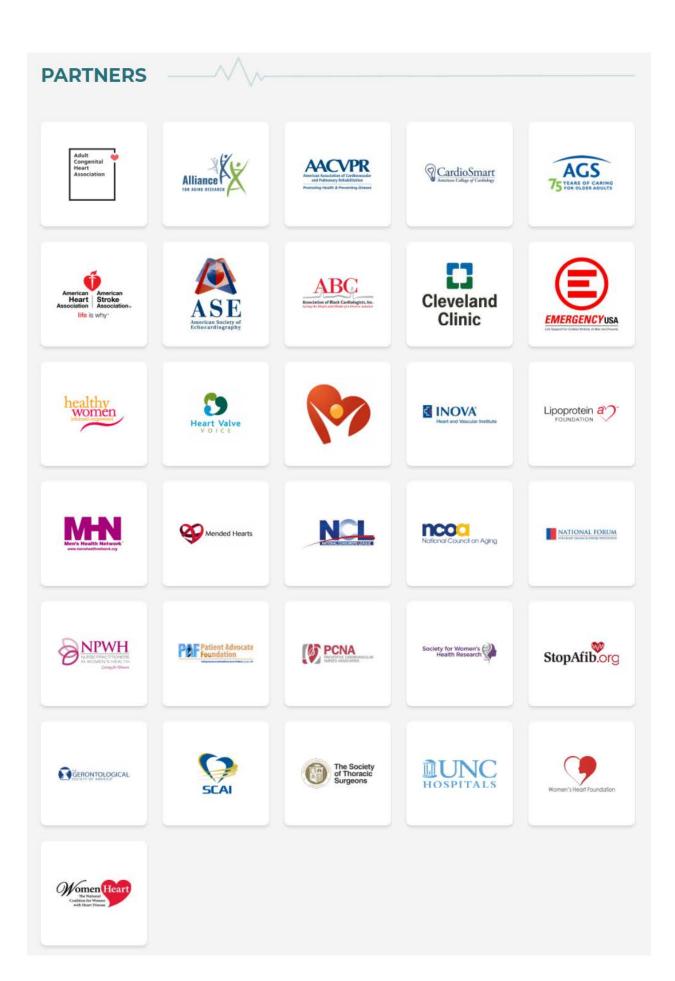
There's strength in numbers so for the above outreach consider joining forces with other organizations, companies, etc. who are interested in raising awareness about heart valve disease and its burden. This could include other health advocates, medical and health professional societies, hospitals and 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 <u>list of current partners</u> to see if they would like to join forces for a specific effort or event. Encourage your partners to amplify your message, join the campaign, co-host an event, and more.

TRACKING SUCCESS

Please share your outreach and successes with us so we can highlight them on <u>www.ValveDiseaseDay.org</u>, use them 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;
- The messages you used, how, and when;
- Campaign assets that you used, such as the graphics and logos; and
- Any engagement you were able to measure such as page views, downloads, likes, shares, etc.





Lindsay Clarke, Vice President of Health Programs Alliance for Aging Research 202-293-2856 Iclarke@agingresearch.org