

Thank you for contacting your Members of Congress to 1) share your perspective on heart valve disease and 2) ask them to do a few simple things. Your outreach will go a long way toward raising awareness of this all-too-common condition. National Heart Valve Disease Awareness Day takes place annually on February 22nd. February is also National Heart Month, so we encourage you to reach out throughout the month, not just on the one day.

Keep in mind that your personal story is your most important tool. Whether you are a patient, family caregiver, healthcare professional, health educator, or just someone who cares about the issue, always start your outreach message with 1) where you are from (city and state) and 2) a short (1-3 sentence) story about why this issue matters to you. Below you will find talking points in a few different formats to help with the second part of your outreach, which are your "asks," the actions that you would like your Members of Congress to take.

Calling and emailing are the quickest ways to get in touch with your Members of Congress' offices, and if you like social media, tweeting is also effective. To find phone numbers, direct email links, and Twitter handles to offices for your 2 U.S. Senators and 1 U.S. Representative, visit <u>www.usa.gov/elected-officials</u>. If you call, you will likely speak with a person who works for your Member of Congress. They are prepared to write down your concerns and convey them, so don't worry if you don't get to speak with your Senators or Representative directly.

If you need additional information or help, either before or after you do this outreach, feel free to contact us at info@valvediseaseday.org.

PHONE CALL SCRIPT

Hello. My name is _____ and I am calling today to talk about heart valve disease with Senator/Representative _____. I live in [city, state] and I care about this issue because...

More than five million Americans have been diagnosed with heart valve disease and 22,000 Americans die from HVD each year. Despite how many people it affects, a recent survey found that around three in four Americans know little to nothing about the disease.

This February 22nd, during national heart month, advocates, organizations, and individuals are teaming up to raise awareness about heart valve disease, and I'm calling to ask you to do a few things to demonstrate your support.

- 1) [THIS ASK IS JUST FOR YOUR ONE REPRESENTATIVE] Please consider cosponsoring a resolution recognizing the day that was introduced by Representative Tony Cárdenas in the 114th Congress and will be reintroduced in the 115th Congress the week of February 13th.
- 2) Help make valve disease information available to your constituents. People with valve disease may suffer from a number of symptoms including a heart murmur, shortness of breath, weakness, dizziness, tightness in the chest, and fatigue. These symptoms can often be dismissed by patients and their providers as a "normal" consequence of aging, leading patients to unknowingly forego necessary treatment to stop the disease progression and prevent heart attacks, arrhythmias, congestive heart failure, other heart diseases, stroke or death. Helpful resources are available for you to share at www.ValveDiseaseDay.org.
- 3) Lastly, we ask that you join the heart valve disease conversation on Twitter. On February 22, 2017 at 4:00 PM ET, experts from the Alliance for Aging Research and other Heart Valve Disease Awareness day partner organizations, will host a Twitter chat. Follow us @ValveDiseaseDay and tweet during the chat using #ValveDiseaseDay.

I am happy to send additional information on any of this, please just let me know where to e-mail it and to whose attention.

Thank you for your time.

SAMPLE LETTER/E-MAIL

Dear Member Name/Staffer,

My name is X and I live in [city, state]. I'm reaching out to you today to share information with you regarding heart valve disease (HVD) and to request Representative/Senator X's assistance in raising awareness of heart valve disease in support of National Heart Valve Disease Awareness Day on February 22, 2017. I care about this issue because...

I hope that Representative/Senator X will take action by:

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Today, more than five million Americans have been diagnosed with HVD and 22,000 people die from HVD each year. Despite its prevalence, public awareness of the disease remains relatively low. HVD involves damage to one or more of the heart's valves, which disrupts blood flow by not opening and 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.

Beginning in 2017, February 22 will serve as an annual day of observance for HVD dedicated to raising awareness about the disease and increasing recognition of the associated risk factors and symptoms—to ultimately save lives and prevent unnecessary deaths. The U.S. Department of Health and Human Services (HHS) listed this new awareness day and an accompanying toolkit on its National Health Observances Calendar (NHO) at <u>Healthfinder.gov</u>. National Heart Valve Disease Awareness Day is sponsored by 30 national organizations representing patients, providers, and older adults.

Included below is a toolkit with sample materials that advocates are sharing with offices to demonstrate ways in which you can participate in supporting this day of awareness. More great information can be found at the links provided under the Additional Resources section below.

Cosponsor a Resolution Supporting Heart Valve Disease Awareness Day

Rep. Tony Cárdenas is once again introducing a resolution in support of National Heart Valve Disease Awareness Day to raise the profile of the disease. The resolution will be the same language as <u>H. Res. 941</u> from the 114th Congress. As a show of support and to raise awareness the Awareness Day partners appreciate your cosponsorship of this resolution. The resolution will be introduced the week of February 13th. (Note that this outreach is specific to your Representative and should be removed for Senate outreach. Also, if you are reaching out after February 13th, you should check to see if your Representative was a cosponsor and instead of the above, send a thank you for their support.)

Promote and Share Information about Heart Valve Disease

Three out of four Americans know little to nothing about heart valve disease. Given this low awareness about a potentially debilitating and deadly disease, I am hoping that you can help get the word out by sharing information about the disease and Heart Valve Disease Awareness Day. Here are some ways to get the word out and some sample language that I hope will help (of course this should be customized and personalized for your office).

Sample Text for Website/Press Release/Facebook:

National Heart Valve Disease Awareness Day

February 22, 2017

More than five million Americans have been diagnosed with heart valve disease (HVD), a disease that kills 22,000 Americans each year – almost 60 people each day. Despite its prevalence, around three in four Americans know little to nothing about the disease.

Today, in observance of National Heart Valve Disease Awareness Day, we are/I am spreading the word to educate people on the risk factors for valve disease, the signs and symptoms they should learn, and the importance of early detection and treatment in reducing HVD related deaths.

When detected early and properly cared for, HVD has a treatment success rate of 97%. However, when left untreated, HVD can lead to heart attacks, arrhythmias, congestive heart failure, other heart diseases, stroke, or even death. In some cases, patients who have experienced symptoms of valve disease and who have not yet sought treatment may have a survival rate of just 50% at 2 years and 20% at 5 years.

This makes detection and treatment critical, so be sure to take these steps to make sure you and your loved ones are **Listening to Your Hearts**:

• Listen to Your Body

Always pay attention to your body and if something changes or just doesn't feel right, go see your doctor.

Shortness of breath, weakness, dizziness, tightness in the chest, and fatigue can all be symptoms of HVD. However, these symptoms may be dismissed by both patients and doctors as simply being "normal" signs of aging. If you or someone you know—especially if over the age of 65—experience these symptoms, consult your doctor as they could be signs of HVD.

• Know the Risk Factors of Valve Disease

While HVD affects people of all ages, it becomes more common with age and one in eight Americans over the age of 75 have HVD. Previous heart conditions also put you at heightened risk, as can abnormalities there from birth, and infection that affects the heart.

• Get Your Heart Checked Regularly

Most HVD can be detected by any type of healthcare professional by listening to the heart with a stethoscope, since there is typically a murmur, or irregular heart sound. Further testing may be necessary to confirm a diagnosis, but getting your heart listened to regularly will help detect HVD.

• Spread the Word and Help Raise Awareness

Help spread the word by joining the campaign at <u>www.ValveDiseaseDay.org</u> and teaching your loved ones about this potentially debilitating and deadly disease.

Sample Tweets:

- Each year, 22,000 Americans die from HVD, a relatively unknown disease with a treatment success rate of 97% for those who know about it. <u>www.ValveDiseaseDay.org/</u> #ValveDiseaseDay
- Spread the word HVD kills 22,000 Americans annually, almost 60 individuals per day. Learn the risk factors & symptoms. <u>www.ValveDiseaseDay.org/</u> #ValveDiseaseDay
- Five million Americans diagnosed with HVD, a sometimes deadly disease, and 40% of Americans have never heard of it. www.ValveDiseaseDay.org/ #ValveDiseaseDay
- Have you heard of heart valve disease? Do you or someone you know experience the symptoms? Look it up @ <u>www.ValveDiseaseDay.org/</u> #ValveDiseaseDay
- Listen to your heart and get it checked regularly so you can detect and treat heart valve disease #ValveDiseaseDay

Additional Resources:

- Awareness Day postcards are available for any offices that would like to distribute them to constituents. Contact Kelsey Allcorn at <u>kallcorn@agingresearch.org</u> to get free copies.
- A toolkit containing **webpage** and **social media graphics** along with additional campaign and press related materials is available <u>here</u>.
- For additional National Heart Valve Disease Awareness Day materials and information on HVD, visit: <u>www.ValveDiseaseDay.org</u>
- A full list of organizations partnered in support of the day is available here: <u>http://www.ValveDiseaseDay.org/partners/</u>

SUGGESTED TWEETS TO SEND YOUR REPRESENTATIVE/SENATORS

FOR ANYTIME OF YEAR

- Each year, 22,000 Americans die from HVD, a relatively unknown disease. Please help spread the word to your constituents. <u>www.ValveDiseaseDay.org/</u> #ValveDiseaseDay
- Help spread the word heart valve disease kills 22,000 Americans annually. Learn the risk factors & symptoms. <u>www.ValveDiseaseDay.org/</u> #ValveDiseaseDay

UNTIL FEBRUARY 13, 2017

• Please support heart valve disease awareness by cosponsoring Rep. Cárdenas's reintroduction of <u>H. Res.</u> <u>941 www.ValveDiseaseDay.org</u> #ValveDiseaseDay

UNTIL FEBRUARY 22, 2017

• Please join the HVD conversation on Twitter for a Twitter chat Feb 22 at 4 PM ET. #ValveDiseaseDay. www.ValveDiseaseDay.org

BECOME A CAMPAIGN PARTNER

Thank you again for your interest in reaching out to your Members of Congress. To officially join the advocates, public health educators, health care professionals, patients, and consumers across the nation who are dedicated to raising awareness about heart valve disease, visit <u>www.ValveDiseaseDay.org</u> and fill-out the **Stay Informed** form at the bottom of this page: <u>http://www.valvediseaseday.org/campaign/</u>.