

How Advocacy Impacts Vasculitis Patients & Caregivers



What is Advocacy & Why Does it Matter?

- Advocacy is the act of speaking up to help ensure that patients have access to the care, treatments, and support they need to live healthier, fuller lives.
- For people living with vasculitis, advocacy is often already part of everyday life. When you call an insurance company about a coverage denial, contact a doctor's office to secure a timely appointment, appeal a medication authorization, or work with a pharmacy to access treatment, you are advocating!
- As a patient or caregiver, you understand firsthand the challenges of delayed diagnoses, navigating complex healthcare systems, managing chronic and often rare conditions, and accessing specialized treatments. That experience carries tremendous power!
- VF encourages patients and caregivers to engage with Members of Congress (and state officials) to share personal stories and to put a human face on healthcare policy to amplify patient voices and help drive meaningful change.

How to Advocate – Engaging Members of Congress

While engaging with Members of Congress (or state officials) may seem intimidating at first, or if you worry you don't have enough information on a topic or how to answer a question they may pose to you, here are some guidelines to help make it easy!

- Find out who are your two U.S. Senators (in the U.S. Senate) & your U.S. Representative (in the U.S. House of Representatives) in Congress in Washington, DC.
- Call the Capitol Hill switchboard number and ask to be connected to their offices:
 - ▶ Here is the number: 202-224-3121.



Find Your
Representative



Ballotpedia.org



USA.gov

- When you reach your Senators/Representative:
 - ▶ Let them know you are a constituent (from their state or city).
 - ▶ Ask for the email of the Health Care Legislative Assistant (L.A.), the person who handles health care issues.
- Calls
 - ▶ Ask to talk with the Health L.A. and simply share your personal story and help that person understand more about vasculitis and why we need more treatments and cures.
- Emails
 - ▶ Email the health staffer, and they will share that with their boss, the Senator or Representative.

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How to Advocate – Engaging Members of Congress (continued)

- Letters – Mail a letter to your Senators and Representative, and be sure to copy the Health L.A.
 - U.S. Senate:
The Honorable (Full Name)
United States Senate
Washington, DC 20510
Cc: (Name of Health staffer)
 - U.S. House of Representatives:
The Honorable (Full Name)
U.S. House of Representatives
Washington D.C. 20515
Cc: (Name of Health staffer)

TIPS:

- Prepare Talking Points on your Personal Story & Educate yourself on the policy issue you want to share.**
 - Checkout VF's Advocacy & Health Policy website tab for information on legislation and VF's specific asks of Members of Congress.
 - The VF website also has information about upcoming events and webinars, opportunities for you to share your thoughts and comments on various topics, and information from coalitions to help you better understand issues.
- Know the name & role of you are meeting with:**
 - Make sure you are meeting with the Health L.A. of your US Senators and Representative as they will care about health care issues & advise their boss.
- Explain who you are. Tell YOUR story.**
 - This is the heart of your advocacy! Explain how vasculitis has affected your life and that of your family. Tell them why and how their involvement with legislation, or reform, or programs relates to you and your vasculitis journey.
 - VF will give you talking points for specific issues.
- Clearly state the reason for your call, letter or meeting.**
 - Get to the point if you want them to vote YES or NO to a specific bill or if you just want to share concerns with an issue.
- Explain why your concern may also be important to others.**
 - Tell them why you believe they should care and why you think they can help. Tell them why it will matter to their constituents or to their supporters, or the economy of the community.
- Be Brief.**
 - Avoid getting into political partisan discussions or sharing other issues unrelated to your primary objective.
- Don't hesitate to ask questions.**
 - Ask about anything you don't understand. Ask how they can help, what they need you to do, or who else you should contact.
- Follow up.**
 - Always send a thank you note or email, but, most importantly, keep the conversation going. Stay in touch, remind them of your request or concern, send any updates.

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