Artist's Statement: This piece explores the complex entanglement of identity, vulnerability, and the human condition. It is about embracing imperfections—both on the canvas and in life. ***Being One With Mess*** *by vasculitis patient Dr. Shanali Perera explains there is 'no calm without chaos' and 'no chaos without calm' in her everyday. It was exhibited at the Women in Art Biennale in London last September, was shortlisted for the Artist of Europe Award in Florence December 2024 and will be video displayed along with other artists at the exhibit in Florence from Jan 15 through Feb 1.*

VASCULITIS
FOUNDATION®

Early Diagnosis · Better Treatment · Improving Lives

ANNUAL REPORT

2023 & 2024

DEAR FRIENDS AND SUPPORTERS

A WORD FROM OUR EXECUTIVE DIRECTOR

Welcome to our 2023-2024 Vasculitis Foundation Annual Report, which provides an overview of our programs, exciting successes, and new initiatives launched over the past two years. Even as we look back in this report, we look forward, always, as we plan the pathways for meeting the vasculitis community's needs.

Throughout this report we share the voices of people living with the disease, care partners, investigators and physicians. We offer details on our research, fellows and our efforts with the VPPRN.

We brought back the VF's in-person regional patient conferences in 2023 and continued them throughout 2024. In 2024 we added Spanish speaking interpreters to some of our meetings. The reaction and attendance to the return of our regional conferences was overwhelming. Patients, care partners and doctors renewed connections and developed new connections through education, sharing stories, meaningful conversations and probing questions. We also continued to expand our printed and online educational materials and now offer information in English, Spanish and Portuguese.

In August 2023 we distributed our What Keeps You Up at Night Survey to 4,000 people and were excited when more than 1,000 people responded within a week. From the survey responses, we learned that the number one concern our community has is access to care. To address this concern, in July 2024 we convened the Vasculitis Summit and gathered a group of about 50 health care providers, patient advocates, patients and family members to explore as many different perspectives as possible as we consider the barriers to care for patients and examine ways to overcome them.

The survey and the summit were vital to helping us better understand the needs of the vasculitis community. The two initiatives led us to commit to revamping and expanding our "Find a Doctor" tool on our website. We also will enhance and build our educational programming to fit patients' needs. The VF will continue to investigate more expansive programs for patients to help them navigate the resources and care they need.

Centering our discussion around the barriers to care will lead us forward in 2025 as we work to bring down those barriers to ensure every patient has access to quality vasculitis treatment. . As always, we continue to invest in the programs and initiatives that will help those living with vasculitis now, as well as those yet to come. Thank you for your support, your partnership, and your care.

- JOYCE A. KULLMAN

WHO WE ARE

We are you. We are people living with vasculitis, care partners, friends, family, physicians, and researchers advocating for early diagnosis, better treatments, and improving quality of life for our community members.

The Vasculitis Foundation's trademark of three rings represents the small, medium and large vessels which are affected by different types of vasculitis. Although each type of vasculitis is different, they all share some common characteristics. The Vasculitis Foundation is committed to improving the lives of everyone living with vasculitis.

OUR MISSION

Building upon the collective strength of the vasculitis community, the Foundation supports, inspires and empowers individuals with vasculitis and their families through a wide range of education, research, clinical, and awareness initiatives.

OUR VISION

The Vasculitis Foundation is the leading organization in the world dedicated to diagnosing, treating, and curing all forms of vasculitis.

OUR HISTORY

The Vasculitis Foundation was founded in 1986 by Marilyn Sampson, RN as the Wegener's Granulomatosis Support Group after Marilyn was diagnosed with Granulomatosis with Polyangiitis (formerly called Wegener's). In just a few decades, the Vasculitis Foundation has grown to encompass support, education, and research for the entire family of vasculitides.

In a welcome letter to new support group members Marilyn wrote, "Believe me when I say you and your family are not alone. And, believe me when I tell you there is hope! We do not have all the answers; but we want to give you hope, and we want you to fight with everything you have. We want you to believe and know you can lick this disease and survive."

Marilyn's words still ring true today. We don't have all the answers, but there is hope, and you are not alone.

BOARD OF DIRECTORS & VF STAFF

Board members serve as champions for the work of the VF. Directors are our Ambassadors and are responsible for sharing the mission of the VF throughout their personal network, the vasculitis community and the community at large. The board is comprised of people living vasculitis, care partners, vasculitis medical experts and investigators. They all commit their time and talents to the VF, as well as their financial support.

2023

BOARD OF DIRECTORS

Kevin Byram, MD, President

Sara Baird Amodio, MSW, EdD, Past- President

Elizabeth J. Brant, MD, Secretary

Don Nagle, Treasurer

Brian Goldman, VP Resource Development

Jocelyn Ashford

Caz Cazanov

Suzanne DePaolis

Anisha Dua, MD, MPH

Victor James

Jason Wadler

2024 BOARD ADDITIONS:

William C. (Kriss) Andrews

Noelle Creamer

Vimal Derebail, MD

Dahlia Mak

Sebastian E. Sattui, MD

2024-2025

VASCULITIS FOUNDATION STAFF

Joyce Kullman
Executive Director

Emily Sybrant
Vice President of Development

Beth Westbrook
Sr. Director of Strategic Partnerships

Toni Jefferies
Sr. Director of Communications

Emily Girdwood
Development Manager

Jennifer Wages
Education Program Manager

Jodi Hall
Patient Support Coordinator

Dana DeMoulin
Support Group Facilitator

Jennifer Price
Accounting Administrator

Jennifer Sullivan
Database Administrator

Ed Becker
VF Media Producer

QUALITY CARE

Vasculitis can affect any organ system and requires a multi-disciplinary team approach to diagnosis and treatment. With that in mind, the VF is dedicated to bringing together healthcare providers from different disciplines and areas of expertise. We not only listen to healthcare professionals, we listen to the patients to make sure we understand their needs and wishes. Patients need a community who understand the seriousness of the disease, the complications, the consequences of misdiagnosis and late diagnosis. The VF has partnered with the VPPRN to support ongoing vasculitis research. In 2023 the VF sent out a survey asking patients "what keeps them up at night". The answer: access to care. That led the VF to host an inaugural summit in 2024 and a V-RED town hall later that year to consider ways we can better serve our VF community. Those conversations have helped the VF set its goals for the future.

SUMMIT

In July 2024, the VF brought nearly 50 stakeholders from across the country to a meeting in Nashville, Tennessee. Stakeholders included vasculitis medical experts, advanced practice providers, patients, family members, patient advocates and industry representatives. The group included a range of specialists who treat the rare disease – rheumatologists, nephrologists, and pulmonologists. The meeting led the VF board to set four strategic anchors for 2025 and beyond.

The VF will work with its partners to explore:

- Expanding patient awareness of vasculitis, the VF and its resources.
- Increasing health care provider awareness and knowledge of vasculitis and of the VF's resources.
- Increasing the workforce and building a pipeline of health care providers with knowledge of vasculitis.
- Making sure everyone has access to care by connecting patients and their providers with experts.

Fellowships and Young Investigators

The Vasculitis Foundation supports the advancement of vasculitis research through fellowships and grants for young investigators. The VCRC-VF Fellowships provide advanced training for physician researchers, increasing the number of specialists equipped to diagnose and treat vasculitis. Since their inception, these fellowships have supported over two dozen physicians.

The Young Investigator grants fund innovative research to improve vasculitis treatment and management.

FELLOWSHIPS & YOUNG INVESTIGATORS

Fellowships:

In 2023 and 2024 the VF helped support 7 physician researchers through the VCRC-VF Fellowships. The fellowships provide advanced training in vasculitis. Each year new fellows are added; increasing the number of highly qualified physicians and researchers who can diagnose, treat, and improve the lives of people living with vasculitis. Over just a few short years more than two dozen physician researchers have received these fellowships.

Young Investigators:

These researchers are discovering ways to more effectively treat and manage vasculitis.

In 2024 **Cecilia Barnini**, **MD,** was awarded a grant to focus on Kidney involvement in ANCA-associated vasculitis.
In 2023 two researchers won grants.

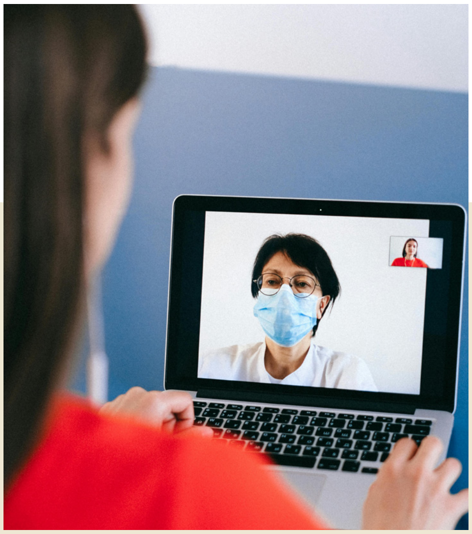
Pei-Yu Chen, a Senior Research Scientist, Cardiovascular Medicine, at Yale University, won a two-year grant for her study, "siRNA Nanoparticle Targeting Endothelial Cell TGFβ Signaling Against ANCA-Vasculitis." The aim is to reveal how large a role TGFβ-mediated EndMT plays as drivers of TGFβ vasculitis. By targeting TGFβ and reducing TGFβ-mediated EndMT, the hope is to decrease blood vessel inflammation, slow down vasculitis progression, and restore vascular normalcy.

David Massicotte-Azarniouch, MD, Assistant Professor at the University of Ottawa and Associate Scientist at the Ottawa Hospital Research Institute in Ontario, Canada, received a two-year grant to study, "Steroid Minimization in ANCA-Associated Vasculitis For Safe Effective Treatment – the SAFE-T project."

VPPRN & FEATURED STUDIES

Vasculitis Patient Powered Research Network

VPPRN



Our vision is to improve the health of vasculitis patients by developing early-diagnosis methods, discovering more effective treatments, and finding cures. We invite patients with vasculitis, caregivers and parents/guardians of patients with vasculitis to come together to learn more about symptoms, share experiences, and to become a part of a research network to improve lives.

You can help us find answers for the questions most important to you and other patients living with vasculitis. This registry gathers essential information, including key diagnostic data, disease extent and progression, medications and treatments, demographic details, healthcare providers involved in care and patient-reported outcomes.

V-SNIFF

Goal: To learn more about how symptoms in the nose and sinuses impact patients living with vasculitis and relate to relapse or flare of vasculitis.

VCRC-VPPRN EGPA Registry

Goal: To conduct clinical research and clinical trials to learn more about EGPA with the goal of improving management and treatment of this complex disease.

Vasculitis Pregnancy Registry (VPREG)

Goal: The primary objective of this study is to understand pregnancy characteristics and outcomes among women with vasculitis.

VascStrength (VascStrong)

Goal: To describe the prevalence of common health conditions associated with frailty in patients living with vasculitis and describe its impact on health-related quality of life and clinical outcomes.

VascSkin

Goal: To better understand the impact of vasculitis-related skin involvement on patients' quality of life.

V-RED

Vasculitis: Recognizing Early Diagnosis (V-RED)

Karen Hirsch, a retired VF board president, initiated the V-RED Award (Vasculitis – Recognizing Excellence in Diagnostics) in 2014 to honor providers instrumental in the early and accurate diagnosis of vasculitis. Over the past decade, the VF has celebrated more than 350 healthcare providers worldwide for their contributions.

Enhancing Education and Training

- Collaborate with vasculitis experts to create a visiting professor program offering Continuing Medical Education opportunities through local hospital visits and webinars for healthcare providers.
- Establish a patient speakers bureau to participate in vasculitis grand rounds at local and regional hospitals.
- Expand fellowship opportunities with short-term rotations at vasculitis centers to build a dedicated network of knowledgeable providers.

Improving Access to Expertise

- Update the VF's "Find a Doctor" search engine to help HCPs more easily locate physicians who treat vasculitis and provide referrals or request consultations.
- Develop an online case study portal and expert panel to assist providers in managing complex cases and improving disease awareness.

Building Collaborative Networks

- Work with the network of rare disease organizations to identify additional channels for sharing educational materials and accessing experts.
- Create printed resources, including a quarterly newsletter and educational brochures, to inform HCPs about vasculitis, treatments, and best practices.

Expanding Awareness and Interest

- Increase the number of residents and fellows participating in programs addressing vasculitis, such as rheumatology, pulmonology, dermatology and nephrology.
- Incorporate vasculitis-focused sessions in regional and national academic events and conferences, such as those hosted by the National Kidney Foundation, the American College of Rheumatology and the American Thoracic Society to help raise awareness.
- Support informal HCP networks by expanding digital discussion boards for posts about complex cases and building a hub-and-spoke model for expert consultations in local communities.

V-RED AWARDS AND TOWN HALL

V-RED Town Hall

On December 7, 2024, the Vasculitis Foundation hosted a town hall meeting to foster dialogue among nearly two dozen physicians, healthcare experts, patients, family members, and corporate partners. The purpose of the meeting was to explore ways to advance vasculitis education within the medical community, improve high-quality care delivery, and enhance early and accurate diagnoses.

V-RED Awards

One of the greatest challenges a patient with vasculitis faces is receiving a definitive diagnosis. Patients can spend months or even years seeking a diagnosis, or worse, living with a misdiagnosis and ineffective treatment. The V-RED award honors healthcare professionals around the world, who make the diagnosis of vasculitis.

Karen Hirsch created the award program after her son, Michael, was diagnosed with granulomatosis with polyangiitis (GPA) in 2011. For 11 years, the VF has called upon patients from around the globe to nominate a medical professional they want to recognize for making a critical, early diagnosis of vasculitis. The V-Red Award is an honor the VF does not take lightly. The foundation believes these diagnoses are critical. These healthcare providers are curious, persistent, caring, compassionate and dedicated to the best interest of their patients. Their diagnoses are preserving the health of patients and even saving lives.

V-RED Awardees

2023 *V-RED Winner*
Prof. Dr. med. Bernd Turowski
Department of Diagnostic and
Interventional Radiology
Düsseldorf University Hospital

2023 *V-RED Winner*
Lindo Terry Spencer Jr., MD
Pediatric Pulmonologist
Providence, Rhode Island

2024 *V-RED First Place Winner*
Sally Mangum, DO
Foundation Health Partners
Internal Medicine and Senior
Care Clinic
Fairbanks, Alaska

THE VF WEBSITE

The Vasculitis Foundation launched a new website in March 2024. The website enables visitors to choose their path to navigate through the website (patient, care partner, parent, physician, researcher and by specific disease.

Early Diagnosis. Better Treatment. Improving Lives.

Welcome to Vasculitis Foundation!

To get you where you want to go quickly, answer the questions below.

I am a: Person w/ Vasculitis

Vasculitis Type: -- select an option --

About Vasculitis

Vasculitis is a general term that refers to inflammation of the blood vessels. It is used to describe a family of nearly 20 rare diseases, characterized by

The VF website receives over 375,000 visitors and 2.1 million visits annually from around the world. While most users are from the U.S., thousands also visit from Australia, Canada, Germany, India, Ireland, Italy, New Zealand, Philippines, Poland, and the United Kingdom. Visitors seek information on vasculitis types, treatments, educational resources, and ways to connect with others. The website offers downloadable materials, with more than 1,000 visitors ordering educational resources directly. It also links to a video library with over 50 medical webinars, including four roundtables from 2024 and 26 webinars from 2023.

New additions in 2024 include the Public Policy and Corporate Council pages. The Public Policy page informs the vasculitis community about legislation and policies that promote equitable access to diagnoses and treatments. The Corporate Council consists of industry leaders committed to advancing vasculitis research and care, bridging gaps between scientific innovation and patient needs.

The website also helps the vasculitis community connect by offering information on support groups, regional in-person patient conferences, webinars, and other upcoming events. The site also features community blogs where members share personal experiences and inspiration.

Additionally, visitors can participate in vasculitis research through the VPPRN, signing up for studies and collaborating with researchers by sharing symptoms, treatments, and experiences to advance medical understanding.

FISCAL YEARS 2023 & 2024

STATEMENTS OF FINANCIAL POSITION

REVENUE	2023	2024
Contributions and Grants	$2,888,211	$2,740,183
Symposium/Conference Fees/Fees for Service*	$258,826	$75,230
Interest and Dividends	$86,328	$141,293
Investment Gain (Loss) Net of Fees	$40,761	$206,837
Total Revenue	**$3,274,126**	**$3,163,543**

EXPENSES	2023	2024
Patient Support, Awareness, and Research	$740,603	$1,497,690
Administrative	$326,394	$344,747
Fundraising	$190,910	$225,654
Total Expenses	**$1,257,907**	**$2,068,091**

NET ASSETS	2023	2024
Change in Net Assets	$2,016,219	$1,095,452
Net Assets - Beginning of Year	$2,429,552	$4,445,741
Net Assets - End of Year	**$4,445,741**	**$5,541,193**

*In 2023, higher registration fees were collected for a 3-day international symposium

CONFERENCES

Our one-day, in-person vasculitis conferences feature engaging and informative presentations from medical experts and researchers as well as chances to connect with other people who, like you, get what it is like to live with vasculitis or love someone with vasculitis. Whether newly diagnosed with vasculitis or you have been navigating a vasculitis diagnosis for years, you will find opportunities to learn, engage, and be empowered.

The VF brought together 500+ patients and family members through five regional conferences and one international patient education conference in 2024. More than 50 medical experts presented over 30 hours of educational content through these conferences. Every conference allows VF community members the opportunity to meet and mingle with the experts.

In 2023 and 2024 the VF chose regional locations close to the patient community to offer access to a wide number of people. We also offer scholarships to attend so no one has to miss out because of conference fees.

2023 Conferences

Los Angeles, California
Boston, Massachusetts
Ann Arbor, Michigan

2024 Conferences

Austin, Texas
Barcelona, Spain
Chapel Hill, NC
Cleveland, Ohio
Scottsdale, Arizona
Washington, DC

2023 Symposium

The 2023 VF International Vasculitis Symposium brought together over 330 attendees from across the globe, representing 16 types of vasculitis and uniting voices from countries including Australia, Canada, Chile, Japan, Kenya, Pakistan, and the United States. With insights from more than 35 renowned medical experts, the event delivered a wide-ranging program of topics tailored to the pressing needs of the vasculitis community. A special highlight was the empowering Pediatric Conference, offering vital support for families. Attendees praised the symposium as “absolutely THE BEST,” citing its hopeful, informative sessions and unique opportunities for connection. Engaging social events like trivia and Family Feud added laughter and bonding to the weekend. The event was a testament to VF’s commitment to education, support, and community.

VASCULITIS AWARENESS MONTH & COMMUNITY HEROES

Ordinary people can become extraordinary in their journey through life — and this has never been truer than for people living with vasculitis. Look around and you'll see that there are everyday heroes living among us. They prove you are not alone. You are surrounded by an amazing, supportive, community of people who "get it." They know what it is like to live with vasculitis—the treatment side effects, the anxiety of the unknowns, and the indescribable fatigue—but also, the joy in small victories, the increased resilience, and the appreciation for each new day.

Every year, during Vasculitis Awareness Month our global VF community comes together to highlight those heroes while revealing this invisible disease to the greater community. We have 31 days of information, inspiration, fun and fellowship. In 2023 and 2024 judges outside of the VF read the nominations and named nearly two dozen community heroes (12 in 2023 and 11 in 2024). Those selected shared their stories to shed light on what it's like to live with vasculitis in all of its various forms.

SUPPORT GROUPS

What We Do

The VF works with a licensed clinical social worker to act as a facilitator for its online support groups. We cap the groups at 15 patients to keep them small so that everyone has an opportunity to talk about what's going on in their lives. This is a chance for people to meet one another, decreasing isolation, feel connected and form a community of support.

The VF also supports a number of affiliated support groups. VF affiliated groups may meet either in-person or virtually and are run by volunteers from the vasculitis community.

Your Donations At Work

The VF is able to have a professional facilitator to lead support groups because of you! All VF support meetings provide a positive, supportive forum where participants can share their challenges, celebrate their achievements, and learn from others how to navigate this disease.

In 2023, we:

- Held 200+ virtual support group meetings
- Managed seven groups
- Hosted over 2,200 attendees
- Provided 250+ hours of support

In 2024, we:

- Began Teen Chat and Young Adult support groups
- Held 225+ virtual support group meetings
- Managed nine groups
- Hosted 3,506 attendees
- Provided 285+ hours of support

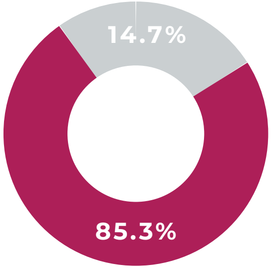
SOCIAL MEDIA

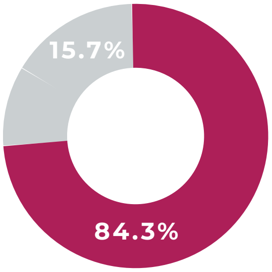
What We Do

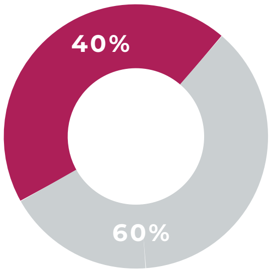
The VF has built a community of more than 5,000 followers on its social media channels. The VF's channels are all about creating community and informing followers about the VF's resources and opportunities. Daily posts include inspiring stories and photos from people living with vasculitis and their care partners, VF educational programs, support groups and messages of support. You can find our channels under Vasculitis Foundation on Facebook, Instagram and LinkedIn.

Your thoughts and stories inspire our work at the Vasculitis Foundation. You provide a steady stream of content by telling your stories and sharing inspiration for others. Your donations also allow us to gather those stories, provide educational materials to post and connect to other organizations who support the vasculitis community.

DIGITAL FOOTPRINT







FACEBOOK

DEMOGRAPHICS
Women - 85.3%
Men - 14.7%

INSTAGRAM

DEMOGRAPHICS
Women - 84.3%
Men - 15.7%

LINKEDIN

GROWTH
Impressions - 60%
Followers - 40%

TOP HASHTAGS

#vasculitisawareness
#vam2024
#vasculitiswarrior
#rarediseaseday

BRAND AWARENESS

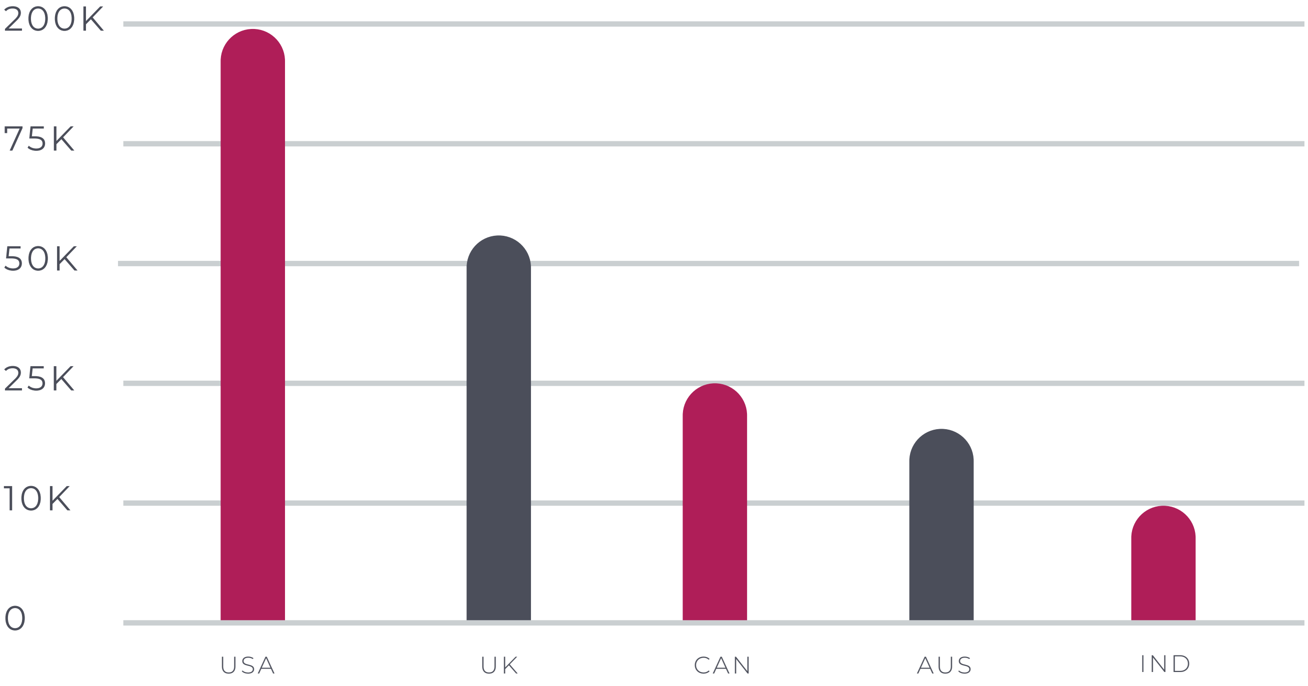
YoY INCREASES
Instagram - 466%
Facebook - 73.7%

FOLLOWERS

Facebook - 12,528
Instagram - 4,726
LinkedIn - 1,249

WEBSITE VISITORS

*In 2024 we created a new website, analytics are not available for the prior year.



PARTNERSHIPS

What We Do

The VF has long partnered with other organizations involved in supporting those living with a rare disease. Our closest partner in research is the Vasculitis Patient Powered Research Network (VPPRN), currently studying pregnancy, Sino-Nasal Indicators For Flares and EGPA.

Other organizations include National Organization of Rare Disorders (NORD), Childhood Arthritis and Rheumatology Research Alliance (CARRA), the Everylife Foundation, Inspire, BioNews, Autoimmune Association, and Steroids and Me (SAM). The VF also partners with the global community of organized groups advocating for patients with vasculitis. In addition, the VF supports vasculitis centers all across the United States, making patient referrals, connecting with doctors who offer programs at our conferences, lead webinars and provide the expertise for all of our educational materials. These partnerships offer the VF an unparalleled depth of resources for the vasculitis community.

CORPORATE PARTNERSHIPS

In 2023 and 2024, the VF partnered with Amgen, AstraZeneca, GSK and Novartis to help provide the vasculitis community with regional conferences, webinars, and educational materials. VF partners also support campaigns such as the V-RED Awards, Community Heroes, and the annual and spring appeals.

CORPORATE SPONSORSHIPS

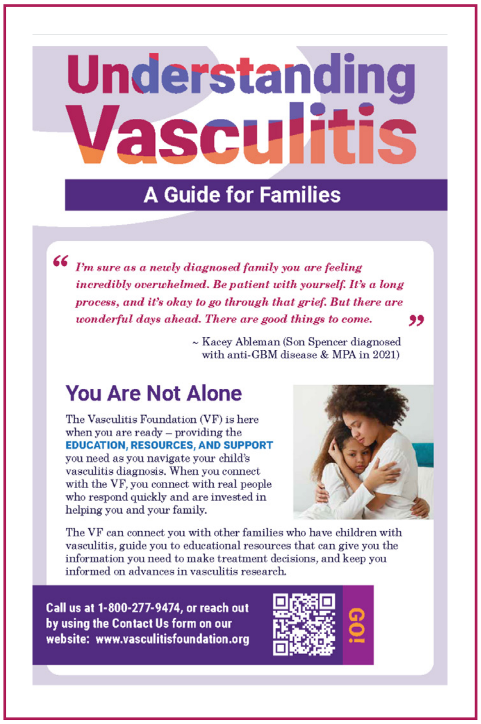
In 2024 the VF launched its new Corporate Council Program. The Vasculitis Foundation Corporate Council represents a carefully selected group of industry leaders who have made a significant commitment to advancing vasculitis care and research. These strategic partners work alongside the VF to bridge critical gaps between scientific innovation and patient needs, contributing their expertise and resources to improve outcomes for the entire vasculitis community.

Our Corporate Council members demonstrate their dedication through active participation in shaping educational programs, research initiatives, and public policy that directly impact patient care. Through structured collaboration with VF leadership and our Board of Directors, these partners help identify unmet needs, accelerate research progress, and develop innovative solutions for the challenges facing vasculitis patients.

Each Corporate Council member has pledged substantial support to the VF's mission of **"Early Diagnosis • Better Treatment • Improving Lives."** Their involvement extends beyond financial commitment to include sharing valuable industry insights, supporting educational initiatives, and helping advance patient advocacy efforts.

RESOURCES

PROVIDING VALUABLE RESOURCES FOR PATIENTS AND THEIR FAMILIES



Understanding Vasculitis

A Guide for Families

I'm sure as a newly diagnosed family you are feeling incredibly overwhelmed. Be patient with yourself. It's a long process, and it's okay to go through that grief. But there are wonderful days ahead. There are good things to come.

~ Kacey Ableman (Son Spencer diagnosed with anti-GBM disease & MPA in 2021)

You Are Not Alone

The Vasculitis Foundation (VF) is here when you are ready – providing the **EDUCATION, RESOURCES, AND SUPPORT** you need as you navigate your child's vasculitis diagnosis. When you connect with the VF, you connect with real people who respond quickly and are invested in helping you and your family.

The VF can connect you with other families who have children with vasculitis, guide you to educational resources that can give you the information you need to make treatment decisions, and keep you informed on advances in vasculitis research.

Call us at 1-800-277-9474, or reach out by using the Contact Us form on our website: www.vasculitisfoundation.org

GO!

What We Do

The VF offers free brochures to educate and raise awareness about vasculitis, covering symptoms, diagnosis, treatment, and disease management. These can be shared with patients, families, and healthcare professionals. The VF also provides a free Empowerment Kit for families of children diagnosed with vasculitis.

Patients can use the VF website's Find a Doctor tool to locate specialists, while the VF YouTube Channel features videos on treatments, mental health, doctor visits, organ impact, pregnancy, and lifestyle management with vasculitis. The VF YouTube Channel is searchable by a wide variety of topics.

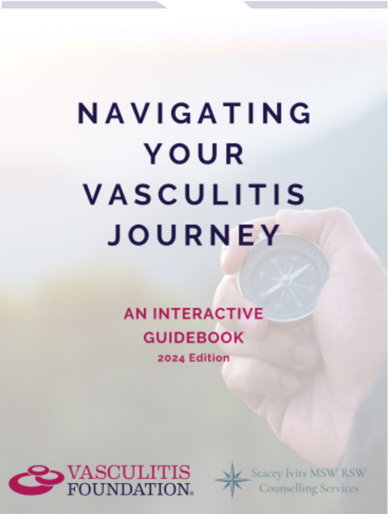
The VF could not provide these resources without your donations. For example, in 2024 the VF produced its video series on vasculitis entirely in Spanish, gaining more than 2,700 YouTube views.

Get Empowered!

People around the world trust us for reliable, life-saving resources and information.

VASCULITIS FOUNDATION.

Educate. Connect. Inspire.



NAVIGATING YOUR VASCULITIS JOURNEY

AN INTERACTIVE GUIDEBOOK

2024 Edition

VASCULITIS FOUNDATION.

Stacey Ivits MSW RSW Counselling Services

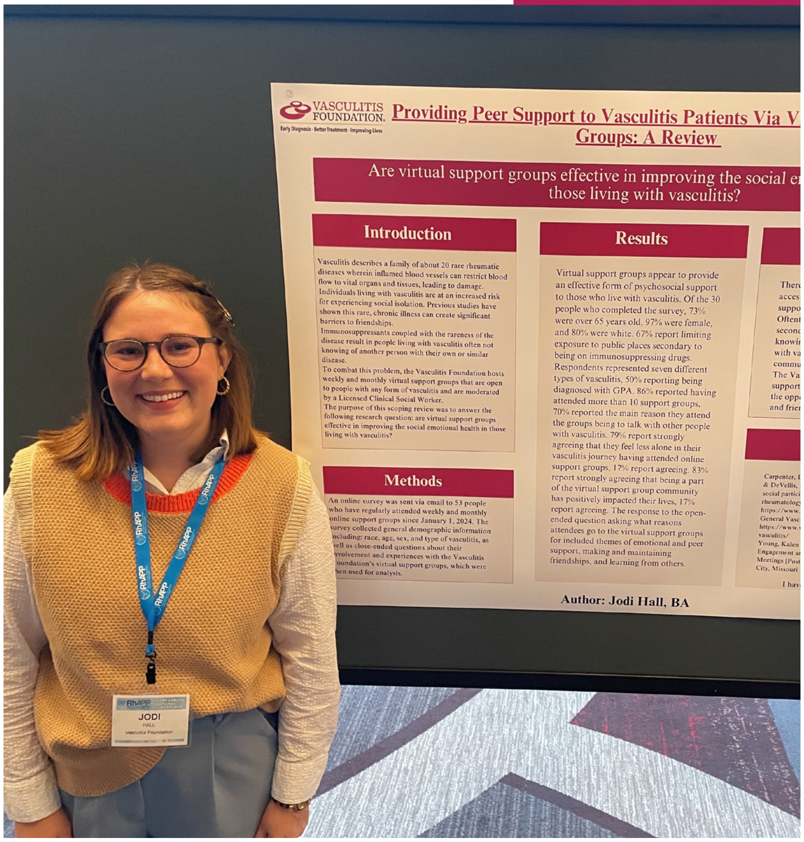
New Educational Resources in 2023-2024

- Vasculitis Foundation Resource Guide
- Understanding Vasculitis: A Guide for Families
- Understanding Vasculitis: Essential Information for Educators
- Expanded Navigating Your Vasculitis Journey Guidebook
- Patient-friendly plain language ACR/VF Vasculitis Treatment Recommendations
- Four disease specific brochures translated into Portuguese
- 19 disease specific brochures translated into Spanish
- VF Resource Guide

2024:

- Distributed hundreds of Vasculitis Foundation Resource Guides at four medical conferences and five patient conferences
- Distributed "What Vasculitis Patients Want Their Healthcare Providers to Know" flyers at six medical conferences
- 1,000+ visitors to the educational materials page on our website

EDUCATION



What We Do

Fundamental to our mission is educating and empowering the entire network of people impacted by vasculitis. Our trustworthy vasculitis information, which we provide free of charge for people around the globe, is backed by more than 150 medical and scientific advisors worldwide.

Research has shown that the more educated people are about their diagnosis the better their health outcomes. The VF is dedicated to making sure educational materials are available to our community, including patients, care partners, schools, healthcare professionals and policy makers.

Through your donations and sponsorships, the VF was able to create six new educational resources and guides, as well as translate four disease specific brochures into Portuguese and 19 brochures into Spanish. More than 1,000 visitors to the VF website ordered educational material. In 2023 and 2024, the VF produced new educational resources including:

- Vasculitis Foundation Resource Guide
- Understanding Vasculitis: A Guide for Families
- Understanding Vasculitis: Essential Information for Educators
- Expanded Navigating Your Vasculitis Journey Guidebook
- Patient-Friendly Plain Language ACR/VF Vasculitis Treatment Recommendations
- VF Resource Guide

The VF offered its six-week Navigating Your Vasculitis Journey course five times in 2023-2024. While class size is capped at 15, the VF saw more than 70 attendees complete the course.

“Thank you so much for the detailed explanations. I was diagnosed in 2019 and didn’t educate myself properly, I had a relapse in 2023 and am determined to understand Vasculitis MPA as much as possible. This was a huge help in my quest.”

WEBINARS & VIDEOS

What We Do

The VF’s Medical and Educational webinars provide vital information for the vasculitis community. This information is presented by vasculitis experts, physicians who treat vasculitis, and by health and wellness experts who can talk about diet, exercise and caring for your mental health.
There you will find videos covering a wide variety of topics such as:

- Vasculitis treatments
- Coping with the mental health impact of vasculitis
- Making the most of your doctor’s appointments
- The impact of vasculitis and vasculitis treatments on your heart, lungs, kidneys, sinuses, ears, eyes, bones, and skin
- Pregnancy and family planning with vasculitis
- Exercise and nutrition with vasculitis

The video library is searchable allowing you to find information on specific types of vasculitis.

We couldn’t do this without you! Your support has allowed us to have the tools we need to produce webinars, both live and recorded. Having staff, facilitators and experts produce these videos takes time and valuable resources. All of our information is vetted to make sure it is accurate.

Videos

The VF produces videos to educate, inspire, and support the vasculitis community. Beyond education, we focus on sharing the latest studies, treatments, and research, including a video series from the 2024 American College of Rheumatology Convergence. We also create videos about living well with vasculitis, covering topics like workplace accommodations. Through our Community Heroes series and annual appeal videos, we share powerful stories about early diagnosis, late diagnosis, and the challenges of living with vasculitis.

Your donations make these videos possible—helping us capture interviews, bring in experts, and deliver valuable content from around the country to everyone in the vasculitis community.

Metrics at a Glance:

2023:

- 26 live and recorded Medical Education webinars with more than 4,800 YouTube Views
- 10 Living Well with Vasculitis webinars with over 1,000 registrants and more than 11,000 views on YouTube

2024:

- Facilitated 20 Live Medical Education Webinars, with over 2,200 registrants
- Produced 28 Recorded Medical Education Webinars that have more than 6,500 YouTube views
- 14 Living Well with Vasculitis webinars, with over 1,300 registrants and more than 3,400 views on YouTube
- Produced first-ever 4 medical roundtable webinars bringing together doctors and patients

VF YouTube Channel

Subscribers: 9,190
2024: 1,625 new subscribers
2023: 1,446 new subscribers

2024: 160,336 total views
2023: 160,169 total views

Produced first-ever six video series on vasculitis entirely in Spanish which has more than 2,700 YouTube views

VASCULITIS FOUNDATION®

Early Diagnosis · Better Treatment · Improving Lives

We would love to hear from you!

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FROM YOUR FRIENDS AT THE VF,

THANK YOU!

OTHER WAYS TO CONNECT

Subscribe to our newsletter, read our blog, join a support group or attend events! Visit our website for more details.