



2021-2022 IMPACT REPORT
NAVIGATING
THE UNKNOWN
VASCULITIS FOUNDATION

Two Years of Impact

Dear Friends,

Welcome to our 2021-2022 Vasculitis Foundation Impact 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 delivering future goals in all our efforts.



As the worldwide COVID-19 pandemic stretched into its second year, we sought new ways to connect with people living with the disease, families, healthcare providers, and researchers. The collective strength and generosity of our community contributed to the expansion of educational programs, training a new generation of physicians, and supporting patient-centered research.

We introduced our Vasculitis Patient Heroes, people living with vasculitis who personify the courage and strength of our community. When faced with a diagnosis, these people living with vasculitis tapped into their superpowers of strength, hope, and resilience



◀ **Get inspired by watching videos of our Patient Heroes' stories on the VF website.**

We also announced our new initiative, Vasculitis – Building Outcomes, Leading Discoveries (V-BOLD), which combines four programs within the scope of VF support: Fellowships, Vasculitis Centers, Research, and the Vasculitis Patient-Powered Research Network (VPPRN).

Throughout this report we share the voices of our community living with the disease, care partners, investigators, and physicians.

As we move forward, we will 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.

Sincerely,

Joyce A. Kullman
Executive Director

2021 - 2022
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Educate & Inspire

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

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

Webinars & Podcasts: Empowering information at the click of a button

We offer wide-ranging live and on-demand webinars and podcast topics that address our community's unique and most-pressing concerns.

"I would absolutely recommend the VF's webinars to others living with vasculitis. They're helpful in two specific ways: 1) They make me feel that I'm not alone. 2) They give me information so I can make decisions about my own care and needs.

The VF is part of saving my life with their information and their caring."

— Priscilla, diagnosed with GPA in 2021



VF YouTube At a Glance (2021-22)

121 Webinars & Videos

7,020 Hours of On-Demand Educational Content

155,906 Views



A Diversity of Topics:

- Disease Spotlights
- Mental Health & Wellness
- Research
- Therapies and treatments





Finding Strength and Connection in Community



When you're living or loving someone with vasculitis, community matters. Community reminds us we're not alone, empowers us with new knowledge and resources, and deepens our sense of meaning. This is why we host weekly and monthly virtual support group meetings for everyone across our vasculitis networks, from people living with the disease, to parents, care partners, and family and friends.

"I could not encourage a newly diagnosed patient enough to try the VF's support groups. The value of these groups is enormous. I've made fast friends here."
— Cheryl, living with vasculitis

7 Groups

4,644 Attendees

396 Meetings

494 Hours of Support

2021-2022 combined data

PATIENT HEROES
LIVING WITH VASCULITIS
2021-2022

21 Patient Heroes

32 Honorable Mentions

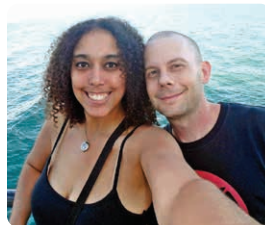
7 Types of Vasculitis

10 Countries

2021-2022 combined data

Patient Heroes

Ordinary people can become extraordinary in their journey through life — and our community of people living with vasculitis display these superpowers every day. Our 2021 and 2022 Patient Heroes were selected from over 50 nominations and come from as far away as Australia, England, Pakistan, Russia, as well as Canada and the US. They represent people living with Behcet's, EGPA, GPA, MPA, PAN, relapsing polychondritis, and Takayasu arteritis. Their stories educate, empower, and remind others they're not alone.



"It's not what happens to us that defines us, it's how we choose to respond to what happens to us that defines us."

— Erica Barram, 2021 Patient Hero



Get inspired by all of our Patient Heroes. Check out the **2022 Patient Hero videos**.



Conferences

The VF is dedicated to connecting people living with vasculitis and their families with the resources, expert knowledge, and empowering information they need. Our conferences are a chance for our community to learn, share stories, network, and ask their most pressing questions of the top vasculitis experts from across the globe.

We meet our community’s unique needs.

In 2021, the VF hosted its first-ever **Women’s Vasculitis Conference** and **Men’s Vasculitis Conference**.

2021 VASCULITIS VIRTUAL CONFERENCE SERIES

Vasculitis Women’s Conference

255 Attendees

8 Dynamic Speakers

Wide-ranging Topics

from the impact of vasculitis on reproductive health, to building a strong care team of specialists, to bone health and steroid therapy, to strategies for good mental health.

2021 VASCULITIS VIRTUAL CONFERENCE SERIES

Vasculitis Men’s Conference

75 Attendees

9 Expert Speakers

Wide-ranging Topics

Relevant discussion on fatherhood and vasculitis, fertility issues, exercise with an autoimmune disease, changes and challenges, and the importance of men’s participation in research.

“This vasculitis community is wonderful. It’s a relief to have people who truly understand what it’s like to live with this disease. They don’t need any explanation; they just get it.”

— **Kate, living with vasculitis**

Good Care Changes Lives



“I wish you knew vasculitis is an invisible disease. I wish more people and doctors were aware it exists.”

— Susan, living with vasculitis

Integral to our mission is ensuring people get the high-quality care they need, when they need it. This is why we’re committed to honoring healthcare providers who recognize the signs and make an early diagnosis. Early diagnoses save organs and save lives.

V-RED: Recognizing Excellence in Diagnostics



The VF’s Recognizing Excellence in Diagnostics (V-RED) award program has grown into a powerful awareness campaign that recognizes medical providers worldwide for making a critical, early diagnosis of vasculitis.



◀ **Celebrate our winners!**

See how they changed their patients’ lives.

“Since the beginning, Dr. Beegle has been dedicated to my care and has a bedside manner unmatched by other providers. His knowledge and understanding assure me that my care is in the right hands.”

— Mary Meliska, who nominated her pulmonary/critical care physician, Dr. Scott Beegle, in Albany, New York



Scott Beegle, MD



Vasculitis - Building Outcomes, Leading Discoveries (V-BOLD)

V·BOLD



Training Future Physicians and Researchers

There's a shortage of healthcare providers throughout the nation, which means appointment wait times are long and people living outside big cities often don't have access to the critical care they need, when they need it. This is why the VF is on a mission to expand access to timely, high-quality care by empowering fellows who choose to specialize in vasculitis care.

Fellowships

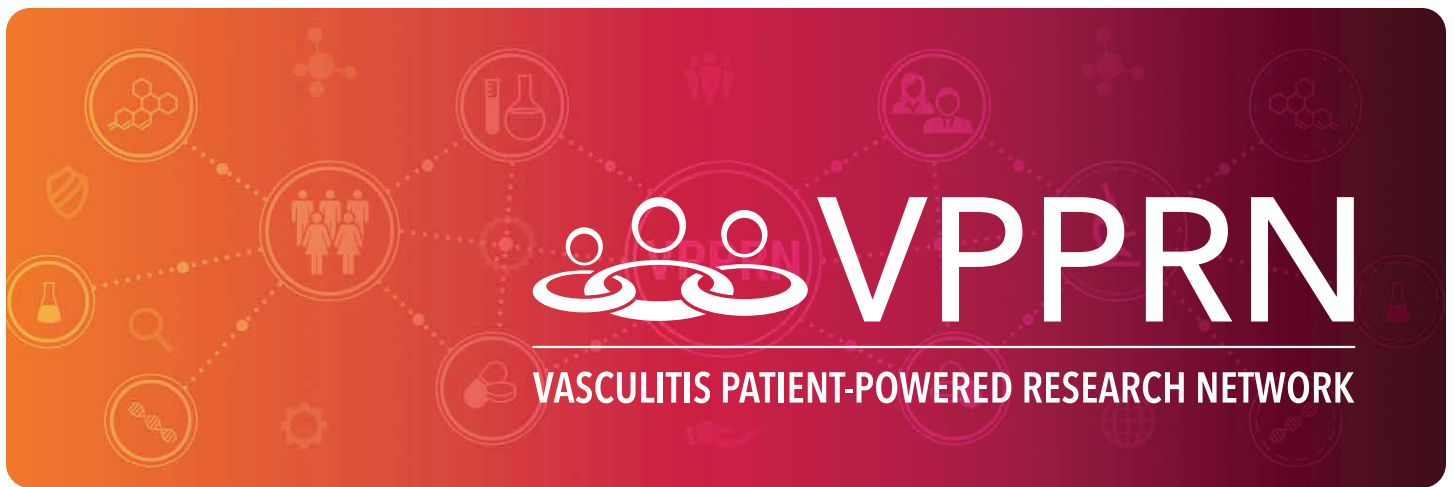
The VF partners with academic institutions and the Vasculitis Clinical Research Consortium (VCRC) to provide fellowships for physician-investigators who have a strong interest in vasculitis. This mentored training program emphasizes clinical, patient-oriented investigation.



“Vasculitis is an underserved area within pediatric rheumatology. Conducting research and clinical care for rare diseases is extremely challenging in children without collaboration and adequate exposure. I saw the opportunity to work with a community of investigators familiar with the methodology, data, and clinical landscape through the VCRC-VF Fellowship as invaluable.”

— **Jessica Bloom, MD, MSCS, 2021 VCRC-VF Fellow**

Dr. Bloom is the VF's first-ever pediatric fellow



When every part of the vasculitis network is empowered and interconnected, people living with vasculitis can thrive.

The VPPRN is the international research network of patients, scientists, clinicians, advocates, and family members who work to improve the health care and quality of life for people with vasculitis through high-level clinical research. Better research means better lives for those living everyday with vasculitis

Key studies include:

Journey to Diagnosis: Diagnostic delays in vasculitis and factors associated with time to diagnosis-This patient-driven study is a shining example of the power of patients collaborating with clinicians to conduct meaningful vasculitis research. Delays in receiving a diagnosis and high-quality care can increase damage to vital organs. This study sought to describe the diagnostic journey of patients with vasculitis and identify factors associated with time to diagnosis.

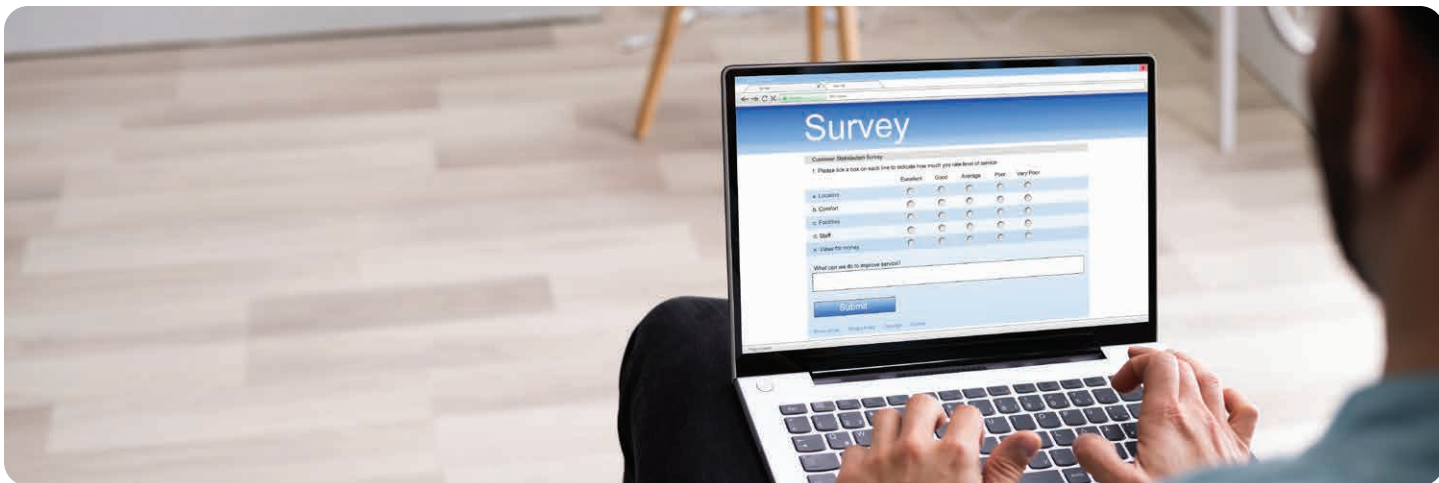


◀ You can **read the full study manuscript** in the *Orphanet Journal of Rare Diseases*.



OPTIONS: Options and Preferences for Treatments Informing recOmmendatiONS: This study is designed to address the question of how patients with ANCA-associated vasculitis (AAV) weigh the benefits and harms (such as end stage kidney disease) of plasma exchange (PLEX).

Key Studies continued on page 8.



Key studies continued:

ANCA-Associated Vasculitis Response Criteria Delphi: This survey is part of a larger project sponsored by the American College of Rheumatology and the European League Against Rheumatism to develop response criteria for ANCA-associated vasculitis (GPA and MPA) for use in clinical studies/trials.

Vasculitis Diagnostic Validation Study: The goal of the study is to evaluate the accuracy of patient-reported diagnoses of vasculitis in the VPPRN and to explore novel methods to provide a feasible approach to diagnostic confirmation for use in future patient-reported registries like the VPPRN.

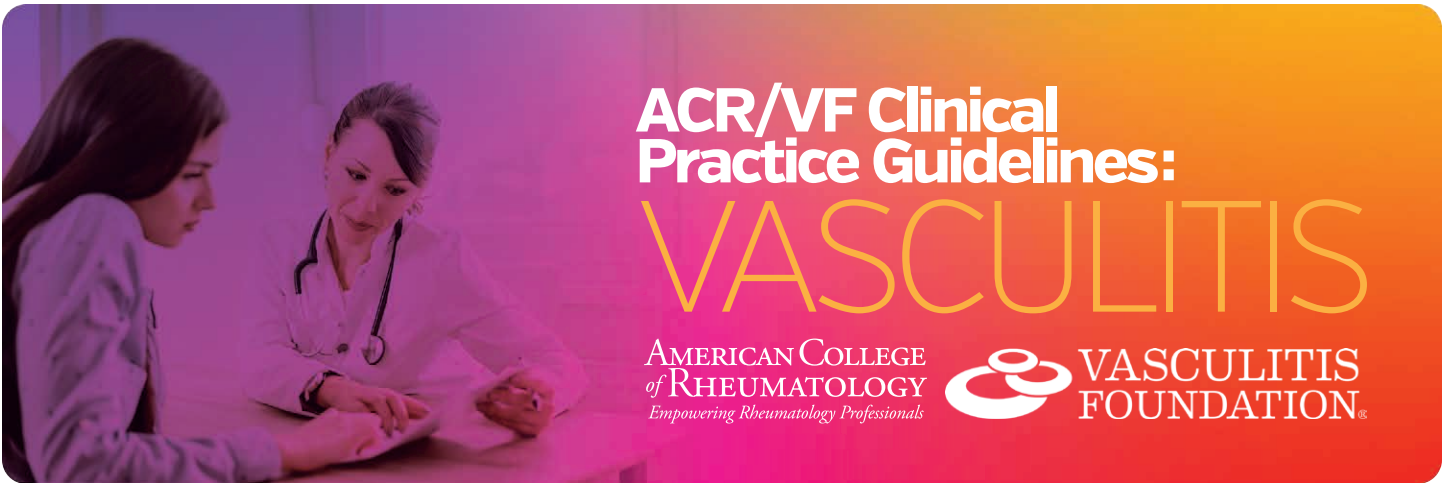
“Face vasculitis with courage, resolve, and hope, knowing that advances in medical science are occurring every day and the outlook for vasculitis patients has greatly improved over just a few years ago. Now more than ever, we are truly living with vasculitis.”

— Glenn, person with vasculitis



Vasculitis Pregnancy Registry (VPREG): Family Planning & Birth Control Information for Vasculitis Patients

We released a new handout designed for patients who have questions about family planning and birth control in order to meet the unique needs of women living with vasculitis. The handout, which was developed by Megan Clowse, MD, MPH, and Catherine Sims, MD, of Duke University Rheumatology and Immunology, offers a reference for patients to use when talking with their healthcare providers.



Raising Standards of Care

One of our most important successes of 2021 was the publication of the ACR/VF Treatment Guidelines for vasculitis. These recommendations provide guidance regarding the evaluation and management of patients, including diagnostic strategies, use of pharmacologic agents, and surgical interventions for the management of:

- Eosinophilic granulomatosis with polyangiitis (EGPA)
- Granulomatosis with polyangiitis (GPA)
- Microscopic polyangiitis (MPA)

Large-vessel vasculitis

- Giant cell arteritis (GCA)
- Takayasu arteritis

Medium-vessel vasculitis

- Kawasaki disease (published in 2022)
- Polyarteritis nodosa (PAN)



These guidelines mean people living with vasculitis will receive the same quality of care based on standardized, comprehensive recommendations. This means better outcomes and better lives.

“Many rheumatologists may have limited experience caring for patients with these diseases. However, the treatment options for patients with vasculitis have expanded in recent years. Thus, these guidelines provide practitioners evidence-based recommendations to help navigate the treatment path for their patients.”

— Sharon Chung, MD, MAS, Director of the Vasculitis Clinic at the University of California, San Francisco, and the lead investigator of the guidelines



Your Support Changes Lives

Why You Give...

Jessica Kent, who's living with polyarteritis nodosa, gives to the VF because it “has a special place in my heart...It was through the VF's recommendation that I met my amazing rheumatologist, Dr. Cornelia Weyand.”



JUST DANCE!

In 2021, Jessica organized two flash mob dances in Seattle, Washington, to raise awareness. 32 dancers, choreographers, photographers, videographers, and a music editor felt the rhythm and got involved. The flash mobs helped raise awareness among people watching, family, and friends, and raised nearly \$7,000 for the VF.

Karen, who's living with vasculitis, and her husband, Joe, choose to support the Vasculitis Foundation because “our lives have been touched by the disease. Therefore, we feel a responsibility to support the Foundation's mission.” They want to pass on the support, empowerment, and resources they've received to others in their shoes.

Brenda, who's living with vasculitis, gives to the VF because “I don't think I would be alive if not for the Vasculitis Foundation. You help improve our lives. You help me know I'm not alone.”



Our Partners

Thank You to our Corporate Supporters

The Vasculitis Foundation is proud of the work we accomplish with our corporate supporters for the vasculitis community. Together we put the patient first in what we do. We're dedicated to connecting our partners with our community, helping them understand the patient voice and develop new advances in treatments so everyone with vasculitis can live better today - and envision a healthier tomorrow.

Thank you to our corporate supporters for your commitment and shared mission.





2021 & 2022 Financials

Vasculitis Foundation Statements of Financial Position June 30, 2022 and 2021

Assets	2022	2021
Cash and cash equivalents	\$ 1,257,332	\$ 569,070
Investments	1,065,294	1,285,472
Pledges and Grants receivable	102,437	200,868
Prepaid expenses	22,543	10,222
Furniture, equipment, & website, less accumulated depreciation & amortization	10,235	16,479
Total Assets	\$ 2,457,931	\$ 2,082,111
Liabilities and Net Assets	2022	2021
Liabilities		
Accounts payable	\$ 83	\$ 3,031
Accrued liabilities	28,326	27,771
Total Liabilities	28,409	30,802
New Assets		
Without Donor Restrictions	626,498	467,344
Board Designated – Endowment	274,635	313,242
Total Net Assets Without Donor Restrictions	\$ 901,133	\$ 780,586
Net Assets With Donor Restrictions	\$ 1,528,389	1,270,723
Total Net Assets	2,429,522	2,051,309
Total Liabilities and Net Assets	\$ 2,457,931	\$ 2,082,111



About the VF

Who Are We?

We are you. We are people with vasculitis, care partners, friends, family, physicians, and researchers advocating for early diagnosis, better treatments, and an improved quality of life for people with vasculitis.

Building upon the collective strength of the vasculitis community, the Foundation is on a mission to support, inspire, and empower individuals with vasculitis and their families through a wide range of education, research, clinical, and awareness initiatives.

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





Early Diagnosis · Better Treatment · Improving Lives

Forms of Vasculitis

- Anti-GMB/Goodpasture's syndrome
- Aortitis
- Behçet's syndrome
- Central nervous system (CNS) vasculitis
- Cogan's syndrome
- Cryoglobulinemia
- Cutaneous small-vessel vasculitis (formerly hypersensitivity/leukocytoclastic)
- Eosinophilic granulomatosis with polyangiitis (EGPA, formerly Churg-Strauss syndrome)
- Giant cell arteritis (GCA)
- Granulomatosis with polyangiitis (GPA, formerly Wegener's)
- IgA vasculitis (formerly Henoch-Schönlein purpura)
- Kawasaki disease
- Microscopic polyangiitis (MPA)
- Polyarteritis nodosa (PAN)
- Polymyalgia rheumatica (PMR)
- Relapsing polychondritis
- Rheumatoid vasculitis
- Takayasu arteritis
- Urticarial vasculitis

For more information, visit:

www.vasculitisfoundation.org