

# Join Our JOURNEY

VASCULITIS FOUNDATION

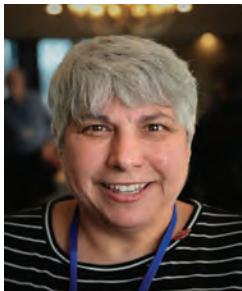
Early Diagnosis • Better Treatment • Improving Lives

## 2020 Impact Report

Dear Friends,

**W**elcome to the 2020 Vasculitis Foundation Impact Report, which celebrates our many successes over the past four years—milestones we couldn't have achieved without the commitment of our caring vasculitis community. In these pages, we also look to the future, highlighting key projects and initiatives ahead.

We recognize the tremendous impact COVID-19 has had on our patients, family and friends, physicians and partner scientists around the world. On behalf of the VF Board of Directors and staff, we hope you and your loved ones are staying well.



Partnerships are the lifeblood of our organization. Thanks to our donors, committed volunteers, and supporters, we've been able to offer enriching educational programs and resources, launch new research initiatives, and collaborate with many scientists internationally. We partner

with other advocacy organizations in the rare disease and autoimmune communities, and with investigators at the National Institutes of Health.

What's next for the Vasculitis Foundation?

- One of our most important initiatives is the dissemination of the first-ever ACR-VF Treatment Guidelines for vasculitis. We anticipate the guidelines to be published

in the *Journal of Rheumatology* later this year—then, we'll launch an extensive grassroots effort to get them in the hands of rheumatologists and other specialists who treat patients with vasculitis.

- In March, we launched the Vasculitis COVID-19 Patient Project to help researchers and clinicians better understand how the coronavirus impacts people with vasculitis. Over the next year, we'll follow more than 800 study participants to gain insight and knowledge.
- This fall, we'll host our first-ever Vasculitis Virtual Conference Series, where worldwide participants can safely learn and share their experiences with vasculitis in the COVID era.

We want to take a moment to thank our sponsors for their generous support of our programs and initiatives. We value these partnerships.

Finally, we thank you for sharing our vision. With your continued support, we can fulfill our mission and improve the lives of people with vasculitis—during this pandemic, and beyond.

Sincerely,



Joyce A. Kullman  
Executive Director

### 2019-2020 Vasculitis Foundation Board of Directors

**Suzanne DePaolis, President**  
Los Gatos, California

**Karen Hirsch, Past-President**  
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Glencoe, Illinois



## EDUCATION & AWARENESS

# VASCULITIS AWARENESS 2020 THE RACE IS ON!



## When it Comes to Vasculitis Information, We're the Trusted Source

**20** Diseases Covered

**200** Volunteers

**1,600** Patients Served through Phone Calls and Emails

Education and awareness are the heart and soul of what we do. Our credible vasculitis information is backed by more than 150 medical and scientific advisors worldwide. More than ever, we're delivering that information online—revamping our website and ramping up our digital presence to keep pace with new and changing ways of learning.

COVID-19 arrived early this spring, presenting new priorities. We launched a coronavirus resource page, and started a series of live Q&A webinars with vasculitis experts. This fall, we'll host our first-ever virtual educational conferences—safely bringing together patients and vasculitis specialists from around the world.



“Because of all the medical experts they have as advisors, I count on information from the VF to be accurate and up to date—it's like the Good Housekeeping seal of approval.”

**NANCY WINKLER**, PARENT OF YOUNG ADULT WITH VASCULITIS

## A Major Upgrade for our Website

The VF website is the backbone of our education, awareness, and communication efforts. In 2019, we embarked on an overhaul of [www.vasculitisfoundation.org](http://www.vasculitisfoundation.org), resulting in a more mobile-friendly, comprehensive, and secure site. The site is home to our up-to-date disease information, podcasts and webinars, research opportunities, awareness campaigns, news, patient and physician success stories, and much more!

[www.vasculitisfoundation.org](http://www.vasculitisfoundation.org)

**2.2M** Visitors

**4M** Page Visits

(2016-2020)



**f** **9,500**  
Followers

**t** **2,580**  
Followers

**ig** **2,500**  
Followers

**in** **335**  
Followers



70

Live and Recorded Webinars

127,000

Views on YouTube

3

Philly Awards for Video

## Webinars & Podcasts

The VF webinars and podcasts reflect our commitment to providing patient education, and amplifying the patient perspective to a wider audience through online platforms.

### Road to Wellness Webinars

Our 2020 Road to Wellness webinars feature vasculitis medical experts sharing their knowledge so patients can manage their vasculitis more effectively. Many of our topics come directly from patients' requests.



**“We have interviewed some amazing doctors and have brought a wealth of information to vasculitis patients and caregivers.”**

**KATHY OLEVSKY**, ROAD TO WELLNESS HOST, MARTIAL ARTS EXPERT, AND PATIENT WITH VASCULITIS

## Vasculitis Visionaries Podcasts

This educational and entertaining podcast series—launched in February 2020 by Young Adult Leaders Ben Wilson and Kaley Beins—features conversations with medical specialists, and appeals to both patients and health care professionals.



**“For me, getting involved with the VF has really helped me cope with my GPA diagnosis. The podcast has helped me regain some sense of control after five years of doctors' appointments and treatment, and I'm so grateful to the VF for giving me this opportunity.”**

**KALEY BEINS**, VASCULITIS VISIONARIES PODCAST CO-HOST, AND PATIENT WITH GPA



**“Even since we recorded our first episode in early March, we've seen a tremendous amount of new research and treatment guidelines emerge. Being able to keep both physicians and patients informed is such a valuable asset for our entire community.”**

**BEN WILSON**, VASCULITIS VISIONARIES PODCAST CO-HOST, AND PATIENT WITH EGPA



100

Subscribers

1,700

Worldwide Listeners



## Symposia & Conferences

Education and support are integral parts of the VF’s mission, and our symposia and regional conferences serve both needs—bringing together patients, families, vasculitis experts, and other members of the vasculitis community for learning, sharing stories, networking, and friendship. This fall, we’ll host our first-ever 2020 Vasculitis Virtual Conference Series, in response to the pandemic.

Join Our  
**JOURNEY**  
2020 VASCULITIS VIRTUAL  
CONFERENCE SERIES



“During the symposium, patients and families have the opportunity to learn from, and interact with, some of the top vasculitis specialists from around the world.”

**KENNETH WARRINGTON, MD**, MAYO CLINIC,  
ROCHESTER, MINNESOTA



“I met so many wonderful, compassionate and optimistic people who really understood my journey, and that really lifted my spirits to know I’m not alone in this!”

**DEDRA DEMARCO**, PATIENT WITH TAKAYASU’S ARTERITIS

## Vasculitis Awareness Month

Vasculitis Awareness Month is our largest, annual grassroots awareness initiative held every May. Despite limitations created by COVID-19 this year, our community members rose to the occasion—sharing our custom graphics on their social media sites, telling their stories, enrolling in studies, watching webinars, sharing their life hacks for living with vasculitis, and more.

## Continuing Medical Education

The VF is proud to co-host CME courses with partners like the Mayo Clinic, Northwestern University, and the Cleveland Clinic. These intensive courses provide the most current knowledge on vasculitis management, the latest research, and more, from experts in the field.



“The CME courses speak to the Foundation’s commitment to educating health care professionals about the diagnosis and treatment of vasculitis.”

**ULRICH SPECKS, MD**, MAYO CLINIC,  
ROCHESTER, MINNESOTA



Dr. Antonio Mastrangelo receives a V-RED Certificate of Appreciation in Italy from his patient Lorenzo Galimberti.



## V-RED: Recognizing Excellence in Diagnostics

Now in its seventh year, the V-RED Award program calls on patients worldwide to nominate a medical professional they want to recognize for making a critical, early diagnosis of vasculitis.

Cinzia Galimberti and her son, Lorenzo, nominated Dr. Antonio Mastrangelo for a V-RED Certificate of Appreciation award, for his “expertise and humanity” in treating Lorenzo’s microscopic polyangiitis (MPA).

“This illness is very serious and the diagnosis was really a shock for us. But with the right treatment and the right doctor, people can hope to return to a normal life, even if they have to take medicine every day,” says Cinzia.

**328** Nominations since 2014

**16** Winners

**13** Specialist Doctors Represented

**15** Countries Represented



**MASKS**  
**ON A MISSION**  
VASCULITIS FOUNDATION

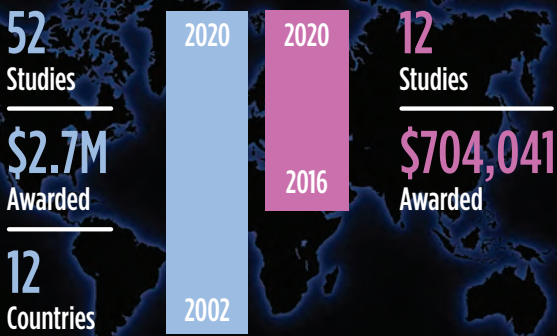
## Masks on a Mission

Patients with vasculitis are often treated with medications that suppress the immune system, so they know what it means to be immune-compromised. In August, we launched our Masks on a Mission campaign on social media to raise awareness about the importance of wearing a mask while the pandemic is still with us. The message: We wear our masks to protect ourselves, our loved ones, and the strangers around us—and we encourage others to do the same.



## RESEARCH

# Moving the Needle Forward on Vasculitis Research



## Two Decades of Vasculitis Research Success

The VF is proud to be a leader in vasculitis research support. Thanks to the generosity of our supporters, we’ve secured our legacy as one of the largest private funders of vasculitis research in the world.

We support investigators through fellowships, grants, and collaborations with international research partners. Since 2016, we’ve awarded grants in Australia, Austria, Canada, France, Germany, Ireland, Italy, Spain, Sweden, The Netherlands, United Kingdom, and the United States.

Researchers are zeroing in on better, smarter treatments to reduce reliance on steroid medications which cause debilitating side effects. We are hopeful precision medicine and targeted treatments will lead to better quality of lives for our patients.

# Grants and Fellowships: Training Future Physicians and Scientists

## Young Investigators

The VF recognizes the importance of championing the next generation of researchers. To that end, we launched the Dr. Chris Cox-Marinelli Young Investigator Award in 2019.

The 2020 award, a one-year grant totaling \$49,822, went to Dragana Odobasic, PhD, a researcher at Monash University in Melbourne, Australia, for her study on MPO-ANCA vasculitis. Her research focuses on specialized cells which can help the immune system protect against factors that contribute to inflammation in ANCA-associated vasculitis.



“The main focus of our research is to find effective, but safer therapies for vasculitis patients, with minimal side effects.”

DRAGANA ODOBASIC, PHD

## 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. The mentored training program emphasizes clinical/translational, patient-oriented investigation.

13 Fellowships

\$337,000 Awarded

(2012 - 2020)



VASCULITIS PATIENT-POWERED RESEARCH NETWORK



VPPRN

## The VPPRN: Where Patient-Partners Drive the Research

The patient voice is the heart of the Vasculitis Patient-Powered Research Network (VPPRN). A collaboration of the VF and the Vasculitis Clinical Research Consortium (VCRC), the VPPRN includes patients, researchers, clinicians, advocates, and family members—all working to improve vasculitis care through high-quality clinical research.

The VPPRN is taking steps to more fully integrate with the VF. Beginning this fall, our online presence will be based on the VF website, streamlining operations and ensuring that patients know they can participate in research through the VF. We're in this together!

### Key studies include:

**The Vasculitis COVID-19 Patient Project:** This study will provide insight into the impact of COVID-19 on people with vasculitis in the US and Canada. More than 800 patients enrolled, and we'll follow their survey responses over the next year.

**Eosinophilic granulomatosis with polyangiitis (EGPA) Registry:** Patients with EGPA provide self-reported data through online surveys, with the goal of improving management and treatment of this complex disease.

**VascSkin: Skin Vasculitis Quality of Life Survey:** This study will shed light on the impact of vasculitis-related skin disease on quality of life for patients with vasculitis.

### Advocating for the Patient Voice

Dianne Shaw's involvement with the VF goes back 25 years. Diagnosed with granulomatosis with polyangiitis (GPA) in 1995, Dianne has been a tireless volunteer and advocate for patients with vasculitis, championing the idea that patients are not just participants—they're co-researchers.



"The VPPRN is a powerhouse team of dedicated expert researchers and engaged, research-savvy patients, developing studies to answer questions of importance to patients and families."

**DIANNE SHAW**, CO-PRINCIPAL INVESTIGATOR FOR THE VPPRN

5,000+ Study Participants\*

17 Completed Studies

18 Types of Vasculitis Covered

1,000+ Patient-Submitted Research Questions to the VPPRN

48 Researchers and Patient-Partners

\*participants in all studies conducted by the VPPRN

### The VPPRN Is Proud to Partner with:

- American College of Rheumatology
- Duke University
- European League Against Rheumatism
- HealthCore
- McMaster University
- Ohio State University
- University of Alabama
- University of California—Los Angeles
- University of California—San Francisco
- University of Chicago
- University of Kansas
- University of North Carolina at Chapel Hill
- University of Pennsylvania
- Vanderbilt University



## FUNDRAISING

# PAJAMA PARTY

We brought the house down in June with our first-ever, virtual Pajama Party benefit. More than 250 attendees joined the sold-out online event—raising more than \$35,000 for the VF.



## Fundraising: We're in this Journey Together

We bring in revenue from a variety of sources—our Annual Appeal campaigns in the spring and fall, corporate giving through grants and sponsorships, fundraising events, and our memorials and honoraria. We've added peer-to-peer fundraising to the mix, where donors rally support from social networks via online platforms.

In 2018, we launched an ambitious, three-year Join Our Journey campaign, highlighting our three pillars: earlier diagnosis, better treatments, and longer, better quality of life. This fall, we enter the last leg of the campaign, but the journey doesn't end there. We're in this for the long haul.

### Individual Donors Make a Difference

Meet Art Diaz. Diagnosed with granulomatosis with polyangiitis (GPA) in 2017, he jumps in with both feet whenever there's an opportunity to help raise funds for the VF. He was instrumental in the 2020 VF Virtual Pajama Party benefit, the 2019 International Vasculitis Symposium, and our 2019 Join Our Journey fundraising appeal. He's used his wide network of personal contacts to raise money for the VF through online peer-to-peer fundraising for the past two years.



**"Doing fundraiser events is my chance to pay it forward and help other patients along their journey, as the Foundation has helped me. Fundraising is instrumental, along with research and raising awareness."**

**ART DIAZ**, PATIENT WITH GPA

### The Impact of Major Gifts

The family of Dr. Darwin James Liao is supporting the vasculitis community with a major gift in his memory. Dr. Liao passed away from complications of eosinophilic granulomatosis with polyangiitis (EGPA) in December 2013. Providing a major gift to support research, awareness, and clinical care was important to his family. Their long-term goal is to help establish a vasculitis clinic in the greater Seattle, Washington area, where Dr. Liao was an ophthalmologist, entrepreneur and inventor.



**"Darwin's sudden passing from EGPA was absolutely heartbreaking. It is why improving vasculitis research, awareness and treatment continues to be critically important to our family. We believe that helping clinicians and patients learn more about vasculitis and best practices in treatment will facilitate more timely diagnosis and care."**

**DAHLIA MAK**, FAMILY REPRESENTATIVE FOR THE DR. DARWIN JAMES LIAO MEMORIAL FUND





**Sunday November 6<sup>th</sup> 3 - 6 PM**

# RALLY IN THE ALLEY

BOWLING, SHOES, PIZZA AND SODA

SILENT AUCTION FEATURING YOUR LOCAL FAVES

FUN ACTIVITIES FOR ALL AGES!

Benefitting the Vasculitis Foundation

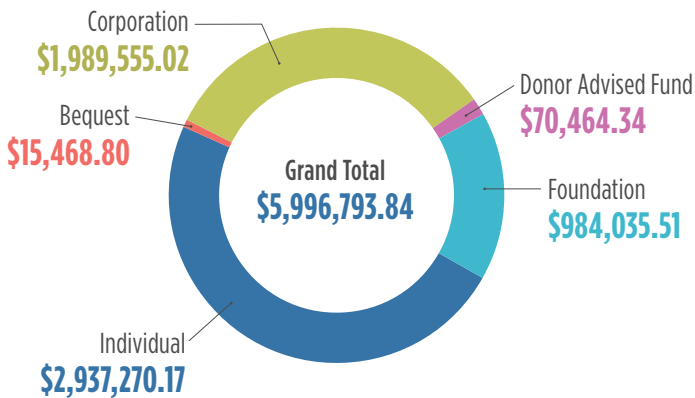
**YOUR HOSTS:**  
Mirach, Smith, Swartzman & Wandler Families

14th Annual  
**CELEBRATING A LIFE**  
Keesha Vessell Vasculitis Walk

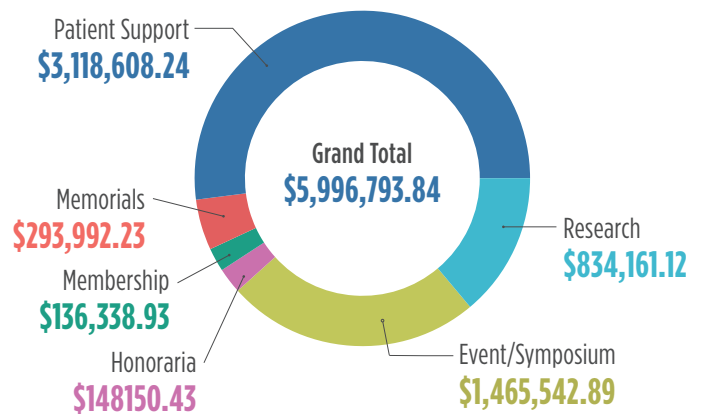
1. Chicagoland VF Golf Open
2. Chicago Rally in the Alley
3. Rocking Bar H Spaghetti Western Dinner
4. Vino for Vasculitis
5. Nick Pascente Memorial Golf Outing
6. Victory over Vasculitis
7. Keesha Vessell Vasculitis Walk
8. Move Over Mozart
9. Bike the Drive for Vasculitis
10. Violin for Vasculitis

## Top 10 fundraising events on behalf of the VF (2016-2020)

### Donations by Category



### Donations by Program or Project





## ACR-VF GUIDELINES



# Breaking Ground: The New ACR-VF Treatment Guidelines

**AMERICAN COLLEGE  
of RHEUMATOLOGY**  
*Empowering Rheumatology Professionals*



In 2019, we kicked off one of our most groundbreaking and ambitious projects to date: The ACR-VF Treatment Guidelines. The VF joined forces with the prestigious American College of Rheumatology (ACR) to develop and distribute the first-ever treatment guidelines for systemic vasculitis in rheumatology patients.

This strategic partnership with the ACR is a first, in and of itself. Together, we'll launch an extensive grassroots effort to disseminate the newly published recommendations to rheumatologists and other specialists around the world who treat patients with vasculitis.

**“These comprehensive guidelines were developed after an exhaustive review of the medical literature, and present the most up-to-date management strategies for patients with vasculitis. We hope our recommendations provide guidance for clinicians and improve outcomes for patients with these complex diseases.”**

**SHARON CHUNG, MD, MAS**, LEAD INVESTIGATOR, GUIDELINE DEVELOPMENT EFFORT

**“These guidelines will allow vasculitis patients to receive consistent care no matter where they live. They will greatly improve the quality of care vasculitis patients receive and hopefully allow them to live longer, with better quality of life.”**

**SUZANNE DEPAOLIS, PRESIDENT**, VF BOARD OF DIRECTORS, AND PATIENT WITH EGPA



Suzanne DePaolis and Dr. Sharon Chung at the 2019 ACR/ARP Annual Meeting.

## The ACR-VF Treatment Guidelines cover:

### ANCA-associated vasculitis (AAV)

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

### Large-vessel vasculitis

- Giant cell arteritis (GCA)
- Takayasu's arteritis

### Medium-vessel vasculitis

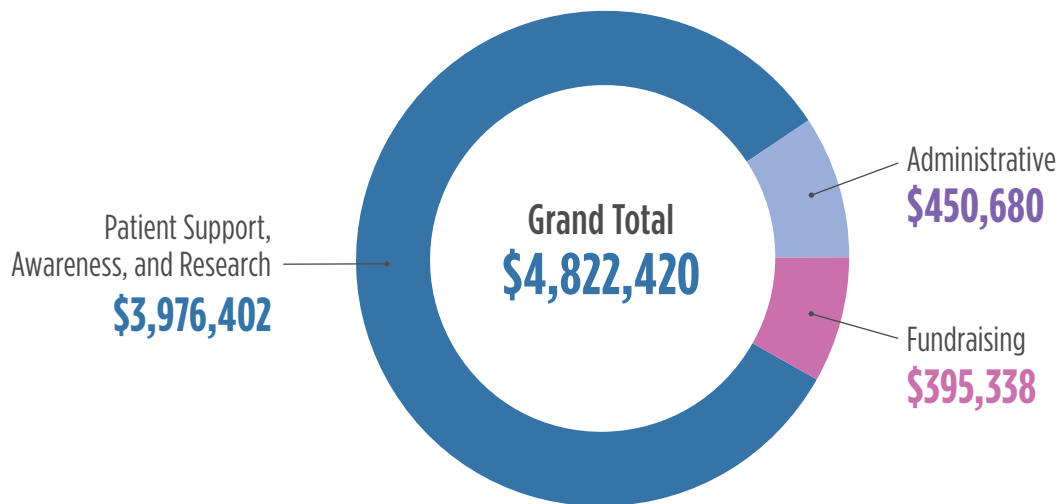
- Kawasaki disease
- Polyarteritis nodosa (PAN)



## FINANCIALS



### 2016-2020 Program Expenses





Early Diagnosis · Better Treatment · Improving Lives

## Forms of Vasculitis

- Anti-GMB (Goodpasture's) Disease
- Aortitis
- Behcet's Syndrome
- Central Nervous System (CNS) Vasculitis
- Cogan's Syndrome
- Cryoglobulinemia
- Cutaneous Small-Vessel Vasculitis  
(formerly Hypersensitivity/Leukocytoclastic)
- Eosinophilic Granulomatosis with Polyangiitis  
(EGPA/Churg-Strauss)
- 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's Arteritis
- Urticarial Vasculitis

For more information, visit:

[www.vasculitisfoundation.org](http://www.vasculitisfoundation.org)