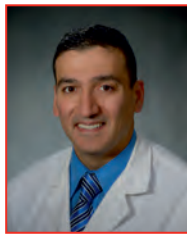




## Innovative Program Using Machine Learning to Address Challenge of Delays in Diagnosis

By Ed Becker,  
Director of Marketing and Communications

Despite advances made in the research, understanding, and treatment of vasculitis, the reality is that delay of diagnosis continues to be a critical issue. As a rheumatologist, Antoine Sreih, MD, says that every day he sees the unfortunate result when patients are referred to him. Dr. Sreih is an Assistant Professor of Clinical Medicine at the University of Pennsylvania in Philadelphia.



*Antoine Sreih, MD*

Many of the patients are suffering from advanced kidney disease or suffering organ damage directly because their vasculitis wasn't detected earlier when critical treatment could be introduced.

Though it's a challenging issue, Sreih is also optimistic that a study called Pathways to Diagnosis (P2D) may be a potential breakthrough which will improve the rate of earlier diagnosis thus significantly impacting the outcome for patients with vasculitis. Sreih is principal investigator and project director for this new study.

Simply explained, P2D is a way that physicians who otherwise wouldn't suspect vasculitis in patients, are alerted to the possibility by a sophisticated computerized program which is integrated with a patient's medical records.



Sreih, in partnership with the Vasculitis Foundation, the Vasculitis Patient-Powered Research Network (VPPRN), the University of Pennsylvania, and many other academic health care systems, has been working on this innovative solution which utilizes today's computing technology to find a possible solution to delayed diagnosis.

### Delays in Diagnosis

Sreih says many factors can impede diagnosis and one of the most common is that when patients exhibit with subtle, unremarkable symptoms the physician doesn't immediately think of a rare disease as the culprit. Moreover, patients are often referred to numerous specialists which results in a loss of valuable time and cost.

"It is becoming more difficult and challenging for physicians to gather and analyze all the data on patients. That is why you often see general physicians referring more and more patients to specialists. Waiting to see a specialist

*(continued on Page 5)*

## Early Diagnosis A Key Challenge for Adult and Pediatric Patients

By Ed Becker



One of the most important ways to potentially improve patients' outcomes is also one of the biggest clinical challenges for doctors. Working to improve the rate of delays in vasculitis diagnosis is an area of keen interest to researchers, and it's also the core theme of the VF's 2018 Annual Appeal.

Unfortunately, the timetable for getting a correct diagnosis of vasculitis can run between six months to more than four years. The longer the disease is unidentified and untreated, the potential for organ damage increases.

A key reason for delay is that vasculitis often manifests in unremarkable symptoms, so the root cause—a rare autoimmune disorder—isn't apparent to the physician. A patient presenting with severe, chronic sinusitis may go through numerous courses of antibiotics before being sent to an ENT for further testing.

*(continued on Page 19)*

*Dear Friends,*

### Will You Join Our Journey?

Over the next three years, our efforts will focus on early diagnosis, better treatments, and longer, better lives for friends and family living with vasculitis. Over the next year, we will focus on the first step — **helping physicians recognize vasculitis as early as possible.**

### Earlier Diagnosis Equals Better Outcomes for Patients

No one will argue that getting diagnosed early allows for treatment to start before the damage is too far along. However, getting to an early diagnosis is a challenge requiring new and novel ways to help physicians recognize the disease. Your support gives us the resources to develop potential tools for achieving the early diagnosis for a patient.

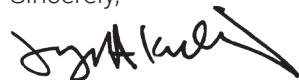
This year has been an exciting year with the Food and Drug Administration (FDA) approval of Nucala for the treatment of EGPA/Churg-Strauss. This is the third drug approved by the FDA for vasculitis. We are encouraged by the increase in developing treatments for vasculitis. We are seeing more research focused on some of the rarer forms of vasculitis, with the results from some of our longer studies such as DCVAS and PEXIVAS completing. In 2019, the Vasculitis Foundation will fund our 50th research grant, all made possible by your support.

We are grateful to all of you for your support, from the children who hosted a bake sale at their school to the basketball and golf tournaments, walks, concerts, wine and dinner benefits, and magic shows. You supported the VF's programs through social media fundraising campaigns for your birthdays and weddings and special anniversaries. Thank you all for your efforts to help others.

As we celebrate this holiday season, we ask you to consider including the Vasculitis Foundation in your year-end giving.

We wish everyone a happy and healthy 2019.

Sincerely,



Joyce Kullman

**If you want to be involved in the  
Join Our Journey Campaign,  
please contact me.**



## Vasculitis Foundation Board of Directors 2018-2019

**GEORGE CASEY, President**

gcasey@VasculitisFoundation.org

**KAREN HIRSCH, Past-President**

dutchblitz@aol.com

**DON NAGLE, Treasurer**

dlnagle@yahoo.com

**RHONDA JOHNSON BYRD, Secretary**

rhonda.johnson.byrd@gmail.com

**PAMELA PEKERMEN, VP, Resource Development**

pamela.pekerman@gmail.com

**SUZANNE DEPAOLIS**

sdepaolis@gmail.com

**PETER GRAYSON, MD, MSc.**

**VICTOR JAMES**

blu4runner@gmail.com

**GREGORY LESKO**

galesko@mac.com

**ALLISON LINT**

violin4v@gmail.com

**JASON SPRINGER, MD, MS**

**JASON WADLER**

jwadler@gmail.com

**MARILYN SAMPSON, R.N., Founder (1933~1997)**

**JOYCE KULLMAN**

Executive Director

jakullman@VasculitisFoundation.org

**ED BECKER**

Director of Marketing & Communications

724.719.1323 | ebecker@VasculitisFoundation.org

**BETH WESTBROOK**

Director of Development

bwestbrook@VasculitisFoundation.org

**KALEN YOUNG, MA**

VPPRN Network Manager

602.748.7615 | kyoung@VasculitisFoundation.org

**SHANNON MORGAN**

Patient Support Coordinator

117 South Street, Excelsior Springs, MO 64024

smorgan@VasculitisFoundation.org

**WHITNEY APPLE**

Communications and Events Coordinator

wapple@VasculitisFoundation.org

1.800.277.9474

Phone: 816.436.8211 | Fax: 816.656.3838

Vasculitis Foundation

PO Box 28660 . Kansas City, MO

64188-8660 USA

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

[vf@VasculitisFoundation.org](mailto:vf@VasculitisFoundation.org)

## Mission Statement

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.

*The Vasculitis Foundation is most grateful to authors who have shared their personal experiences with vasculitis in the newsletter. The reader should be aware that these contributions are personal reflections by the writer and do not represent medical scientific statements. Therefore, such information while being accurate perceptions of the writer, may not be scientifically accurate and may not apply to other patients.*



## VF Board Welcomes New Members During Its Fall Meeting

The VF held its annual membership meeting on Thursday, October 18, 2018 in Chicago. Karen Hirsch, VF President, reported on the organization's accomplishments and recognized Dr. Jeffrey Fishbein, who retired from the board, for his service and dedication to the patients and families of the VF.

Over the past five years Dr. Fishbein and his extended family have hosted the VF Chicagoland Golf Open, raising over \$364,000, to support the establishment of the Northwestern Vasculitis Clinic and the VF-VCRC Fellowship Program. With the generous support of their donors, they have funded four fellowships to train physician-investigators.

The following members were elected to the VF Board of Directors: Suzanne DePaolis and Don Nagle were elected after being appointed in January; Drs. Peter Grayson and Jason Springer were re-elected for their second term; Jason Wadler was elected to the board after a one-year absence, and we are pleased to welcome Victor James and Allison Lint to the board for their first three-year term.

Victor lives in Stafford, Virginia with his wife, Brenda, a school teacher. He was diagnosed with GPA/Wegener's in 2012 and recently retired after 34 years as an Allstate Insurance agent. Victor has extensive financial experience running his own agency and serving on committees for his church and other nonprofits. He is active on social media and he and Brenda have shared their experiences as part of the VF Extraordinary Stories' series: <https://bit.ly/2Pv1ox9>



*Victor James*

Allison Lint lives in Overland Park, Kansas and is a professional violinist for several orchestras. She also teaches music and is the founder of Violin for Vasculitis (V4V), a nonprofit awareness organization. Her goal is to travel to all 50 states, giving free recitals in public venues to promote rare disease awareness. To date the V4V has presented 35 events in 23 states.



*Allison Lint*

Allison has amassed experience organizing events in various venues from start to finish, making personal contact with community leadership as well as vasculitis patients, and navigating the process to gain nonprofit status with the IRS. She was diagnosed with GPA/



*l-r: Suzanne DePaolis, Peter Grayson, MD, Jason Springer, MD, George Casey, Karen Hirsch, Rhonda Johnson Byrd, Victor James, and Don Nagle*

Wegener's at 17 and now, at age 30, provides a link between the adult world of VF management and young adults, a population which we observe increasing every year.

Jason Wadler, Glencoe, Illinois, returns to the VF Board after a one-year absence. As Past-President, Jason continues to raise awareness of vasculitis and fundraise for the VF's programs, including planning a rock-n-roll concert to kickoff next year's Vasculitis Awareness Month.

### New Leadership Elected

The VF Board of Directors held their fall retreat after the VF membership meeting. George Casey, who has served on the board for five years, was elected president, Don Nagle treasurer, Rhonda Johnson Byrd secretary, and Pamela Pekerman vice president of resource development.

George thanked Karen Hirsch for her service as President for the past two years. Karen is the co-organizer of the annual Chicago Rally in the Alley fundraiser, which has raised over \$162,000, over the past five years.

The board reviewed the organization's current programs and engaged in a special strategic planning session to discuss plans for 2019.

## ACR Abstracts Available Online

The American College of Rheumatology (ACR) held its annual meeting in Chicago in October. Over the course of the three-day meeting, speakers presented updated information on diagnosis and treatments for the different forms of vasculitis and other autoimmune diseases.

To access all of the research abstracts, visit the [ACR](https://www.acr.org) website.

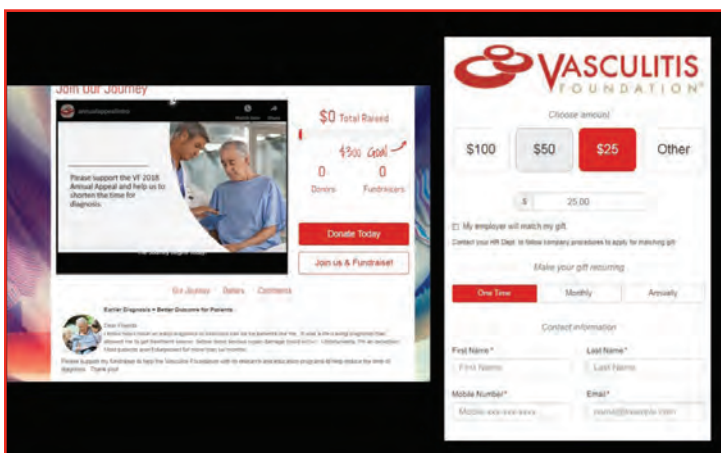


## A Guide to Making Annual Appeal Online Donations Using Mobile Cause

Making an on-line donation or doing a personal peer-to-peer fundraiser just got easier thanks to Mobile Cause. The VF chose the online fundraising software because more people are utilizing their phones to make online donations, or to access the VF website.

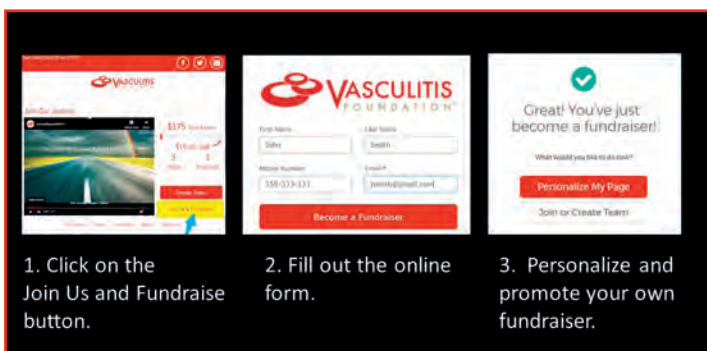
### Donate

- Simply click on the *Donate Today* button and fill out the online form.
- You will then receive an email confirmation for your contribution.
- Watch a short video with more details about making a donation: <https://bit.ly/2ELTJWb>



### Create a Personal Fundraiser

- The VF is encouraging more people to do their own fundraiser during Annual Appeal and it's never been easier. You can create and customize your own campaign landing page complete with artwork showing how much you raised, and a list of your donors.
- Watch a short video about customizing your personal fundraising page at: <https://bit.ly/2Jle7ME>



## End the Year with a New Journey: Get Engaged with the VF

By Beth Westbrook  
VF Director of Development

Never put off for tomorrow what you really, really want to do today. My argument against New Year's resolutions has been if I really want to do something, I don't wait until January 1st to start (that's not true when it comes to diets). Sometimes getting started can be a bit rough, especially when I hit unforeseen obstacles. Then I must decide – how bad do I want to do it?

Getting involved with the vasculitis community is within your reach. If you have ever said, "How can I help?", we have answers. If for any reason there are obstacles, we can work together to figure them out.

### Why Not Resolve To Join Us On The Journey? Here Are Some Of The Ways You Can Make A Meaningful Impact:

- Join our Facebook Group. Learn what is currently going on, be part of a supportive network and make new friends. Knowing you are on a journey with others may be the boost you need.
- Make the commitment to join us at a Regional Conference, if there is one nearby. By participating for the day, you will learn about vasculitis, meet other people touched by the disease, and strengthen the caring community.
- Become an area contact or become part of a local chapter if there is one in your area. Contact the VF office if you want to be active in your community.
- Donate towards getting more done. There are many projects underway at the VF. We will move closer towards reaching the goals of earlier diagnosis, better treatments and living well with your valuable gifts given today.

There are also many opportunities throughout the year to volunteer on-site at an event.

Making a resolution is one thing. Getting started is important. Reaching your destination gives you a feeling of accomplishment and pride. For the next three years, our goals are to reach earlier diagnosis, find better treatments, and strengthen the ability for a friend or family member touched by vasculitis to live a longer, better quality of life. Don't let friends or family make that journey alone.

Thank you for your commitment to the vasculitis community. Be well and happy holidays!

## Delays in Diagnosis, *cont. from page 1*

can sometimes take months, so we're losing valuable time as the disease causes further damage," says Sreih. "There is often insufficient time for the primary care physicians to understand, gather, or even piece together patients' complex and often fragmented medical histories."

### Today's Technology: Harnessing the Power of "Big Data."

The core idea behind P2D is a program which integrates with a patient's medical records so that multiple, seemingly unrelated symptoms can be analyzed quickly, and the physician is alerted to consider a diagnosis that would otherwise never be on his/her radar.

Sreih likens the P2D application as an invisible physicians' electronic aide processing volumes of data looking for symptoms and test results that may point to vasculitis.

"Imagine a patient presents with a chronic cough that doesn't respond to standard treatment. He may be sent to a pulmonologist where a CAT scan reveals a nodule and immediately the doctor thinks cancer," explains Sreih. "However, the patient also has a history of chronic sinusitis and hearing loss. P2D will analyze this cluster of symptoms from an individual's medical history and alert the doctor to consider vasculitis. Getting that notification will help the doctor to think about a cause that he/she might otherwise never have considered. Now we have that ability to use artificial intelligence or predictive analytics to help us shorten that time and expedite treatment."

A pop-up alert would not only suggest testing for vasculitis, but it would also provide a link so the physician can make an immediate referral to a rheumatologist or other specialists. Also, it would raise awareness by reminding physicians about vasculitis for any future patients that may present in the same way.

### Next Steps to Implementation

The study has been in development for nearly two years and is currently being evaluated as sources of funding are explored. Sreih says two major healthcare networks are prepared to participate in its implementation and once funding is secured, the project will be ready to launch.

Sreih credits a diverse team, including support from predictive analytics experts at the University of Pennsylvania, the Vasculitis Patient-Powered Network, and the Vasculitis Foundation for its development.

However, he credits an obvious source – patients themselves – for P2D's creation. "Through our interaction with patients in the VPPRN we learned that improving delays in diagnosis was a top goal for research," said Sreih. "It was one of the ways patients' outcomes with this disease could be positively impacted. We are hopeful that P2D will be a tool that will make it a reality."

## VF Expands Area Contact Program

By Ed Becker

The growth of the VF's Area Contact Program tells you why it's such an important part of the organization's patient support services. Approximately 30 years ago, the VF created an international network of volunteers to be contacts for patients seeking to talk with other vasculitis patients.



*Shannon Morgan, VF  
Patient Coordinator*

The program began with just five area contacts. Today, there are nearly 80 volunteers throughout the world who listen and direct patients to additional resources. The process begins when Shannon Morgan, the VF Patient Coordinator, receives an email, or a phone call from someone who would like to talk with a fellow patient.

"Many of the patients or caregivers who call us are understandably scared, and they simply want to talk with someone who understands what they are going through," says Morgan. "I connect the patient with one of our area contacts via email. Our volunteers can't give specific medical advice, but they will listen, or share their own experiences. That alone is invaluable to a patient with a rare disease."

Morgan says that being a volunteer contact doesn't require any special training, and it's not a huge time commitment. "We just want people who are positive, good listeners, and have some knowledge of the VF and other online resources to help the patient. If our contacts need us to get involved for additional help we are happy to assist."

If you would like to learn more about being an area contact, please contact Shannon at: [smorgan@VasculitisFoundation.org](mailto:smorgan@VasculitisFoundation.org)

Many thanks to all of our area contacts, many of who have volunteered for years helping other patients.

## Minnesota Physician Given 2018 V-RED Honorable Mention Award for Early Diagnosis

Daniel Watson, MD, FACS, an otolaryngologist at the Park Nicollet Clinic in St. Louis Park, Minnesota, has been named a recipient of the 2018 Excellence in Diagnosis (V-RED) Award from the Vasculitis Foundation, the world's leading vasculitis support, education and research organization.



*Daniel Watson, MD, FACS  
and Nicole Shankey*

The V-RED Award is presented annually to a medical professional who made a quick diagnosis of vasculitis, thus enabling the patient to receive timely and appropriate treatment, potentially sparing the patient permanent and ongoing health complications.

Watson was nominated for the award by his patient, Nicole Shankey of Minneapolis, following his early diagnosis of Wegener's/GPA.

Shankey first encountered Dr. Watson in December 2010 when she went to the Methodist Hospital for a bronchoscopy after experiencing extreme coughing, shortness of breath and sinus symptoms for two months. During the procedure, her vocal cords began to swell and she was rushed to the ER, where she was intubated

and scheduled to receive a tracheotomy. Watson, who happened to be on rotation that day, believed that she likely had an autoimmune disease and prescribed a high-dose of steroids for several days, instead of an emergency tracheotomy.

After five days on high-dose steroids, the vocal cord swelling had reduced. Shankey was extubated and was released from the hospital two days later. Eighteen months later, a biopsy confirmed that she had Wegener's.

"Dr. Watson saved my life," said Shankey. Had Watson not intervened, Shankey said she would have been given a tracheotomy, which would have done irreversible damage to her trachea.

She nominated Watson for the V-RED Award because, in her words, "He listens to his patients, takes their concerns and symptoms seriously and does what he can to get behind the cause. He has knowledge beyond his spectrum of ears, nose, and throat that he puts to good use. And he is willing to go the extra mile for his patients. Educating the medical community about early diagnosis is so critical but also so challenging. Often it's not a rheumatologist who first sees a patient manifesting symptoms of vasculitis."

In addition to Watson, 41 other medical professionals throughout the world were nominated for the 2018 award. Three of them were selected for Honorable Mention, and all of the other nominees were given a certificate of appreciation by the VF.

Learn more about the V-RED Award at [www.VasculitisFoundation.org](http://www.VasculitisFoundation.org)

## Artists Adopt Orphan Diseases

By Catherine Lucas

Any child illness is disruptive for a family, but having a child with a rare disease comes with its own set of challenges. Parents are faced with terrifying and obscure combinations of symptoms, and doctors are often just as mystified when it comes to diagnosing one of the 7,000 diseases designated "rare".

One of these parents is Rhode Islander Patricia Weltin. She is the mother of two daughters diagnosed with a rare disease known as hypermobile Ehlers-Danlos syndrome, and founder of the advocacy group Rare Disease United. When a high school student with an art class assignment asked Weltin's charity if she could paint a boy with

osteogenesis imperfecta, a rare bone disease, Weltin saw potential to propagate the idea and connect with audiences in a new way. Pairing local artists with children known to her through her advocacy work, she created Beyond the Diagnosis, a portrait series that put a young face to a number of these illnesses.

What followed exceeded all of her expectations. Starting with 17 portraits in the project's first launch in February, 2015, it has achieved global status with artists and patients from places as far flung as Iraq, Ghana, and Venezuela. The number of portraits has now reached 100. Demand for the exhibition has exploded and today, whether it's at a university, government agency, or clinical conference, it is almost permanently on display somewhere in the U.S.

Source: **The Lancet Child & Adolescent Health, Volume 2, Issue 10, October 2018, Page 703**

## FDA Approves Label Update for Genentech's Rituxan® (rituximab) in GPA and MPA

October 19, 2018 — Genentech, a member of the Roche Group, announced today that the U.S. Food and Drug Administration (FDA) has approved an update to the Rituxan® (rituximab) label to include information on follow up treatment of adult patients with Granulomatosis with Polyangiitis (GPA) and Microscopic Polyangiitis (MPA) who have achieved disease control with induction treatment.

The label update was based on data from a Roche-supported study by the French Vasculitis Study Group showing that treatment with the rituximab regimen\* resulted in fewer major relapses by month 28 compared to treatment with azathioprine.

The observed safety profile was consistent with that previously observed in this patient population. Rituxan, in combination with glucocorticoids (GCC), was approved by the FDA in 2011 for adult patients with GPA and MPA.

"Options for continued treatment in GPA and MPA, chronic autoimmune diseases in which patients experience periods of flares, are currently limited," said Sandra Horning, MD, Chief Medical Officer and head of Global Product Development. "As part of our commitment to support people living with rare diseases, we are pleased to provide updated prescribing information for Rituxan to help physicians make more informed decisions about therapeutic options for patients who have achieved disease control with induction treatment."

GPA and MPA are two types of ANCA-associated vasculitis (AAV), a form of vasculitis, or inflammation of the blood vessels, that largely affects the small blood vessels of the kidneys, lungs and a variety of other organs.

Rituxan, in combination with glucocorticoids (GCC), was approved by the FDA in 2011 for adult patients with GPA and MPA, with the precaution that limited data were available on the safety and efficacy of subsequent courses of Rituxan in patients with GPA and MPA, and that the safety and efficacy of retreatment with Rituxan had not been established. As part of this label update, the precaution has been removed from the Rituxan prescribing information.

The U.S. label update is based on data from the MAINRITSAN trial, a Roche-supported, randomized, controlled clinical trial, conducted by the French Vasculitis Study Group, that used Roche-manufactured, European Union (EU)-approved rituximab as the clinical trial material. The study evaluated the efficacy and safety of the rituximab regimen\* compared to azathioprine as follow up treatment in 115 patients (86 with GPA, 24 with MPA, and 5 with renal-limited AAV), who had achieved disease control after induction of remission with GCC and cyclophosphamide. The primary endpoint was the occurrence of major relapse† through month 28. By month 28, major relapse occurred in three patients (five percent) on the rituximab regimen\* and 17 patients (29 percent) in the azathioprine group.

\*Rituximab regimen = Roche-manufactured, European Union (EU)-approved rituximab + glucocorticoids

†Major relapse in the trial was defined by the reappearance of clinical and/or laboratory signs of vasculitis activity that could lead to organ failure or damage, or could be life threatening.

Source: <http://www.rituxan.com/>

## Additional Way to Support the VF

### Required Minimum Distribution (RMD)

In the U.S., donors 70.5 years and older who have IRA's are obligated to take a "required minimum distribution" each year. When they receive those funds, it's a taxable event for them. To avoid paying that tax they can donate the distribution in part or in whole to the Vasculitis Foundation!

The donor's required minimum distribution is the minimum amount that he or she must withdraw from

their account each year. The IRA holder generally must start taking withdrawals from their IRA, SEP IRA, SIMPLE IRA, or retirement plan account when age 70.5 is reached. However, Roth IRA's do not require withdrawals until after the death of the owner.

Please contact your tax accountant for details. The IRS also provides detailed information here: <https://bit.ly/2z72S6L>



## Understanding EGPA (Churg-Strauss Syndrome) and Nucala Webinar

**Tuesday, November 27, 2018:  
12:00 p.m. - 1:00 p.m. EST**

Michael Wechsler, MD, MMSc - National Jewish Health, a pulmonologist at National Jewish Health, will lead a discussion on EGPA (formerly Churg-Strauss Syndrome) and the recently FDA-approved drug, Nucala. Dr. Wechsler is in the Division of Pulmonary, Critical Care and Sleep Medicine and his areas of research include EGPA, asthma, and eosinophilic lung diseases. The webinar will include time for Q&A with the participants.



Michael Wechsler, MD, MMSc

**Webinar will be recorded and added to the VF Webinar Library**

## Vaccines and Vasculitis Webinar By Eric Ruderman, MD

Should I, or shouldn't I? That is the question. Actually, this question about getting a vaccine is asked by hundreds of patients as we enter the peak flu season. Moreover, aside from the flu vaccine, patients with a compromised immune system need to know about the other immunizations for Swine flu, shingles, typhoid, and other diseases.



It's a complex topic, but in this webinar, Dr. Ruderman breaks it down in layperson language so patients can make the best decisions.

### Topics include:

- Two types of flu vaccines (standard and super)
- What is a live vaccine?
- Vaccinating kids
- What is the "super dose" vaccine

Watch this informative VF webinar: <https://bit.ly/2PuzGzJ>

## Study Enrolling Patients

### Evaluation of Efficacy and Safety of Sarilumab in Patients with Giant Cell Arteritis

**Primary Objective:** To evaluate the efficacy of Sarilumab in patients with giant cell arteritis (GCA) as assessed by the proportion of patients with sustained remission for sarilumab compared to placebo, in combination with a corticosteroid (CS) tapering course.

**Secondary Objective:** To demonstrate the efficacy of Sarilumab in patients with GCA compared to placebo, in combination with CS taper with regards to:

- Clinical responses (such as responses based on disease remission rates, time to first disease flare) over time.
- Cumulative CS (including prednisone) exposure.
- To assess the safety (including immunogenicity) and tolerability of sarilumab in patients with GCA.
- To measure sarilumab serum concentrations in patients with GCA.
- To assess the effect of sarilumab on sparing glucocorticoid toxicity as measured by glucocorticoid toxicity index (GTI).
- Valuation of efficacy and safety of Sarilumab in patients with GCA.

**Detailed Description:** Study duration per participant is approximately 82 weeks, including an up to 6-week screening period, 52-week treatment period, and 24-week follow-up period.

### Inclusion criteria:

- Diagnosis of giant cell arteritis (GCA) according to European League Against Rheumatism/American College of Rheumatology classification criteria.
- New onset active disease or refractory active disease.
- At least one of the symptoms of GCA within 6 weeks of baseline.
- Either erythrocyte sedimentation rate  $\geq 30$  mm/hour or C-reactive protein  $\geq 10$  mg/L within 6 weeks of baseline.
- Receiving or able to receive prednisone 20-60 mg/day for the treatment of active GCA.

**Contact:** 800.633.1610, ext 1

**Email:** [US@sanofi.com](mailto:US@sanofi.com)

**Study Locations:** Denver, Colorado  
Boca Raton, Florida  
Duncansville, Pennsylvania

To learn more about the study, including the exclusion criteria: <https://clinicaltrials.gov/ct2/show/NCT03600805>



## Organization Supports Patients and Research in the UK and Scotland

By Ed Becker

One of the most important vasculitis awareness and advocacy organizations in Scotland and throughout the United Kingdom is the Lauren Currie Twilight Foundation (LCTF). Grant and Adrienne Currie established the LCTF in memory of their daughter, Lauren, who passed away at the age of 15 from GPA/Wegener's in October 2010. The organization's name also reflects Lauren's love of the popular Twilight book series.



*Lauren with her parents, Grant and Adrienne Currie*

Grant and Adrienne were devastated by the loss of their daughter, but it also left them determined to build a lasting legacy to Lauren. The LCTF raises vital awareness of vasculitis and provides a wide range of services including support groups, respite facilities, helplines, guidance booklets and public awareness events.

The LCTF is the country's only dedicated vasculitis registered charity committed to investing and funding vasculitis research and support.

Since 2010, the LCTF has raised over £650,000 to fund patient support, awareness campaigning, and medical research. Among their projects is a three-year study with the University of Aberdeen "Live Cell Imaging to Study the Evolution and Pathophysiology of Autoimmune Disease."

According to Julie McKissock, LCTF Events & Fundraising Manager, holding regular support meetings is a large part of their commitment to bring patients together for support.

"These are informal meetings where patients will hear guidance talks on a wide variety of topics that affect patients in their daily lives," says McKissock. "It's an opportunity for patients to come together which is so important when dealing with a rare disease like vasculitis. Twice a year we also hold "The Wellbeing Event" here in Scotland. The event provides 24-hour accommodation and catering for patients and caregivers and a programme of well-being activities including light exercise. At the end of the first day there is social time for patients and carers to meet others in a relaxed and informal setting."

LCTF's flagship event is the Black and Red Ball which has grown from 80 guests when it started in 2011, to more than 250 attendees in 2018. The annual gala features live entertainment, food, and dancing all designed to support the LCTF's mission.

Learn more about LCTF at their website:

<https://bit.ly/2Q2198W>



## Patient Advocates Warn Against New Insurance & PBM Policy That Increases Patient Out-of-Pocket Drug Costs

Posted by Christina Jensen

*As Open Enrollment Begins, Beneficiaries who Rely on Copay Coupons Must Consider this New Policy When Selecting a Health Plan*

The AIDS Institute, Arthritis Foundation, and National Organization for Rare Disorders (NORD) hosted a press briefing on a harmful new health insurance and Pharmacy Benefit Manager (PBM) policy quietly being slipped into insurance plans and dramatically increasing patient cost-sharing for prescription drugs. As open enrollment is set to begin, beneficiaries must be on the lookout for "copay accumulator adjustment programs" that deny copay

assistance from counting towards a patient's annual deductible and out-of-pocket maximum. The programs can increase patient drug costs by thousands of dollars at the pharmacy counter, leading to treatment abandonment.

"Choosing a health plan that best meets a patient's needs is already hard enough, particularly at a time of rising deductibles and co-insurance," said Carl Schmid, Deputy Executive Director of The AIDS Institute. "Adding in copay accumulators, which are being implemented with little to no warning, will lead to sticker-shock at the pharmacy counter, and worse, treatment abandonment for patients who cannot afford increases in their drug costs by the insurance companies and PBMs."

For more information on copay accumulator adjustment programs, here are some helpful resources:

<https://bit.ly/2PTgxYE>

# 2019 Vasculitis Foundation Pacific Northwest Vasculitis Patient & Family Conference Seattle, Washington

- Saturday, January 12, 2019
- Time: 9:00 a.m. - 3:30 p.m.
- Registration Fee: \$40; \$25 VF Member
- Deadline: January 7, 2019
- Crowne Plaza Airport  
17338 International Boulevard, Seattle, WA
- Register Now! <https://bit.ly/2PH2pl4>

## Registration Form (Please print clearly)

## Seattle

Last Name \_\_\_\_\_

First Name \_\_\_\_\_

- ☐ Patient
 ☐ Pediatric Patient  
☐ Family Member
 ☐ Health Care Provider

Diagnosed with \_\_\_\_\_

Special Needs \_\_\_\_\_

Last Name \_\_\_\_\_

First Name \_\_\_\_\_

- ☐ Patient
 ☐ Pediatric Patient  
☐ Family Member
 ☐ Health Care Provider

Diagnosed with \_\_\_\_\_

Special Needs \_\_\_\_\_

Address \_\_\_\_\_

City \_\_\_\_\_ State \_\_\_\_\_ Zip \_\_\_\_\_

Cell Phone \_\_\_\_\_

Email \_\_\_\_\_

### Payment Method

☐ Check (payable to Vasculitis Foundation) Amount \$ \_\_\_\_\_

☐ Visa
 ☐ Mastercard
 ☐ Discover
 ☐ American Express

Credit Card Number \_\_\_\_\_

Exp. Date \_\_\_\_\_ Amount \$ \_\_\_\_\_

Name on Card \_\_\_\_\_

Authorized Signature \_\_\_\_\_

**Mail to: Vasculitis Foundation, P.O. Box 28660  
Kansas City, MO 64188 USA**

## preliminary schedule

- 9:00 a.m. **Check-in and Light Continental Breakfast**
- 9:50 a.m. **Welcome and Introductions**  
Gregory C. Gardner, MD, FACP  
Gilliland-Henderson Professor of Medicine  
Division of Rheumatology  
University of Washington
- 10:00 a.m. **Vasculitis Update: What's New for Patients**  
Phillip Seo, MD  
Associate Professor of Medicine  
Director, The Johns Hopkins Vasculitis Center  
Baltimore, Maryland
- 10:40 a.m. **Being Impatient for Our Patients: Fast Track Clinic for Giant Cell Arteritis**  
Ingeborg Saksen, MD, FACP  
Clinical Associate Professor  
Division of Rheumatology  
University of Washington
- 11:00 a.m. **Update in ANCA Vasculitis: The Team Approach**  
Sarah Chung, MD  
Division of Rheumatology  
University of Washington
- 11:30 a.m. **Rarer Forms of Vasculitis: (Behcet's, Hepatitis C, GBM disease, etc.)**  
Alison Bays, MD, MPH  
Acting Instructor, Division of Rheumatology  
Associate Fellowship Program Director  
University of Washington
- 12:00 p.m. **Lunch and Guest Speaker**
- 1:00 p.m. **Lung Involvement in Vasculitis**  
Gregory C. Gardner, MD, FACP
- 1:30 p.m. **Staying Healthy In Spite of Having Vasculitis**  
Jenna Thomason, MD, MPH  
Acting Instructor, Division of Rheumatology  
University of Washington
- 2:00 p.m. **Panel Discussion: Now Is Your Chance To Ask The Experts!**
- 2:20 p.m. **Vasculitis Patient-Powered Research Network**  
Kalen Young, MA  
VPPRN Network Manager
- 2:35 p.m. **Concluding Remarks**  
Joyce A. Kullman  
Executive Director, Vasculitis Foundation
- 2:45 p.m. **Mingle**

**Note: A limited number of scholarships are available.**

**Contact [vf@VasculitisFoundation.org](mailto:vf@VasculitisFoundation.org)  
or 816.436.8211 for questions.**



# Vasculitis Foundation and the Mayo Clinic Arizona present Mayo Clinic Arizona Patient Conference

- Saturday, March 9, 2019
- Time: 8:30 a.m. - 2:45 p.m.
- Registration Fee: \$40; \$25 VF Member
- Deadline: March 4, 2019
- Mayo Clinic Education Center - Waugh Auditorium  
5777 East Mayo Boulevard, Phoenix, AZ 85054
- Register Now! [www.VasculitisFoundation.org](http://www.VasculitisFoundation.org)

## preliminary schedule

- 8:30 a.m. **Registration and Light Continental Breakfast**
- 9:15 a.m. **Welcome and Introductions**  
Rodrigo Cartin-Ceba, MD  
Pulmonary and Critical Care Medicine  
Mayo Clinic Arizona
- 9:30 a.m. **Large Vessel Vasculitis**  
Kenneth J. Warrington, MD  
Chair, Division of Rheumatology  
Mayo Clinic, Rochester, MN
- 10:00 a.m. **Lung Involvement in Vasculitis**  
Rodrigo Cartin-Ceba, MD  
Pulmonary and Critical Care Medicine  
Mayo Clinic Arizona
- 10:30 a.m. **Morning Break**
- 10:45 a.m. **Advances in Treatment of ANCA-Associated Vasculitis**  
Ulrich Specks, MD  
Chair, Division of Pulmonary and Critical  
Care, Mayo Clinic, Rochester, MN
- 11:15 a.m. **Upper Airway Involvement in Vasculitis**  
David G. Lott, MD  
Division of Otolaryngology  
Mayo Clinic Arizona
- 11:45 a.m. **Vasculitis Patient-Powered Research Network (VPPRN)**  
Kalen Young, VPPRN Network Manager
- 12:00 p.m. **Lunch/Patient Experience Story**
- 1:00 p.m. **Kidney Involvement in Vasculitis**  
Alicia Rodriguez-Pla, MD, PhD  
Arthritis Center, University of Arizona  
Tucson, AZ
- 1:30 p.m. **New Biologicals for Asthma Management**  
Matthew A. Rank, MD  
Chair, Division of Allergy and Immunology  
Mayo Clinic Arizona
- 2:00 p.m. **Managing Long-Term Corticosteroid Therapy**  
Speaker TBA
- 2:30 p.m. **Wrap-Up And Thank You**  
Dr. Cartin-Ceba  
Joyce Kullman, Executive Director  
Vasculitis Foundation

**Note: A limited number of scholarships are available.**

**Contact [vf@VasculitisFoundation.org](mailto:vf@VasculitisFoundation.org)  
or 816.436.8211 for questions.**

### Registration Form (Please print clearly)



Last Name \_\_\_\_\_

First Name \_\_\_\_\_

- ☐ Patient
 ☐ Pediatric Patient  
☐ Family Member
 ☐ Health Care Provider

Diagnosed with \_\_\_\_\_

Special Needs \_\_\_\_\_

Last Name \_\_\_\_\_

First Name \_\_\_\_\_

- ☐ Patient
 ☐ Pediatric Patient  
☐ Family Member
 ☐ Health Care Provider

Diagnosed with \_\_\_\_\_

Special Needs \_\_\_\_\_

Address \_\_\_\_\_

City \_\_\_\_\_ State \_\_\_\_\_ Zip \_\_\_\_\_

Cell Phone \_\_\_\_\_

Email \_\_\_\_\_

### Payment Method

☐ Check (payable to Vasculitis Foundation) Amount \$ \_\_\_\_\_

☐ Visa ☐ Mastercard ☐ Discover ☐ American Express

Credit Card Number \_\_\_\_\_

Exp. Date \_\_\_\_\_ Amount \$ \_\_\_\_\_

Name on Card \_\_\_\_\_

Authorized Signature \_\_\_\_\_

**Mail to: Vasculitis Foundation, P.O. Box 28660  
Kansas City, MO 64188 USA**



## Ronnie Saunders Inspired by the VF Victory Over Vasculitis Campaign

By Ben Wilson

For our final VF Patient Profile of 2018, I had the pleasure of sitting down with Ronnie Saunders, a senior at Wheeling Park High School in Wheeling, West Virginia.

Like many of the other young vasculitis patients I've met over the past two years working with the VF, Ronnie's path to diagnosis included a litany of painful symptoms like rashes, fever, and strep throat. Unlike just about all of those patients, Ronnie has a unique trait: his ability to run incredibly fast.

As a sophomore in the fall of 2016, Ronnie burst on to the West Virginia cross-country running scene with a 3rd place finish at the state track meet.

Going into his junior year, Ronnie felt he was ready to take the next step in his running endeavors. But that summer, the symptoms struck. After traveling to Children's Hospital in Pittsburgh in July 2017, Ronnie was diagnosed with GPA Wegener's.

While his parents worried about his health, Ronnie worried about how long he would be sidelined. "I just love to run," Ronnie says. "I started training as soon as the doctors allowed it. Physically, I felt terrible when I started running again; but mentally, it felt amazing to be back."

Ronnie's path to recovery was not immediate. Multiple flare-ups last winter forced him to undergo rounds of Rituximab and Cytoxan treatments, along with high doses of prednisone. By the time he had to endure a second bronchoscopy, a track and field race was only days away.

Although he wasn't close to feeling 100 percent and didn't automatically qualify for the state meet, Ronnie received an at-large berth to compete in the following week's race. There, he made a remarkable turnaround, taking second in the 3200 metres (2-mile) run with a time of 9:38, just a half-second behind the winner.

Among those who looked on in awe was his coach, Jacob Galik, who says he had never seen anyone overcome that type of adversity in the middle of a season. "There were 100 different times where I wouldn't have had the perseverance he showed," Galik says. "I've never been prouder of him than what he did last year. We're a good team, and it's largely because the rest of the guys look up to Ronnie and see him as an inspiration."

As his recovery process began, Ronnie's mom, Lori McLaughlin, started researching the disease online. That's where she came across both the VF and Brandon Hudgins, a world-class runner who leads the Victory over Vasculitis Campaign. "I've really leaned on the VF for support," Lori says. "I wanted Ronnie to have someone to lean on as he gets ready to go off to college and enter the real world."

Lori bought Brandon's book "Going the Distance" for Ronnie, who says it's served as a great motivation. While he eventually wants to become an engineer, Ronnie has some immediate goals he's paying more attention to. "I would love to run in college and be an All-American at least once. I'd also like to qualify for the Olympic trials."

With all the accolades Ronnie has racked up, it's his performances off the track that his dad, Walt, is the proudest. "The biggest thing I've seen is his responsibility level. It's been off the charts for going through the things that he's faced as a 16- and 17-year-old."

Luckily, Ronnie is back to full health and in remission. As he begins his senior year, we are all rooting him on and hope that he can take his goals the distance.

**UPDATE: On Saturday, October 27th, Ronnie became the new West Virginia Cross Country State Champion!**



Ronnie Saunders

## Support the VF by Shopping Through AmazonSmile

If you're looking for a simple, way to support the Vasculitis Foundation, please start your Amazon shopping at [smile.amazon.com](https://smile.amazon.com). You shop as you normally would on the site, at no extra cost to you, and you don't need to make a separate account. Tens of millions of products are eligible for donations — just look for "Eligible for AmazonSmile donation" on its product detail page.

Through AmazonSmile, Amazon donates 0.5% of the purchase price from your eligible AmazonSmile purchases to a charity of your choice. Since it is the AmazonSmile Foundation is directly making the donation for you, you won't pay extra for anything when you use AmazonSmile. However, this also means you won't receive a tax deduction. The program is an easy way to supplement your existing charitable contributions to the VF.



## Erica Barram's Amazing Vasculitis Journey and the Phone Call that Changed Her Life

By John Fries

Thirty-two-year-old Erica Barram was just 22 when she was diagnosed with microscopic polyangiitis. Previously healthy, Erica didn't know anything about autoimmune diseases until learning she had one.



Erica Barram

She was completely unaware about how many people have vasculitis. "I was very scared when I was first diagnosed. I was also very angry, and I felt very alone. Thank goodness for the Vasculitis Foundation. It really opened my eyes."

### Initial Misdiagnosis, Then A Breakthrough

When Erica first presented with symptoms of stomach pains and dark urine with an unpleasant odor, her doctor had no clue it was vasculitis. "He told me 'Fifth Disease' was going around my neighborhood and prescribed medication which didn't help." According to HealthOnline.com, Fifth Disease is a viral disease that often results in a red rash on the arms, legs, and cheeks. It's fairly common and mild in most children, but it can be more severe for pregnant women or anyone with a compromised immune system.

In reality, Erica's symptoms were indicators that something much more serious was happening. While at work, her supervisors pulled her aside and told her she looked anemic. Following another physician appointment and more tests, Erica was advised to go to Iowa City Hospital immediately. "My boyfriend, Jesse, and I had just moved across the country to be closer to my school. We were on our own, far from home and I had just started a new job. Now, we were dealing with this health issue."

At Iowa City Hospital, Erica was diagnosed with microscopic polyangiitis. "At one point they conferenced in doctors from the Mayo Clinic to try to figure out my diagnosis. Before my biopsy, while I was in the ICU, a

doctor or nurse who was with my roommate, suggested checking me for an autoimmune disease."

### "A Teacher, A Caregiver, A Best Friend, And A Boyfriend."

"Everyone needs a person who can make them smile when they don't want to, and remind them of the good days during the bad ones," says Erica, "Jesse has been this person for me for 13 years. He has been more than just a boyfriend. He has been a teacher, a caregiver, a support, a best friend, a therapist at times, and one of the most patient and loyal men I've ever met."

Jesse found the Vasculitis Foundation's website. "He called them," says Erica. "The person he spoke with spent over an hour talking with him and giving him advice on how this was going to impact our future."

They realized the severity of what they were going through. For Jesse, having someone to talk with was huge. "I don't even know who he spoke with, but we remember the advice from that person. It truly benefited us and shaped our future. I learned that day that one helpful person could have a profound impact on our lives."

Erica adds, "I just love that the VF is made up of patients, caregivers, friends, family, and physicians because they relate to the ones actually living with vasculitis. It comes across this way each time I've had the pleasure of interacting with them. The VF has some of the most compassionate people I have come across, and I love what they do! Not every day will be easy, but there are others like you, and the Vasculitis Foundation is one place you can look to find support if you need it."

Erica travels to the Mayo Clinic in Rochester, Minnesota for treatment. She says that managing her health has become a full-time job.

She's very grateful that her treatment is working and looks forward to when she can "celebrate the end of my infusions and hopefully prednisone therapy, and find the next immunosuppression medication that will keep my illness quiet for, hopefully, a long time."

**"We are still spreading the word about the Vasculitis Foundation when we travel. The funniest thing happened when we were taking this picture at Dead Vlei, Namibia. We had the banner all ready and a woman and her daughter put themselves in our picture. They didn't say anything so I don't know if they knew about vasculitis or not."**

**Nina Adams and Olaf Westgaard**







## VASCULITIS CLINICAL RESEARCH CONSORTIUM

## VCRC

<https://www.rarediseasesnetwork.org/cms/vcrc/>

The Vasculitis Clinical Research Consortium (VCRC) is the major clinical research infrastructure in North America dedicated to the study of vasculitis. The VCRC has grown to include 18 academic medical centers in the United States and Canada conducting investigator-initiated clinical and translational research. The VCRC also partners with 50 other centers worldwide for the conduct of clinical trials.

The VCRC conducts observational cohort studies, biomarker development, studies of genetics and genomics, clinical outcomes research, studies using an online patient registry, pilot clinical projects, and multicentered, randomized clinical trials. Core components of the VCRC include the VCRC Clinical Data Repository, the VCRC Biospecimen Repository, the RDCRN VCRC Patient Contact Registry, the VCRC-NIH Data and Safety Monitoring Board.

### Join The VCRC Contact Registry!

Research offers no guarantees, but research cannot move forward without your help. Every active role a patient takes may possibly play a part in discovering new groundbreaking research and finding new treatments.

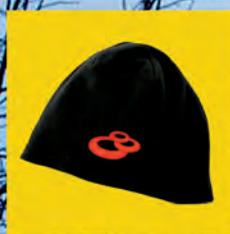
### Participating Institutions:

- Boston University School of Medicine Vasculitis Center
- Cedars-Sinai Medical Center United States
- The Cleveland Clinic
- Hospital for Special Surgery Vasculitis & Scleroderma Center
- Istanbul University
- The Mayo Clinic College of Medicine
- Mount Sinai Hospital
- Northwell Health
- Oregon Health & Science University
- St. Joseph's Healthcare, Hamilton
- University of California, Los Angeles Health
- University of California, San Francisco
- University of Kansas Medical Center
- University of Michigan
- University of Pennsylvania
- University of Pittsburgh
- University of Utah

Please visit the VCRC website to join the registry and to review the complete list of all current research studies available for patients to participate in. <https://www.rarediseasesnetwork.org/cms/vcrc/>

"COMFY"  
"COZY"  
"WARM"  
"TOASTY"

These are just a few of the adjectives people use to describe their cold-weather wear from the VF Store.



WARM UP YOUR WINTER!  
with cool gear  
from the VF Store!



*T-shirts, sweatshirts, jackets, caps, and fleece!*



SHOP NOW at  
**VFStore.com!**



## August, September and October Donors

Thank you for your gift of \$50 or More!

AB Distributing  
Julius Alexander  
Diann and Rex Alford  
Danielle and Craig Alshouse  
Amazon Smile Foundation  
America's Charities  
Karen and Joseph Anderson  
Jean and Allan Anderson  
David Angelini  
Ryan Anglin  
Amy Archer, MD, PhD  
David Armistead  
Aronberg Goldgehn  
AT&T  
Andy Balbirer  
Bank of America Employee  
Giving Campaign Campaign  
Paul and Ellen Barnett  
Louisette Basa  
Scott Bauer  
Ed Becker  
Michael Berk  
Kenneth Bevy  
Michael Blechman  
Howard Bloom  
Marc Boorstein  
Julie Bostick  
Dee Brown  
Bob Brownstein  
Patricia and Albert Buehler  
Foundation  
C. Brendan Noonan and  
Company, Inc.  
Cambridge Landscape Co, Inc.  
Robert and Antonette Caren  
Paula Carey  
Fern Carlin  
Kevin Carroll  
Christine Caserta  
George Casey, Jr.  
Lee Casty  
Rebecca and Christopher Cates  
Gerald and Marsha Chanan  
Barbara Chotiner  
CJBS, LLC.  
Mel Cohen  
Christa Collier  
Collins Insurance and  
Financial Services  
Patricia Connolly  
Barbara and John Cosaert  
Kenneth and Pamela Cosper  
Brian Cvelbar  
Judith Cvelbar  
Dillon Darcy  
Bernie Darcy  
Meredith and Jeff Davis  
Sherry Dawson  
Suzanne and Marcel DePaolis  
Melinda and Bob Deuster  
The Dolins Group, LTD.  
David Dorfman  
Jim and Donna Duffy  
David Eaton  
Charles Ebbecke  
Pat Ebersole  
Robert Eshenour  
Pete Espinoza  
Barry Feinberg  
Jessica Fischer  
Jeff and Sharyl Fishbein  
Daniel and Stacey Fishbein  
Kenneth and Debra Fishbein

Fishman Public Relations, Inc.  
Jessica and Kyle Foster  
Foster and Eldridge, LLP.  
Frederick Frein  
Norman and Sharel Fuenfer  
Bob Furio  
Steven and Terri Garcia  
Gateway Sales of Georgia  
Henry and Susan Gault  
GlaxoSmithKline  
Henry Gonzales  
Allen and Arlyn Goodman  
Andrew Gordon  
Robert Graham  
Graph-Pak  
Steven Greenberg  
Evelyn and Nate Grossman  
David and Lauren Grossman  
Arleen and Kenneth Grossman  
Brian Gryn  
Leonard and Elaine Gryn  
Randy Haberman  
Bob Hamer  
Ron Hamu  
Philip Hannon  
Harris and Murphy, LLP.  
Maervis and Jack Harrison  
Kersten Hastings  
Susan Healy  
Brad Hecht  
Elizabeth Heiny-Cogswell  
Clay Hessel  
Jayne and Seth Heyman  
Karen and Dan Hirsch  
Carlene and L.C. Hobbs  
Mark Hockey  
Edward Hockfield  
Dorothy Hubeli  
Paul Hughes  
IBM Employee Service Center  
IBM Retiree Charitable Campaign  
J.K. Group Inc.  
Victor and Brenda James  
Joan and Norman Chapman  
Foundation  
David Johnson  
Savita Jolly  
Melissa Kahn  
Joshua Kahn Living Trust  
Sanford and Judith Kahn  
Louis and Barbara Kahn  
Charitable Foundation  
David Kahn  
Martin Karlov  
Connor Kenneally  
Niesha Kennedy  
James Kennen  
Patricia Kerr  
Janie Klein  
Patricia and Ralph Koons  
James Krausen  
Ronald and Julie Krefta  
Mary Kress  
Jeffrey Kutchin  
Kathleen Lane  
Patrick Lane  
Christopher Lane  
Mary Lane  
John Lane  
William Lane  
Jack Lasday  
G.B. and Jacqueline Lassetter  
Kenneth Lebovic

Edward Leshin  
Jeffrey Levin  
Jennifer and Thomas Lovitt, II  
Barbara Lynch  
Jennifer Martin  
Bret Martin  
Andrew Mass  
Laura McLaughlin  
Mark McSweeney  
Judi Medaglia  
Frances and James Medaglia  
John Merlo  
Anthony Miscioscia  
Susan and Lou Mongillo  
Paula and Leon Moore  
Joseph Mullhall  
Kevin Mulvey  
Brad and Mona Murphy  
Nationwide Foundation  
Diane Nelson  
Network for Good  
Northwestern Medicine  
Anne Marie and Michael O'Connor  
Theresa O'Connor-Heisler  
Mark and Gina O'Dea  
Ohio Combined Federal Campaign  
On A Roll Trucking, Inc.  
Packaging Design Corporation  
John Parcellin  
Alan and Marla Patzik  
Sybil R. Paullin Marital Trust  
Michael and Anne Pedrigi  
Dave Pendleton  
Licia Phang  
Carlie Pierson  
Rosemary Pumo  
Dan and Steph Rasmussen  
Richard and Judith Ravin  
Patrick Rentz  
Nancy Riley  
Theodore Rodriguez  
Romo Fit Inc.  
Nancy Rosenbaum  
Michael Rosenson  
David Ruddy  
Eric Ruderman, MD  
David and Nikki Rust  
Glassman Sal Darigo  
Natacha Santoro  
Magda Schafler  
Schlesinger Associates, Inc.  
Stephen and Tiffany Schneider  
John Seward  
Sharon and Michael Shapiro  
Dennis Shine  
Harvey Silverberg  
Jessica and Joshua Skolnik  
Laurence Slavin  
Jill Slutler  
Sandra Smith  
Victoria Smith  
Michael and Donna Socol  
Genevieve Songer  
Robert Sosa  
Ashleigh Spellens  
Dr. and Mrs. Jason Springer  
Anna Squillante  
George and Janith Steiner, Jr.  
Lynne and Philip Stockman  
John Sumner  
Trudy Taylor  
Jacqueline and David Taylor  
Sheena Teckchandani

Jennifer A. Tempio  
The Zall Family Fund  
Charles Thiry  
Andy Tobias  
Raitis and Vija Treiberis  
Aaron and Jessica Tudyk  
Kristin McDaniel  
United Way of Buffalo and  
Erie County  
United Way of Los Angeles  
United Way of Miami-Dade, Florida  
United Way of Providence,  
Rhode Island  
United Way of the Virginia  
Peninsula  
United Way of Williamson County  
Zolton and Patricia Ur  
Louann Van Zelst  
Billie and Christopher Walden  
Kenneth Weiss  
Barry and Barbara Weiss  
Clarissa White  
Rickey Williams  
Kayse Williams  
Sherryl and Riser Williams  
David Wischmeyer  
Carol Zamb  
Marc Zaslavsky  
Justin Zovas

## IN MEMORIAM

Thank You to all those who made donations  
to the VF in memory of a loved one.

Laurel Anderson  
Lucinda Ann Basso  
Lola Bowlen  
Crystal Ann Branch  
Linda Briggs  
Claire Cantin  
Rev. James Carmody  
Anthony Cvelbar  
Robert L. De Lillo, Sr.  
Dalia Espinoza  
Ruth Fain  
Shirley Fischer  
Christopher Gomes  
Christopher M. Gonzales  
Timothy Allen Gregoire  
Jack Hogg  
Leo Jeyowski  
Beatrice Johnson  
Om Jolly  
Sutton Marie Kinsley  
Jane Marie Lynch  
Marsha D. McCary  
Joanne McMahon  
Brent Mangum  
Ross Nelson  
Nick Pascente  
Jeannette Perch  
Mae Betty Rainville  
James Springer  
Keesha Vessell  
Danielle Walling

## VF Medical and Scientific Advisory Board

**Abdou, Nabih I., M.D., Ph.D.,**  
FACP (Retired)  
University of Missouri  
Rheumatology/Immunology  
Kansas City, Missouri

**Allen, Nancy B., M.D.**  
Duke University  
Rheumatology/Immunology  
Durham, North Carolina  
919.684.2965

**Archer, Amy M., M.D.**  
Northwestern Medical Group  
Rheumatology Vasculitis Clinic  
Chicago, Illinois  
312.695.8628

**Benseler, Susanne, M.D., MSc., Ph.D.**  
Alberta Children's Hospital  
Rheumatology, Department  
of Paediatrics  
Calgary, Alberta, Canada  
403.955.2253

**Bradley, Elizabeth A., M.D.**  
Mayo Clinic - Ophthalmology  
Rochester, Minnesota  
507.284.8538

**Brant, Elizabeth, J., M.D.**  
Nephrology and Hypertension  
Dartmouth-Hitchcock Medical  
Center  
Lebanon, New Hampshire  
603.653.3830

**Byram, Kevin, M.D.**  
Vanderbilt University  
Rheumatology & Immunology  
Nashville, Tennessee  
615.322.4746

**Cacoub, Patrice, M.D.**  
Department of Internal Medicine  
La Pitié-Salpêtrière Hospital  
Paris, France  
33.142178027

**Capizzi, Stephen A., M.D.**  
Mid State Pulmonary Associates  
Nashville, Tennessee  
615.284.5098

**Carette, Simon, M.D., FRCP(C).**  
Division of Rheumatology  
University Health Network/  
Mount Sinai Hospital, Toronto,  
Ontario, Canada  
416.603.6751

**Cartin-Ceba, Rodrigo, M.D.**  
Division of Pulmonary and  
Critical Care Medicine,  
Mayo Clinic, Scottsdale, Arizona  
480.301.1735

**Chonko, Arnold M., M.D., FACP.**  
University Of Kansas  
Nephrology/Hypertension  
Kansas City, Kansas  
913.588.6074

**Chung, Sharon, M.D., MAS.**  
University of California -  
San Francisco  
Division Of Rheumatology  
San Francisco, California  
415.514.1673

**Cid, Maria C., M.D.**  
University of Barcelona  
Hospital Clinic  
Barcelona, Spain  
34.93.227.5774

**Dooley, Mary Anne, M.D.**  
WakeMed Rheumatology  
Raleigh, North Carolina  
919.235.6454

**Dua, Anisha, M.D., MPH**  
University of Chicago  
Rheumatology/Vasculitis  
Chicago, Illinois  
773.834.4150

**Falk, Ronald J., M.D.**  
University of North Carolina  
Nephrology/Hypertension  
Chapel Hill, North Carolina  
919.966.4615

**Fervenza, Fernando, M.D., Ph.D.**  
Mayo Clinic - Nephrology  
Rochester, Minnesota  
507.266.7083

**Flores-Suarez, Luis Felipe, M.D.**  
Primary Systemic Vasculitides  
Clinic  
Instituto Nacional De  
Enfermedades Respiratorias  
Tlalpan, México  
52.55.5536.3702/  
52.55.5536.5777

**Forbess, Lindsay, M.D., MSc.**  
Rheumatology  
Cedars Sinai Medical Center  
Los Angeles, CA  
310.854.3539

**Garrity, James A., M.D.**  
Mayo Clinic - Ophthalmology  
Rochester, Minnesota  
507.284.8538

**Geetha, Duvuru, M.D., MRCP.**  
The Johns Hopkins University  
Vasculitis Center  
Baltimore, Maryland  
410.550.6825

**Goeken, James A., M.D.**  
(Retired)  
University of Iowa  
Pathology  
Iowa City, Iowa  
319.356.1966

**Gota, Carmen E., M.D.**  
Department of Rheumatology  
Cleveland Clinic - Center for  
Vasculitis Care and Research  
Cleveland Ohio  
866.275.7496

**Grayson, Peter, M.D., MSc.**  
National Institute of Arthritis  
and Musculoskeletal and Skin  
Diseases Bethesda, Maryland  
301.451.1450

**Gross, Wolfgang L., M.D., Ph.D.**  
(Retired)  
University of Lübeck  
Dept. of Rheumatology  
Bad Bramstedt, Lübeck, Germany

**Guillevin, Loic, M.D.**  
Groupe Francais d'Etude des  
Vasculitides  
French Vasculitis Study Group  
Hopital Cochin-Paris University  
Paris, France

**Hajj-Ali, Rula, M.D.**  
Cleveland Clinic - Center for  
Vasculitis Care and Research  
Cleveland, Ohio  
216.444.9643

**Hashkes, Philip J., M.D., MSc.**  
(For Pediatric Patients)  
Shaare Zedek Medical Center  
Pediatric Rheumatology Unit  
Jerusalem, Israel  
972.2.6666242

**Heeringa, Peter, Ph.D.**  
Department of Pathology  
& Medical Biology, University  
Medical Center Groningen,  
The Netherlands  
31.50.3610789

**Hellmann, David, M.D., MACP.**  
The Johns Hopkins University  
Dept. of Medicine  
Baltimore, Maryland  
410.550.0516

**Hoffman, Gary S., M.D., MS.,**  
M.A.C.R.  
Professor Emeritus  
Cleveland Clinic Lerner  
College of Medicine  
Center for Vasculitis Care  
and Research  
Cleveland, Ohio

**Jayne, David, M.D.**  
Renal Unit  
Addenbrooke's Hospital  
Cambridge, United Kingdom  
44.1223.586796

**Kermani, Tanaz, M.D.**  
Division of Rheumatology  
UCLA Medical Center  
Santa Monica, California  
310.582.6350

**Khasnis, Atul, M.D., MS.**  
Piedmont Peachtree City  
Rheumatology  
Peachtree City, Georgia  
770.506.1400

**Koenig, Curry, M.D., MS.**  
University of Utah  
Division of Rheumatology  
Salt Lake City, Utah  
801.581.4333

**Koster, Matthew J., M.D.**  
Mayo Clinic  
Rheumatology  
Rochester, Minnesota  
507.266.4439

**Lally, Lindsey, MD**  
Hospital for Special Surgery  
Rheumatology  
New York, New York  
212.774.2434

**Langford, Carol A., M.D., MHS.**  
Cleveland Clinic - Center for  
Vasculitis Care and Research  
Cleveland, Ohio  
216.445.6056

**Lebovics, Robert S., M.D., FACS**  
Otolaryngology/Head  
& Neck Surgery  
New York, New York  
212.262.4444

**Lee, Augustine S., M.D.**  
Mayo Clinic  
Pulmonary and Critical Care  
Jacksonville, Florida  
904.953.2000

**Levine, Stuart, M.D.**  
MedStar Harbor Hospital  
Baltimore, Maryland  
410.350.3483

**Lorenz, Robert R., M.D.**  
Head & Neck Institute  
Cleveland Clinic Main Campus  
Cleveland, Ohio  
216.444.3006

**Mahr, Alfred, M.D., Ph.D.**  
Department of Internal Medicine  
Hospital Saint Louis  
Paris, France  
33.1424.099780

**Maksimowicz-McKinnon,**  
**Kathleen, D.O.**  
Rheumatology  
Henry Ford Medical Group  
West Bloomfield, Michigan  
313.916.2631

**Matteson, Eric L., M.D.**  
Mayo Clinic (Retired)  
Rheumatology  
Rochester, Minnesota

**Maz, Mehrdad, M.D.**  
Allergy, Clinical Immunology  
and Rheumatology  
KU Medical Center  
913.588.6009

**Mcdonald, Thomas J., M.D., MS.**  
F.A.C.S. (Retired)  
Mayo Clinic  
Otorhinolaryngology  
Rochester, Minnesota

## VF Medical and Scientific Advisory Board

**Merkel, Peter A.**, M.D., MPH.  
Division of Rheumatology  
University of Pennsylvania  
Philadelphia, Pennsylvania  
215.614.4401

**Molloy, Eamonn**, M.D., M.S., FRCPI.  
Department of Rheumatology  
St. Vincents University Hospital  
Dublin, Ireland  
353.1221.3142

**Monach, Paul**, M.D., Ph.D.  
Brigham and Women's Hospital  
Division of Rheumatology  
Immunology, and Allergy  
Boston, Massachusetts  
617.732.5325

**Nachman, Patrick**, MD, FASN  
University of Minnesota  
Minneapolis, Minnesota  
612.626.6100

**Pagnoux, Christian**, M.D., MSc., MPH.  
Division of Rheumatology  
Mount Sinai Hospital  
Toronto, Ontario, Canada  
416.603.6751

**Quinn, Kaitlyn A.**, MD  
MedStar Health  
Washington, D.C.  
202.444.6200

**Rodriguez-Pla, Alicia**, M.D., Ph.D., MPH.  
University of Arizona  
Division of Rheumatology  
Tucson, Arizona  
520.694.8888

**Sawalha, Amr**, M.D.  
Division of Rheumatology  
University of Michigan Health  
System  
Ann Arbor, Michigan  
734.763.1858

**Senior, Brent A.**, M.D., FACS., FARS.  
Division of Rhinology, Allergy,  
and Endoscopic Skull Base  
Surgery  
University of North Carolina at  
Chapel Hill  
984.974.6484

**Seo, Philip**, M.D.  
The Johns Hopkins University  
Vasculitis Center  
Baltimore, Maryland  
410.550.6825

**Silva, Francisco**, M.D.  
Vasculitis Unit of Pontificia,  
Universidad Catolica de Chile  
Santiago, Chile  
562.2354.3078; 562.2354.307

**Spalding, Steven J.**, M.D.  
Phoenix Children's Group  
Phoenix, Arizona  
602.933.0909

**Specks, Ulrich**, M.D.  
Mayo Clinic  
Pulmonary and Critical Care  
Rochester, Minnesota  
507.284.4348

**Spiera, Robert**, M.D.  
Hospital For Special Surgery  
New York, New York  
212.860.2100

**Springer, Jason**, M.D., MS.  
Allergy, Clinical Immunology  
and Rheumatology  
KU Medical Center  
Kansas City, Kansas  
913.588.6009

**Sreih, Antoine**, M.D.  
Medicine/Rheumatology  
University of Pennsylvania  
Philadelphia, Pennsylvania  
312.942.6641

**Stone, John H.**, M.D., MPH.  
Massachusetts General Hospital  
Rheumatology Associates  
Boston, Massachusetts  
617.726.7938

**Villa-Forte, Alexandra**, M.D.  
Cleveland Clinic - Center for  
Vasculitis Care and Research  
Cleveland, Ohio  
866.275.7496

**Warrington, Kenneth J.**, M.D.  
Mayo Clinic  
Rheumatology  
Rochester, Minnesota  
507.284.2970

**Weisman, Michael H.**, M.D.  
Rheumatology  
Cedars Sinai Medical Center  
Los Angeles, CA  
310.423.2170

**Weyand, Cornelia**, M.D., Ph.D.  
Immunology & Rheumatology  
Clinic  
Stanford University  
Stanford, California  
650.723.5521

**Yazici, Yusuf**, M.D.  
Rheumatology  
Hospital for Joint Diseases  
New York, New York  
646.356.9400

**Yeung, Rae S. M.**,  
M.D., Ph.D., FRCP(C).  
Paediatrics, Immunology  
Rheumatology  
The Hospital for Sick Children  
Toronto, Ontario, Canada  
416.813.8964

## Events

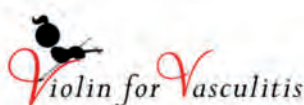
## V4V - Giving Tuesday Two Hour Special: "Violin Request Hour"

**Tuesday, November 27, 2018**  
**7:00 p.m. - 9:00 p.m.**

Mark your calendar now!  
This is a fun annual Giving  
Tuesday tradition through my  
nonprofit organization, Violin  
for Vasculitis, Inc. If you have a Facebook account, you  
can tune in at any time to request any song you wish,  
and I'll do my best to honor it on the live broadcast!

The event is a two-hour fundraiser for V4V's 2019  
travels. Your contributions are tax-deductible, with 10%  
of proceeds going directly to the Vasculitis Foundation.

Location: [online at www.facebook.com/v4vinc](https://www.facebook.com/v4vinc)  
For more info: [www.ViolinForVasculitis.org](http://www.ViolinForVasculitis.org)



## Fishbein Golfing Event

The Fifth Annual Chicagoland Golf Open was held on  
Wednesday, August 29th at the beautiful Twin Orchard Golf  
Club in Long Grove, Illinois. The tournament, organized by  
Dr. Jeff Fishbein, a recently retired member of the VF Board  
of Directors, and his brother, Danny, and their extended  
family, has raised over \$364,000 for the VF since 2014.

The funds raised from the event have funded the creation  
of the Northwestern Vasculitis Center, which provides  
coordinated care for patients with vasculitis. Donations  
from the event have also funded four fellowships through  
the VF-VCRC Fellowship Program over the past four years.  
The goal of the program is to provide the training needed  
for these physicians to become the future leaders in patient  
care and research efforts.

We are extremely grateful to Jeff and Danny and all of  
their family and friends for their generous support of the  
Vasculitis Foundation over the years.



## Vasculitis Foundation Membership Campaign – JOIN!

PLEASE FILL OUT FORM COMPLETELY, DETACH AND SEND TO VF OFFICE

### I Am Pleased To Support The Vasculitis Foundation Through My Membership Dues.

DUES: \_\_\_\_ \$35 U.S. for all members \_\_\_\_ \$500 U.S. Lifetime Membership

In addition, I would like to make a tax-deductible gift \* of: \_\_\_\_ \$45 \_\_\_\_ \$60 \_\_\_\_ \$75 \_\_\_\_ \$100 \_\_\_\_ \$150 \_\_\_\_ Other \$ \_\_\_\_

Enclosed is my Check or Please Bill My Credit Card (circle one). Visa/MasterCard/Discover/American Express

Card #: \_\_\_\_\_

Name as listed on Card: \_\_\_\_\_

Signature: \_\_\_\_\_

Exp. Date: \_\_\_\_\_ Total: \$ \_\_\_\_\_

Email: \_\_\_\_\_

\_\_\_\_ I would like to make a monthly pledge of \$ \_\_\_\_\_ billed to my credit card.

\_\_\_\_ Check if you would like to designate the VF as a beneficiary in your will.

\* This gift is: \_\_\_\_ In memory of \_\_\_\_ In honor of \_\_\_\_ A Gift Membership for

Name: \_\_\_\_\_

Address: \_\_\_\_\_

City: \_\_\_\_\_ State: \_\_\_\_\_ Zip: \_\_\_\_\_

Country (if outside the U.S.): \_\_\_\_\_

**Mail to: Vasculitis Foundation, P.O. Box 28660, Kansas City, MO 64188**

### Celebrating a Life and Raising Funds for Research

By Diann Alford

Eighty five people participated in the 13th Annual Celebrating A Life: Keesha Vessell Vasculitis Walk on September 22nd at the Veterans' Park in Newnan, Georgia.

The walk is held each year in memory of Keesha Jones Vessell, a Newnan native who died in January 2006 from Wegener's (now GPA). Keesha struggled with health issues for approximately two years prior to an emergency admission to Piedmont Atlanta Hospital in August 2005.

She remained hospitalized until her death in January. Her wish was to increase awareness of vasculitis, and to conduct fundraisers to help expand research to find cures.

Keesha's family began the annual walk in September 2006 to honor her wishes. The walks have raised over \$34,000 for the Vasculitis Foundation.

### VF UCLA Patient Conference Brings Together Patients and Vasculitis Specialists

Despite the threat of wildfires near the Westwood Campus of UCLA, Los Angeles, California, more than 60 people attended the Vasculitis Foundation Patient Conference on Saturday, November 10. The event featured vasculitis specialists giving presentations such as Nerve Involvement in Vasculitis, Earlier Diagnosis of Vasculitis, Resilience, and Vasculitis Risk. The speakers engaged the audience with important information about the disease and how to manage some of the challenges on a day-to-day basis.



## Early Diagnosis, *cont. from page 1*

Another patient with Behcet's may be initially seen with mouth or genital ulcers, but their condition grows worse because the underlying vasculitis isn't identified.

### Obstacles to Diagnosis: Todd's Story

Todd Brusa's story is a classic delay in diagnosis obstacle course that went on for more than three years.



Todd Brusa

He began to have trouble breathing, along with an excessive amount of mucus in his lungs in 2006. Even after repeated albuterol breathing treatments, and short-term prednisone treatments, his condition would improve only temporarily before he would feel worse.

"I saw many doctors and specialists," recalls Brusa. "They usually said it was late stage asthma."

One doctor said I had Valley Fever caused from living in the Arizona climate. Finally, in late 2009 my ER doctor looked at my bloodwork and saw that my eosinophils and white blood cell counts were through the roof. That doctor consulted with a rheumatologist. Ultimately a lung biopsy revealed eosinophilic granulomatosis with polyangiitis (EGPA, formerly Churg-Strauss)."

Unfortunately, the untreated vasculitis had three years to leave Brusa with numerous complications including a loss of hearing. For other patients, a delay in diagnosis can result in kidney failure, or other organ system damage.

### Early Intervention with Children and Young Adults

While early diagnosis is difficult in adults, the challenges can be even greater in pediatric patients. Sometimes

symptoms may be overlooked in children because kids are "supposed" to be healthy and it is not until a more serious disease manifestation that they come to a providers' attention.

Emily Brunner understands that dilemma because she sees it happen on a routine basis as a pediatric rheumatologist at the University of Pittsburgh Medical Center Rheumatology and Clinical Immunology.

"Getting an accurate history from a child is completely different from an adult. Kids will answer your questions but may not use the words you're expecting, or they may not be able to elaborate beyond, 'I feel yucky'."

The speed with which a pediatric patient comes to medical attention depends on a number of factors: the severity of the symptoms, family resources, awareness of medical providers, and proximity to a pediatric rheumatologist," says Dr. Brunner.

She says helping to provide awareness and education to the medical community about vasculitis is a critical task and one the VF does particularly well through its Continuing Medical Education (CME) initiatives, and support for studies such as the Pathway to Diagnosis.

Joyce Kullman, Executive Director of the VF, says that improving early diagnosis is the first of the three core goals supporting the VF's Join Our Journey campaign.

"If we reduce the time it takes for patients to get a diagnosis, that will potentially be a game-changer in affecting the overall outcome and quality of life for a patient. Our focus is making a difference in the first step of that journey."

**It has been a banner year for the VF as we made progress in our mission to fund research, support patients, and raise awareness about the need for early diagnosis.**

\$89,000

How much our 15+ fundraisers brought in this year

\$162K

VF-funded new research

43

Record number of medical professionals nominated for V-RED Award

9,000+

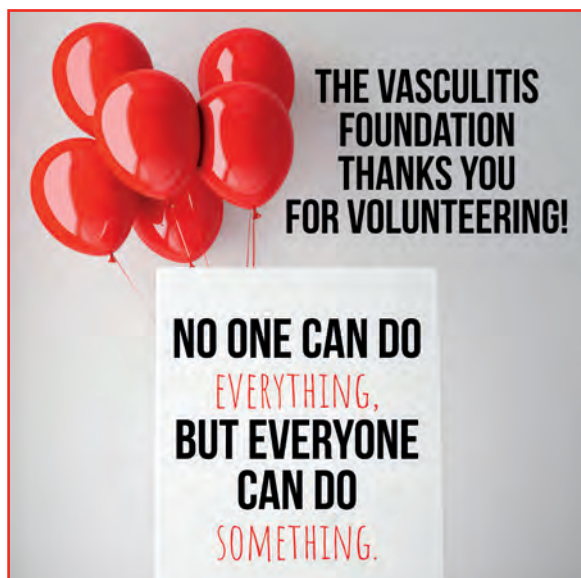
Phone calls and emails answered by VF Patient Support

6,000+

Number of members in the VF Facebook Group

28

New Patient Videos



## VF Calendar of Events • 2018 - 2019

Go to our online calendar with the latest information about  
our upcoming events: **Vasculitis Foundation**

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

**November 27, 2018**

**Understanding EGPA/CSS and Nucala Webinar**

- › Speaker: Michael Wechsler, MD
- › 12:00 p.m. - 1:00 p.m. EST
- › Register: <https://register.gotowebinar.com/register/7688067170756391939>

**November 27, 2018**

**V4V - Giving Tuesday 2-Hour Special:  
Violin Request Hour**

- › 7:00 p.m. - 9:00 p.m.
- › Online at [www.facebook.com/v4vinc](http://www.facebook.com/v4vinc)

**January 12, 2019**

**Seattle VF Patient Conference**

- › Crowne Plaza Seattle Airport  
17338 International Boulevard  
Seattle, Washington
- › 9:00 a.m. - 3:30 p.m.

**February 28, 2019**

**International Rare Disease Day**

**March 9, 2019**

**VF - Mayo Clinic Arizona Patient Conference**

- › Waugh Auditorium  
5777 East Mayo Boulevard  
Phoenix, Arizona
- › 8:30 a.m. - 3:30 p.m.

**April 7-10, 2019**

**The 19th International Vasculitis & ANCA Workshop  
For Physicians and Researchers**

- › Loews Hotel  
Philadelphia, Pennsylvania
- › [www.vasculitis2019.org](http://www.vasculitis2019.org)

**May 1-31, 2019**

**Vasculitis Awareness Month**

**July 19-21, 2019**

**2019 International Vasculitis Symposium**

- › Hyatt Regency - Bloomington  
Bloomington, Minnesota