Register Today for the 2019 International Vasculitis Symposium

By Ed Becker
Director of Marketing & Communications

On July 19-21, 2019, hundreds of patients and their families, vasculitis medical experts and researchers, will converge in Bloomington-Minneapolis for a weekend of education, entertainment, and fellowship for the 2019 International Vasculitis Symposium.

This marks the 14th international symposium the Vasculitis Foundation (VF) has held since 1994. There’s a good reason VF symposia are only held every other year—it requires two years of planning to make each new symposium even better than the previous one.

Symposium Education: A Diverse Patient Population
The 2019 International Vasculitis Symposium will feature a full slate of presentations that meets the needs of a diverse, and broad audience. As Joyce Kullman, executive director of the VF, explains, the challenge is connecting with patients who are at different stages of their illness.

“For the newly diagnosed, there are presentations providing a basic understanding about vasculitis,” says Kullman. “We also have sessions for those patients who have been managing their disease for many years and may require more advanced information. Also, our attendees include young adults, parents of pediatric patients, and other family members. We want to provide everyone with the latest, most valuable information over the weekend.”

Annual Appeal Exceeds Expectations

By Beth Westbrook
Director of Development

THANK YOU for coming together and successfully raising $217,880 during our 2018 Annual Appeal. Your contributions support development of research, educational programs, and other resources to help patients with vasculitis, and their families.

Your donations give us momentum toward our common goals—earlier diagnosis, better treatments, and improved quality of life. How quickly we get there depends on the science, the treatment options, and the continued funding to make it happen. Your investment in the work the Vasculitis Foundation (VF) does is making a difference.

Sharing Insights
As a stakeholder, the VF would like to share a few insights from the 2018 Annual Appeal—Join Our Journey.

We took a bold move by asking you to embrace a three-year campaign to see how far we can go together, and here’s what we learned.

The 2018 campaign saw a 20% increase in the number of donations, and an increase in support from new donors. Online giving popularity is growing because donors like the ease of the process.

To better meet supporter needs, in 2018, the VF added a new online giving tool using peer-to-peer fundraising. The online campaign raised $63,769 in its first year.
Dear Friends,

Do you know what the abbreviation ROI means? If you’ve ever attended a staff or Vasculitis Foundation (VF) Board of Directors meeting, you know the term stands for Return On Investment. It’s used when discussing whether the time and effort invested in a project will yield a greater result.

Put another way, will you get back more than you put into a project, a goal, or endeavor?

I think of this term, ROI, when it comes to the VF Symposium, and the regional patient conferences that we offer throughout the year. For patients and family members, these educational forums are an investment of time, money, and energy.

The critical question—will you get more from the event than what it cost you to get there? If you’ve ever attended a three-day symposium, I’m confident that answer is yes!

Check out our feature story about the upcoming 2019 International Vasculitis Symposium taking place in Bloomington, Minnesota, July 19-21. You’ll find a list of preliminary presentation topics and logistical details.

I believe that when you leave the symposium, you will have a better understanding of vasculitis, the individual forms of the disease, and how to manage it. Equally important, you will make friends with other attendees who face many of the same challenges. Now, that’s what I call a good return on your investment.

Mark your calendars! May is Vasculitis Awareness Month, and it’s fast approaching! Please join us in raising awareness about vasculitis and the impact it has on people’s lives.

Sincerely,

Joyce A. Kullman
Executive Director

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 Recognizes Service of Three Board Members

Serving on the Vasculitis Foundation (VF) Board of Directors is a voluntary position, requiring many hours of work and service. This month we bid farewell to two of our members, George Casey, and Rhonda Johnson, who resigned due to personal reasons. Additionally, we note the passing of one of our champions, Chris Cox-Marinelli, MD.

George Casey, MBA, joined the VF board in 2011, and served as the organization’s treasurer and as president. Since its establishment in 2014, he also served as the co-investigator of the Vasculitis Patient-Powered Research Network (VPPRN), a partnership of the VF, investigators at the University of Pennsylvania, and the Vasculitis Clinical Research Consortium (VCRC).

Under George’s guidance, the VF almost doubled its financial growth, expanded its research funding, and helped establish the Northwestern University Vasculitis Center. He was instrumental in expanding efforts to partner with industries and institutions to expand our ability to serve and develop the assets required for continuing to advance the vasculitis research agenda.

Rhonda Johnson Byrd joined the VF board in 2015. As a retired attorney, she oversaw the review and update of the organization’s bylaws in 2016 and employee handbook, and often provided guidance to the organization on other legal matters. Rhonda enjoyed meeting other people with vasculitis and helping others develop lifestyle coping strategies. She often said, “I have Wegener’s, but Wegener’s doesn’t have me.”

We are sad to announce that Dr. Chris Cox-Marinelli, former chair of the VF Research Program, passed away after a long and difficult battle with vasculitis. Chris joined the VF board in 2011 and organized the annual review of applications.

In a report Chris shared on the 2016 Research Program, she stated, “I was a practicing neurosurgeon who developed Takayasu arteritis in 2001, and became disabled. As both physician and patient, I thought I could best contribute to the VF by chairing the research committee. Research is our hope for the future, and it is exciting to work on studies which will take us to our goal.”

Sara Baird Amodio Brings Nonprofit Experience to VF Board Role

When she attended the 2017 International Vasculitis Symposium, Sara Baird Amodio summed up the experience as simply, “life-changing.” As a patient with EGPA, she found the event to be a powerfully positive opportunity to learn how to manage her illness, and to connect with both patients and medical specialists.

The symposium clearly showed her the Vasculitis Foundation’s (VF) mission of providing education, research, clinical, and awareness initiatives. When Suzanne DePaolis, president-elect of the board, suggested she apply to be on the VF board, Sara agreed it was the right move.

She brings a strong background working in the nonprofit world to the VF. In addition to being an Assistant Professor of Nonprofit Management at Regis University in Denver, Sara served in key roles on numerous boards including City Club of Denver, the Longmont Performing Arts Initiative, and the Longmont Youth Symphony.

Sara lives in Erie, Colorado, with her husband, two teenage daughters and “a menagerie” of pets. The Amodios love to travel, with Italy being a favorite destination. She also enjoys practicing her crochet skills, reading, and tutoring.

Sara believes that her experiences in strategic planning, marketing and development, and donor cultivation align with the goals of the VF. As a patient, Sara feels that she can address the needs of the vasculitis community and help translate them into the organization’s goals.

“I am honored to serve the VF in this role,” says Sara. “To be able to connect with such strong, inspirational, and passionate people who share similar experiences is a gift I could’ve never imagined when I was first diagnosed. Living with a rare disease can sometimes make you feel so isolated and alone, but the VF has given me the virtual and face-to-face support that I need to live my best life now.”
2019 Symposium, cont.

The 2019 Symposium will tackle another challenge—discussing the latest topics affecting the vasculitis community, such as integrative health, nutrition, and even the emerging issue of using cannabidiol (CBD) oil in the pain management of vasculitis.

“These are the things our patients are asking about on social media. What is the anti-inflammatory diet? Is it safe to use CBD oils? The symposium is our best venue to provide answers from vasculitis medical professionals,” says Kullman.

While education is a key goal, the VF also wants attendees to enjoy what is a positive, fun, and uplifting event.

To learn more or to register for the symposium, visit: https://bit.ly/2ECDyZm

Symposium Headquarters:
Hyatt-Regency (next to the Mall of America)
3200 E. 81st Street, Bloomington, Minnesota

Room Information
» Room rate: Single/Double: $125 + taxes; Triple: $145 + taxes; Quad: $155 + taxes
» Room block closes June 25, 2019 or as soon as block is filled
» Reserve: Call 800.233.1234
» Click here to reserve: https://bit.ly/2IE2xiX
» Group code: G-VASC

Register Today!
Registration Fee
» $240/person April 1 – July 13, 2019
» To register online visit: https://bit.ly/2UBwLVc

Scholarships
A limited number of scholarships for registration and travel expenses are available. For an application, please email the VF office at vf@VasculitisFoundation.org. The deadline for submitting an application is June 7, 2019.

All ages are welcome to attend the symposium. This year, we are organizing some special groups by age and interest.
» Pediatric Patients (17 and under) and Parents/Guardians
» Teenagers (13-17)
» 18-35 Years Old: Life + Vasculitis
» Caregivers and Managing Families

Preliminary list of topics:
» Vasculitis 101 for the Newly Diagnosed Patient
» Vasculitis 201
» Individual Disease Sessions
» Parents of Children with Vasculitis (under age of 20)
» Bone Health
» Cardiology/Vascular Involvement
» Caregivers and Family Dynamics
» CBD Oil Discussion
» Dermatology/Skin Involvement
» Disability/Medicare/Insurance
» Ear/Nose/Throat Involvement
» Exercise—Making it Work
» Eye Involvement
» Fertility and Pregnancy
» Genetics in Vasculitis
» Immunology
» Journaling for Better Health
» Integrative Medicine in Vasculitis
» Medications: The Good, the Bad, What’s on the Horizon?
» Mental Health/Wellness/Alternative and Integrative Medicine
» Mindfulness and Meditation
» Neurological Involvement/Neuropathy
» New Findings and Results from the 2019 Vasculitis and ANCA Workshop
» Nutrition’s Role in Disease Management
» Pulmonary Involvement
» Remission: Getting There, Maintaining It
» Renal Involvement
» Research Advances Funded by the Vasculitis Foundation
» Stress Management and Relaxation
» Transition from Teen Years to College through Adulthood
» Wound Care
What’s Does a VF International Symposium Look Like?

Here are some photos from the 2017 International Symposium in Chicago

Learn
Vasculitis medical specialists present the latest developments in the diagnosis, treatment, and management of the disease.

Share
Patients from around the world meet new friends who understand what it means to live with vasculitis.

Celebrate
A diverse community that shares the same challenges provides positive, uplifting support to each other.

This is what you will find at the 2019 symposium. We hope you will be able to attend and that you, too, will enjoy a life-changing and meaningful event. The symposium is scheduled for July 19-21, 2019. For details or to register, go to www.vasculitisfoundation.org/ and click the LEARN MORE button on the home page.

What Do People Say about VF Symposia?

“The Vasculitis Patient Symposium is a critical forum for physicians, researchers, and patients with vasculitis to connect and learn from each other as we work together to cure these diseases.”

Peter Grayson, MD, PhD

“For me, attending the 2017 VF Symposium was a life-changing experience because it gave me what I needed to fully understand and manage my disease.”

Sara Baird Amodio, MSW, EdD

“For patients, the International Symposium offers an exceptional opportunity not only to hear from vasculitis specialists, but also to meet others with similar forms of vasculitis and shared experiences. As a doctor, it allows me to meet patients to learn what is most important to them.”

Jason Springer, MD, MS
New VF Website Developed With Your Needs In Mind

By John Fries

The Vasculitis Foundation (VF) launched a new website in March. The new site is easier to navigate, provides more resources and is aesthetically more pleasing than our old site, which was more than 5 years old. The site upgrade was made possible through grant support from Genentech and GSK.

“We’re thrilled to be able to provide patients, families, physicians, the public, and other members of our audience with a much-improved user experience,” said VF Executive Director Joyce Kullman, who worked for several months with VF staff and external professionals to plan and develop content. “Our goal was to create a new website that provides critical information quickly and easily to viewers. Although it’s now live, it will continue to be a work in progress with updates, enhancements, and fresh content.”

Visit the new VF Website: www.VasculitisFoundation.org

Upgrades and Improvements Include:

The latest clinical info on all vasculitic diseases
Each form of vasculitis has its own section, with updated and expanded information on diagnosis, symptoms, treatments, research, and disease management. Ed Becker, director of marketing and communications, organized an extensive, easily searchable section for the educational webinars, presentations, videos and patient spotlights for each of the diseases.

Find an updated list of vasculitis specialists worldwide
The Find A Doctor platform provides a more robust map, where physicians and clinics are located. The map is a work in progress and will be updated on a regular basis.

Mobile-Friendly, Multi-Platform
It’s more responsive, so it works equally well on all web browsers and mobile devices. Moreover, the new site incorporates the latest safeguards and security.
EGPA Association in Italy Connects Patients and Physicians

By John Fries

Italy has its first professional association dedicated to vasculitis, with an emphasis on eosinophilic granulomatosis with polyangiitis (EGPA), thanks to Dr. Marco Folci, a clinical immunologist in Milan, and several other medical professionals who founded the group.

Through the Associazione Pazienti Sindrome di Churg Strauss (APACS), established in 2016, Dr. Folci and his colleagues are working to build an Italian registry, connect patients and specialists, raise funds to stimulate independent research, and produce informational materials.

“We estimate that there are around 1,000 EGPA patients among vasculitis patients in Italy,” said Dr. Folci. “There are very few vasculitis specialists here, and there was no real way for patients to interact with and support each other. We created APACS with the aim of improving diagnosis and patient support, by fostering research, grouping Italian patients and connecting specialists,” he said.

APACS’ goal is to reach every patient in Italy. The group is also working to collaborate with the European reference network on rare diseases to improve vasculitis awareness in Europe, and to connect Italian EGPA patients with other European patients.

Dr. Folci first shared the idea to create APACS in early 2016 with Dr. Jan Schroeder, a colleague at Milan’s Niguarda Hospital, and members of the EGPA group on Facebook. He also conferred with Francesca Torracca, who is the group’s future president, before developing the association.

APACS has an administrative board composed of nine patients and a scientific board made up of specialists, mainly clinical immunologists and nephrologists, who treat patients with EGPA and conduct research on the vasculitides.

“At the moment, I’m one of five doctors” he said. “Every staff member is a volunteer. We have about 100 patients associated with us at the moment.”

Last year, APACS held its first two meetings, to introduce the organization and its mission to medical professionals, patients, and the general public.

This year, he contacted the Vasculitis Foundation (VF). “We believe that our mission is in agreement with VF, so I suggested that we join together in the effort and grow it over the geographic boundaries,” said Dr. Folci.

The association’s website is https://apacs-egpa.org/

VF Conference Highlights Need for Patient Education in Arizona

On March 9, the Vasculitis Foundation (VF) and the Mayo Clinic Arizona partnered to hold the first vasculitis patient conference at Mayo’s Phoenix Education Center.

The event drew more than 65 patients and families from more than nine states, including Illinois, Texas, Utah, and Kansas. Based on the feedback from the patients and the physicians who attended, it was a welcome opportunity for an underserved community in the Southwestern region of the country.

Six medical professionals delivered clinically focused presentations designed to give both newly diagnosed and “experienced” patients the latest information in the diagnosis, treatment, and maintenance of the disease.

Rodrigo Cartin-Ceba, MD, a pulmonologist and critical care specialist at the Mayo Clinic Arizona, served as the conference’s host and provided a presentation on lung issues associated with vasculitis.

“We were really pleased by the turnout for this conference,” said Joyce Kullman, executive director of the VF. “It tells us there is a definite interest and need to bring educational conferences to this particular part of the country.”
Annual Appeal 2018, cont.

We also learned that many supporters liked the ease of clicking on the “Donate Now” button in our email messages. Of the 1,040 gifts supporting our community of patients, 36% came in through an email request.

In the fundraising community, we often hear that direct mail letters are on the way out. Not necessarily true. While the number of gifts coming into the VF from the direct mail letter dipped slightly, contributions from this campaign still made up almost one-third of overall giving.

What Does This Tell Us Going Forward?

Donors continue to generously support patients in their quest to ensure earlier diagnosis, better treatments, and improved quality of life. The VF will continue to reach out to our members in the ways that meet their needs. We will continue to look to the future of online giving and send emails and letters making our case as to why your investment will yield results.

This summer, the VF will begin the second phase of our three-year campaign by focusing on better treatments. We will promote medical education, research, and the spotlight on earlier diagnosis with the V-RED award. Look for exciting news about better treatments, which will be featured at the 2019 International Vasculitis Symposium in July.

Tell Us Your Thoughts

We value YOU! As a stakeholder, we want to hear from you about why you give and what we can do to make your experience in giving a positive one. Please share your thoughts with us by emailing us at bwestbrook@vasculitisfoundation.org.
New Test May Help Determine Disease Activity in GPA Patients

Alejandra Viviescas, PhD
ANCA Vasculitis News

A new test measuring the relative abundance of immunoglobulin G4 (IgG4) RNA could be an indicator of granulomatosis with polyangiitis (GPA) activity and distinguish active disease from remission, a study suggests.

The study, “IgG4:IgG RNA ratio differentiates active disease from remission in granulomatosis with polyangiitis: a new disease activity marker? A cross-sectional and longitudinal study,” was published in Arthritis Research & Therapy.

ANCA vasculitis is an autoimmune disease where patients produce self-antibodies—called anti-neutrophil cytoplasmic autoantibodies, or ANCAAs—against a type of immune cells called neutrophils.

GPA is a subtype of ANCA vasculitis in which masses of immune cells accumulate and damage small- and medium-size blood vessels.

GPA normally has periods of active disease followed by periods of remission. Long-term symptoms and treatment with immunosuppressants can lead to secondary conditions that reduce the quality of life. Therefore, it is important to clearly identify disease activity to optimize treatment.

Currently, there are no specific molecules that indicate GPA disease activity, so doctors use general parameters of inflammation, which are not very reliable and cannot determine if the symptoms are due to vasculitis or other factors such as infections.

In addition, the presence of ANCAAs is specific to ANCA vasculitis, but these are better for diagnosing the condition than to indicate its activity.

B-cells—cells that produce ANCAAs and other antibodies—that express a molecule called immunoglobulin G4 (IgG4) are present at higher levels when GPA develops and therefore could indicate disease activity. However, the level of IgG4 in the serum does not seem to be a specific biomarker.

To create a more effective indicator, researchers used a technique called quantitative PCR (qPCR) that allowed them to measure the relative abundance of the RNA that holds the instructions to produce IgG4, among the RNA of all immunoglobulins present in the serum.

Read the full article at: https://bit.ly/2NKCSUQ

DADA2: A New Disease for Rheumatologists to Understand

By Jason Liebowitz, MD
Reprinted from The Rheumatologist

Rheumatologists from the National Institutes of Health (NIH) and from Jerusalem, Israel, have identified deficiency of adenosine deaminase 2 (DADA2) as an important cause of familial polyarteritis nodosa, which tends to present in childhood and can manifest with hematologic, immunologic and inflammatory signs, says Chip Chambers, MD, founder and president of the DADA2 Foundation. Following the Second International Conference on Deficiency of ADA2 in November 2018, Dr. Chambers spoke with The Rheumatologist to answer questions about this condition:

Q: What leads to deficiency of adenosine deaminase 2, and what do we know about this enzyme?
A: DADA2 is caused by loss-of-function mutations in the ADA2 (formerly known as CECR1) gene. We still have a lot to learn about the physiological functions of ADA2. It has been linked to the differentiation of macrophages between their pro- and anti-inflammatory forms, as well as a growth factor for the endothelial cells.

Q: What are the signs and symptoms that should prompt a physician to consider the diagnosis of DADA2?
A: Patients with DADA2 can present with a wide variety of symptoms, including childhood-onset stroke, systemic inflammation, immunodeficiency and hematological defects; overlapping vascular/inflammatory, hematological and immunodeficiency phenotypes exist. Skin manifestations—livedo reticularis, livedo racemosa and cutaneous vasculitis—are common and often initially diagnosed as polyarteritis nodosa (PAN). Neurological symptoms include ischemic stroke, intracranial hemorrhage and neuropathy. Inflammation associated with DADA2 can cause recurrent fevers and affect the liver, spleen, kidneys and gastrointestinal system. Many patients present with cytopenias, including anemia and neutropenia. Primary immune deficiency can also be a hallmark of the disease.

Pediatric stroke patients without a clear etiology should be screened for DADA2, as well as children and adults diagnosed with atypical PAN. In addition, patients with Diamond-Blackfan anemia (DBA), pure red cell aplasia or immunodeficiency without another genetic diagnosis should be considered for screening.

Read the full article at: https://bit.ly/2Uq3xZH
Becoming An Educated Patient Through VF Conferences

By Ed Becker

Obviously there’s never a “good” time to be diagnosed with vasculitis, but sometimes an onset happens with ironic impact at the worst possible time.

In 2016, Caz Cazanov was looking forward to enjoying her new life after retiring from Kaiser Permanente, where she had spent 24 years working in health insurance legislative and regulatory policy.

She was in good health, having not had a sick day for nearly 20 years. Unfortunately, that is exactly when she began having symptoms that would turn out to be vasculitis.

In January 2017, Caz was diagnosed with EGPA/Churg-Strauss Syndrome at the Kaiser Permanente hospital in Walnut Creek, California. She was treated with high-dose steroids and cyclophosphamide (Cytoxan®) infusions, and spent three weeks in the hospital and in a multidisciplinary rehabilitation facility.

Two years later Caz is thankful that her disease is in remission—although problems remain from the vasculitis. “I had a good response to my initial treatment and have been in remission since June 2017 without any disease flare,” says Cazanov. “Mycophenolate mofetil (CellCept®) is serving me well as a maintenance immunosuppressant, and I have a wonderful team of doctors caring for me. Some of my initial symptoms have resolved completely or improved. I do have issues that persist, including cognitive deficits, fatigue, hearing loss, tinnitus, and pain, strength, and mobility problems from nerve damage.”

When she was diagnosed, Caz and her husband, Steve Alexander, wanted to learn everything about the disease. Fortunately, the Vasculitis Foundation (VF) was holding its 2017 International Symposium in Chicago and it proved to be exactly what they were looking for to begin their vasculitis education.

“My husband and I were in serious information-gathering mode, and I was well enough to travel,” says Cazanov. “The symposium was especially useful because the multiple-day structure offers the opportunity to attend disease-specific and topic-specific break-out sessions. We learned a tremendous amount, and had the opportunity to ask questions of the physicians and others presenting.”

Caz was so impressed with the event that she and Steve have attended the last three VF conferences in Los Angeles, Seattle, and Phoenix. They are also planning to attend the 2019 International Symposium in Bloomington. She says the VF conferences are invaluable both for patients and caregivers.

“I have met many spouses, parents, and other caregivers at these meetings, and I think it’s such a wonderful opportunity for them to get information and support. I never really understood the role of the caregiver until I got sick and learned what it was to become dependent upon other people in so many ways,” she explains. “We learn something new and meet new people at every meeting.”

Although the disease leaves her with an uncertain future, Caz believes the more you can learn about vasculitis the better decisions you can make. “It’s a lifetime disease, and the best we can do is become educated, and find support from others. We feel fortunate we can find these things through the VF conferences and symposia.”

Have you considered receiving your bimonthly newsletter in a new way—delivered to your email Inbox instead of your postal mailbox?

More of our members are asking to opt out of the hardcopy version because they prefer the convenience of getting the newsletter in a PDF format via email.

- The digital newsletter contains hyperlinks. That means you can instantly link to the resources mentioned within an article.

- Every article is bookmarked so you can immediately click and go to that article or section in that issue. You can’t do that with your hardcopy newsletter.

Yes, we will continue to offer the newsletter in hardcopy format for those who prefer it. But if you’re ready to switch to our email version, let us know!

Contact the VF Office to change how you receive the VF newsletter at: vf@VasculitisFoundation.org
Why Young Adults and Their Parents Should Attend the 2019 International Symposium

By Ben Wilson

Believe it or not, it's almost that time—after a year hiatus, the International Vasculitis Symposium returns this summer in Bloomington, Minnesota.

I've been asked the same questions over the past few months, from parents of young vasculitis patients who want to know if it’s an event worth going to, especially for a teenager or young adult. The answer is always an emphatic YES!

I went to the 2017 Symposium in Chicago, my first, and to be honest, I wasn’t sure what to expect. After being diagnosed with EGPA in 2014, I’d never talked to anyone outside of my parents or team of doctors who had ever heard of the disease, let alone had any idea what it was like to deal with it on a daily basis. I didn’t think there would be many others my age at the Symposium. I figured I’d give it a shot, hear an interesting presentation or two, and then be on my way.

What happened over that 48-hour span in Chicago blew away even my highest possible expectations. My fellow Young Adult group leaders (Allison Lint, Brandon Hudgins, Meaghan Carpenter and Kate Tierney) agreed with that assessment.

Over 40 young adults attended the initial one-hour session (we expected maybe a dozen), and they had so much to say and share, that we created another two-hour session for the following day. Besides meeting new people and making friends, the most powerful thing, to me, was seeing so many of our participants open up and talk candidly about their experiences with vasculitis outside of the bubble of their parents and doctors.

I could see on many of their faces the transition from thinking they were alone in their fight against the disease, to realizing there were others they could lean on who were just like them. I went into the Symposium hoping I could impact one or two people with my story. Instead, I came away from the weekend greatly inspired by everyone I met.

As a result, we are doing everything in our power to make the 2019 Symposium even better. We are planning multiple sessions each day that are tailored to our Young Adults’ needs. And for our first-time guests, we can’t wait to welcome you into our family.

So, if you are a parent of a teen or young adult who was either recently diagnosed or just heard about the Vasculitis Foundation and are wondering if the Symposium is a worthwhile endeavor: trust me and the rest of our community when I say, emphatically, YES! Yes, it is.

Former Chapter Leader Recognized at Phoenix Conference

By Ed Becker

Carole Studdard was honored March 9, 2019, for her volunteer work as a Chapter Leader at the Vasculitis Patient Conference in Phoenix, Arizona.

Although she now lives in Richmond, Virginia, Carole travelled to the conference, where she was recognized with a special plaque for leading and growing the Arizona Vasculitis Foundation (VF) Chapter for many years.

Carole was diagnosed with Takayasu’s arteritis in 2003 and has been in remission since 2008.

It was her experience as a patient that led her to create the Phoenix VF chapter.

“When I learned the VF had chapters in various parts of the country, but not in the Phoenix area, I thought one could be created and I could do that. So, I did,” recalls Carole. “Interestingly, it wasn’t just patients seeking information, but medical professionals, also. Having a chapter allowed us to invite specialists to speak with patients in an informal setting.”

Although she lives on the other side of the country now, being involved with the VF is still a priority. “I am grateful for the commitment of the VF as the organization that is responsible for lobbying, accessing funding and investing in vasculitis education—all of which are contributing to better health. Let’s all continue to work together; we know the value of partnerships. Together, much has been learned. Together, this will continue,” says Carole.
Brandon Hudgins Looks Ahead To New Season of Competitive Racing

Three years ago, professional runner, Brandon Hudgins, beat the challenges from his granulomatosis with polyangiitis (GPA, formerly Wegener’s) to qualify for the 2016 Olympic Trials in the 1500 meter run. Although he didn’t make the Olympic team, Brandon hasn’t lost his determination to race competitively and is keeping a hopeful eye on the 2020 Olympic Games.

In this exclusive interview with the Vasculitis Foundation (VF), Brandon talks about some serious health setbacks, and why he’s optimistic about his goals this year.

**VF:** Talk about the past few years and how you’ve overcome some serious health setbacks due to your vasculitis.

**BH:** For those that aren’t aware, I suffered a severe relapse in 2017 that nearly cost me my kidneys. It was by far my worst year of health since my initial diagnosis in 2008. After two rounds of four rituximab infusions in 2017, my disease activity seems to be calming down.

**VF:** How would you summarize last year, in terms of training?

**BH:** In 2018, my body never seemed to soak up the training, no matter how hard I trained. I was running times 10 to 15 to 20 seconds slower than my best marks. Now that might not seem like a lot to the average runner, but often the gap between 1st place and 12th place in professional races is only 4 or 5 seconds.

I received the last of my four scheduled infusions in October (now only down to one each time instead of four thankfully) and have set my sights on 2019!

While 2018 brought a lot of disappointing results, I continued to keep putting myself out there and competing without fear. I can hold my head high and look towards the future.

**VF:** What’s ahead for this year?

**BH:** For 2019, the main goal is to get healthy, and do the training we know is required for me to be in the shape I need to be to race at the professional level. Ultimately, this year is about getting in as much work as possible and finding a few opportunities to race at a high level again.

**VF:** What about the next Olympics? Is that something on your radar?

**BH:** With the Olympic Trials and Olympic Games on tap for 2020, I have to make sure that everything we do this year is in preparation for next year. We can’t cut any corners this year that will affect us down the road. By late April or May, I should have some concrete race plans for June and July. If things continue to progress at the level I’m currently training, I could see another trip under 4 minutes in the mile this summer!

Longtime VF Member, Bruce Macdonald, Leaves a Legacy of Service and Patient Education

The vasculitis community lost a special friend, Bruce Macdonald, on Monday, March 25, 2019.

Bruce was a longtime member and volunteer of the Vasculitis Foundation (formerly the Wegener’s Granulomatosis Association/Support Group). Years ago, Bruce taught many of our members about the internet—what it was, how to use email, and look for information.

He was the most amazing researcher! He helped moderate our WG Listserv with over 1,000 patients around the world, plus our message boards, and chat rooms. This was all prior to Facebook. Bruce, along with other volunteers, built the organization’s first two websites, which enabled patients from around the world to find and help build our community. He also developed a complex list of 76 questions for newly diagnosed patients to ask their doctors.

The list was a tremendous informational guide for patients. Bruce always focused on helping patients and their families find the information they needed on treatments, doctors, research to participate in, or results of studies. He always offered support and encouragement to other patients.

In 2006, he was recognized with the Bruce Macdonald Spirit Award for his many years of service to our patients. He will be missed.
**Evaluation of Efficacy and Safety of Sarilumab in Patients With Giant Cell Arteritis**

**Primary Objective:**
To evaluate the efficacy of KEVZARA® (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.

- **Ages Eligible for Study:** 50 Years and Older
- **Sexes Eligible for Study:** All

**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 ≥30 mm/hour or C-reactive protein ≥10 mg/L within 6 weeks of baseline.
- Receiving or able to receive prednisone 20-60 mg/day for the treatment of active GCA.

For the full study description, design, full inclusion and exclusion criteria, and enrolling sites around the United States, please visit: [https://clinicaltrials.gov/ct2/show/NCT03600805](https://clinicaltrials.gov/ct2/show/NCT03600805)

If you do not have internet access, please contact the VF office for a study flyer: **800.277.9474**

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**Evaluation of the Efficacy and Safety of Sarilumab in Patients With Polymyalgia Rheumatica**

**Primary Objective:**
To evaluate the efficacy of KEVZARA® (sarilumab) in patients with polymyalgia rheumatica (PMR) as assessed by the proportion of subjects with sustained remission for sarilumab with a shorter corticosteroid (CS) tapering regimen as compared to placebo with a longer CS tapering regimen.

- **Ages Eligible for Study:** 50 Years and Older
- **Sexes Eligible for Study:** All

**Inclusion criteria:**
- Diagnosis of polymyalgia rheumatica (PMR) according to European League Against Rheumatism/American College of Rheumatology classification criteria.
- Patients must be on prednisone of at least 7.5 mg/day (or equivalent) and not exceeding 20 mg/day at screening and during the screening period.
- Patients are willing and able to take prednisone of 15 mg/day at randomization.
- Patients must have a history of being treated for at least 8 weeks with prednisone (≥10 mg/day or equivalent).
- Patients must have had at least one episode of unequivocal PMR flare while attempting to taper prednisone at a dose that is ≥7.5 mg/day (or equivalent) within the past 12 Weeks prior to screening.
- Unequivocal symptoms of PMR flare include shoulder and/or hip girdle pain associated with inflammatory stiffness.
- Patients must have erythrocyte sedimentation rate ≥30 mm/hr and/or C-reactive protein ≥10 mg/L associated with PMR disease activity within 12 weeks prior to screening.

For the full study description, design, full inclusion and exclusion criteria, and enrolling sites around the United States, please visit: [https://clinicaltrials.gov/ct2/show/NCT03600818](https://clinicaltrials.gov/ct2/show/NCT03600818)

If you do not have internet access, please contact the VF office for a study flyer: **800.277.9474**
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 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. www.rarediseasesnetwork.org/cms/vcrc/

**TAPIR Trial Recruiting Patients**

The Assessment of Prednisone in Remission (TAPIR) Trial has recently expanded its eligibility criteria to enroll patients that have recently taken or are currently taking rituximab.

**What we are studying:**
TAPIR is a clinical trial for patients with granulomatosis with polyangiitis (GPA) in remission—individuals who had a reduced number of symptoms or no change in GPA symptoms.

The study asks the question, is it more beneficial for patients with GPA to maintain low-dose prednisone intake during remission versus eliminating prednisone intake altogether?

TAPIR aims to find the answer to this question and ultimately establish the most favorable treatment option for patients with GPA in remission.

You can participate in the TAPIR trial if...

1. You have been diagnosed with granulomatosis with polyangiitis (GPA, also known as Wegener’s granulomatosis)
2. You have needed to take 20 mg or more of prednisone each day at some point in the last 12 months
3. Your current prednisone dose is between 5-20 mg/day
4. You are at least 18 years of age
5. Your treating physician is based in the United States or you can travel to a VCRC Clinical Center

*Other conditions may apply

**How to join the TAPIR trial:**

1. You can participate from the privacy of your own home.
2. You do not have to be seen at a participating medical center to enroll in this study. You can join online and continue to see your own doctor. If you already receive your care from a participating VCRC clinical center, you can talk to your doctor about participating in TAPIR.

Visit www.TAPIRTrial.org
The Power of Peer-to-Peer Fundraising

And that is how change happens. One gesture. One person. One moment at a time."
— Libba Bray, The Sweet Far Thing

By Beth Westbrook  
VF Director of Development

Raising the funds which are critically needed for research, education and support is challenging at times. As a fundraiser, one of the greatest joys I experience in my work is witnessing a donor realize the value of his, or her, donation.

JOIN OUR JOURNEY
The Vasculitis Foundation’s (VF) Join Our Journey campaign is a three-year endeavor to highlight the uniqueness of each of us and showcase how together we can make positive change happen. Sharing our journeys will help the VF build a community which is ready to tackle the BIG ISSUES—how do we achieve earlier diagnosis, what will it take to provide better treatments, and when will we reach a better, longer life?

During the 2018 Annual Appeal the VF introduced Peer-to-Peer Fundraising. This program focuses on you telling your story and leveraging the VF website to ask your friends and family to support the VF. Through your stories, we hope the community will support us in the push to answering those BIG ISSUE questions.

You do not have to be a patient to participate in the Peer campaign. Last fall, I conducted a Peer-to-Peer campaign when I turned to my relationship with the Pittsburgh Pirates baseball team to raise money to support the VF. I had fun and I was able to educate my family and friends about vasculitis and the importance of improving outcomes for people living with the disease.

Consider creating your own Peer-to-Peer Fundraising page. Simply go to the “Give” tab at the top right of the page on our website www.vasculitisfoundation.org and look for the “Start A Fundraiser” link. If you need help, let us know. We are here to guide you through the process. Your goal can be $5 to $5000 or more! You decide what you want to do.

May Opportunity
May is Vasculitis Awareness Month. I encourage you to create a fundraiser to highlight awareness to celebrate the month. Be creative and put a large dose of FUN in your fundraising. You don’t need to organize a walk, run around organizing a big event, or raise a large amount of money. All you need is an idea and the VF team can help you make it happen. Give us a call today at 1.800.277.9474 with your idea.

Annual Appeal Thank You!
This past year, the VF’s Annual Appeal raised over $217,880 for programs and research to support patients with vasculitis. Most of these gifts were $50 or less and the number of people who gave increased over 16%. This is how change happens, one person and one contribution at a time.

As the Development Director, I cannot do it alone. I promise I will roll up my sleeves with you to do more. Take a moment to see how much has been accomplished but don’t forget that we still have work to do. Will you Join Our Journey?

Be Well.
Beth

Preview of Vasculitis Awareness Month 2019

This year you can expect Vasculitis Awareness Month (VAM) in May to be a mix of the familiar, and an introduction of a few new ways to help raise awareness about vasculitis. VAM is always a centerpiece to the Vasculitis Foundation’s (VF) goal of spreading the word about the disease—and the organization—to a global audience.

On Wednesday, May 1, the VAM campaign will officially launch. Throughout the month of May, we will provide the tools and resources to successfully get out in front of friends, family, and co-workers.

▶ A new VAM2019 web landing page will debut. It will have everything needed to customize your social media profiles, and share messaging.

▶ Creating an online fundraiser during May will be even easier thanks to the new VF MobileCause platform similar to the one used during Annual Appeal last year. You can set up a personal fundraiser in minutes so you can reach a wide network of friends and family.
Donors

February 2019 Donors
Thank you for your gift of $50 or More!

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Kathryn and Don Whitehead

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

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Pamela Carlson
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Terrell L. Eppes

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The CME Conference on Vasculitis is for medical professionals only.

Plan to attend the 2019 CME Conference on Vasculitis
Sponsored by the Vasculitis Foundation

Plan to attend the 2019 CME Conference on Vasculitis
Sponsored by the Vasculitis Foundation. Jointly sponsored with Mayo Clinic.

AGENDA

7:00 - 8:00 a.m.
Breakfast and Registration

8:00 - 8:40 a.m.
ANCA-Associated Vasculitis:
Management Update
Ulrich Specks, MD
Mayo Clinic

8:40 - 9:10 a.m.
Ocular Manifestations of ANCA-Associated Vasculitis
James A. Garrity, MD
Mayo Clinic

9:10 - 9:40 a.m.
Sinus Disease in Vasculitis
Erin K. O’Brien, MD
Mayo Clinic

9:40 - 10:00 a.m.
Coffee Break

10:00 - 10:30 a.m.
Practice Gaps and Clinical Pearls in Cutaneous (Small-Vessel) Vasculitis
David A. Wetter, MD
Mayo Clinic

10:30 - 11:10 p.m.
EGPA
Ulrich Specks, MD
Mayo Clinic

11:10 - 11:30 a.m.
Panel Discussion
ANCA-associated vasculitis
Morning Speakers

11:30 a.m. - 12:00 p.m.
Vasculitis Mimics
Tanaz A. Kermani, MD
UCLA

12:00 - 1:00 p.m.
Lunch

1:00 - 1:40 p.m.
Giant Cell Arteritis
Matthew J. Koster, MD
Mayo Clinic

1:40 - 2:10 p.m.
Takayasu Arteritis
Kenneth J. Warrington, MD
Mayo Clinic

2:10 - 2:20 p.m.
Panel Discussion
Large Vessel Vasculitis

2:20 - 2:30 p.m.
Conclusion
Kenneth J. Warrington, MD

For more information and to register:
mayocl.in/2ud2Yqq
VF Medical and Scientific Advisory Board

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416.813.8883

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: ___________

Name: ____________________________

Address: __________________________________________

City: ____________________________State: ____________Zip: ____________

Country (if outside the U.S.): __________________________

Mail to: Vasculitis Foundation, P.O. Box 28660, Kansas City, MO 64188
Save the date!

VF Calendar of Events • 2019

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

www.vasculitisfoundation.org/events/

April 7-10, 2019
The 19th International Vasculitis & ANCA Workshop For Physicians and Researchers
› Loews Hotel, Philadelphia, Pennsylvania
› vasculitis2019.org

April 13, 2019
North Carolina/Raleigh Chapter Vasculitis Support Group Meeting
› UNC Wellness Center at Meadowmont in Chapel Hill 100 Sprunt Street Chapel Hill, North Carolina 27517
› 10:00 a.m. - 2:00 p.m.
› Contact: Jill Powell,
Administrator – Vasculitis Support Group
Jill_powell@med.unc.edu

April 13, 2019
Kansas City Chapter Meeting
› BEST Conference Center, Room 125
University of Kansas Edwards Campus
12600 Quivira Road, Overland Park, KS 66213

May 1-31, 2019
Vasculitis Awareness Month

May 18, 2019
Spaghetti Western Dinner
› 37811 176th Ave S.E., Auburn, WA 98092

July 19-21, 2019
International Vasculitis Symposium

August 24, 2019
The 3rd Annual Nick Pascente Memorial Golf Outing at Prairie Isle Golf Club
› Crystal Lake, Illinois
› Contact: Craig Alshouse
calshouse1@yahoo.com
(815) 245-9848