Vasculitis Awareness Month Now A Year-Long Campaign

by Ed Becker, Director of Marketing and Communications

This year it was only fitting the Vasculitis Foundation decided to “go big” to raise awareness. Combining the successful Dream Big campaign with Vasculitis Awareness Month (VAM2018), the central theme focused on three key areas: early diagnosis; better less evasive treatments; and ultimately a cure for the disease.

However, simply having a message isn’t enough. Creating a message that resonates with people and makes them want to share it is equally critical.

“Raising awareness is a partnership with patients, their families, and the medical community,” said Joyce Kullman, Executive Director of the VF. “In addition to our traditional awareness activities, we decided to think outside the box to offer the best resources that would appeal to the widest audience. Based on initial feedback I think we met and even surpassed that goal.”

While Vasculitis Awareness Month featured many of the familiar things such as a new awareness tee shirt, the VF also adopted some of the social media trends and technologies to spread the messages.

Facebook Live
On May 7, Joyce Kullman participated in a Facebook Live session hosted by Allison Lint, founder of the Violin for Vasculitis Campaign. During the hour-long, real-time event broadcast from Lint’s home in Overland Park, Kansas, they engaged with participants sharing what they most wish people knew about vasculitis.

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Longtime VF Consultant Retires

The Vasculitis Foundation is fortunate to work with many wonderful clinician-scientists. In April, one of our most valued consultants, Dr. Eric Matteson, retired after 30 years with the Mayo Clinic Division of Rheumatology. As a volunteer VF Medical Consultant, Dr. Matteson helped develop educational materials for all of the vasculitides, hosted patient and researchers’ conferences, and helped transform the VF’s Research Program into an international funding resource for vasculitis research.

We asked Dr. Matteson to reflect back on his career and his decision to go into rheumatology, and specifically his focus on vasculitis.

Q: Over the years you have met and treated many, many patients. Is there one patient who is most memorable, or inspired you as a doctor?

In the first years on staff at Mayo, I had primary responsibility for a patient who came to the Clinic after about six months of feeling poorly, with obvious kidney and heart disease, and gangrene on his fingers and genitals, and who was severely short of breath. He had been diagnosed and treated by a number of physicians for various suspected problems including infections and cancers. By the time we saw him, he was near death. It was apparent he had GPA, but the disease by then was so far advanced that we could not save him. It made it clear to me that I had to be involved in understanding the disease, improving treatments for vasculitis, and very importantly, teaching our colleagues about vasculitis and how to recognize it. Although we still have a long way to go, I think we have made remarkable progress in all of these areas since then. But the image of that patient has always stayed with me.

(continued on Page 6)
Executive Director Message

Dear Friends,

Vasculitis Awareness Month is celebrated each May, and throughout this newsletter, you can read about ways to raise awareness and support this annual effort. We encourage you to participate as you can. Watch a video, change out your social media picture, or bring a brochure to someone who has never heard of vasculitis. We need your help to raise awareness of vasculitis so that patients get diagnosed earlier and people better understand the challenges of living with the disease. Please visit pages 4-5 to learn more.

Do you want to advocate for vasculitis and other rare diseases? The Vasculitis Foundation is partnering with NORD’s Rare Action Network (RAN) to improve the lives of the 30 million Americans living with a rare disease at the state level. While working predominantly at the state level, the network filters information up to NORD’s national federal policy team to help address issues of national concern. The goals of the network are to connect a unified network of rare disease advocates, increase awareness of the challenges of rare diseases to key decision-makers and elected officials, and address issues of access and coverage to essential treatments and therapies.

If you are interested in learning more about RAN, please contact me. We’d love to have members advocating for vasculitis in every state in the US.

Matching Gift Challenge! A generous donor family is matching every donation up to $10,000 in support of Vasculitis Awareness Month! Please donate today to double your donation.

Thank you for all your support.

Sincerely,

Joyce A. Kullman
Executive Director
New Staff Member to Increase Outreach and Communication

We are pleased to welcome Whitney Apple, our new administrative and communication coordinator, to the Vasculitis Foundation. Whitney will have a wide range of responsibilities, including strengthening outreach to our patients and families, working closely with our event organizers, and helping with social media messaging. She has a degree in Management and Marketing from Park University. Whitney and her fiancee, Ben, have two sons, Alex and Nicholas. Visit her Instagram account (appleyeveraftersweets) to see some of the beautiful cakes she decorates for family and friends.

The VF GoToStage: The next step in evolution of the VF E-Learning Library

This summer the VF will unveil a new (and better) way to view its collection of webinars and video presentations.

Currently the VF has more than 65 educational videos on its VF YouTube Education Channel which collectively attracts thousands of viewers every year.

The VF GoToStage will present its archived videos in a simple, easy-to-navigate, layout that provides a detailed description of the key topics discussed in the presentation.

VF GoToStage will house all the VF monthly webinars from 2012 to 2017. Also, full-length videos of previous symposium lectures will be available. There will be no cost for viewing the videos.

The new video platform opening will be announced in the July-August VF Newsletter.

VF Research Funding Announcement

The Vasculitis Foundation is pleased to announce requests for grant applications for our 2019 research funding cycle. The deadline for this year’s grant applications is August 3.

The VF Research Program provides one- or two-year seed grants to support pilot studies in researching:

- Etiology/Pathogenesis (could include a broad range of studies of immunity, inflammation, or vascular biology. Relevance to human vasculitis will be taken into account by the reviewers.)
- Epidemiology, including genetics
- Diagnosis, including identification of disease subtypes
- Treatment/Management, including therapeutics to treat vasculitis or prevent complications, bio markers, and psychosocial outcomes
- Psychosocial outcomes
- Human vasculitis will be taken into account by the reviewers.

Funding: Maximum awards will be for $50,000 for 12 months. Some awards will be available for two years at a maximum of $50,000 per year.

International Funding Available: The VF Research Program funds research worldwide.

Goals: To improve the quality of life for patients with vasculitis, and ultimately find the cause/s and cure for vasculitis.

New Procedure: Letter of Intent (LOI) Submission

This year we are requiring applicants submit a Letter of Intent (LOI) outlining their proposed research project prior to submitting a grant application. The LOI should include a brief description of the project, relevance to vasculitis disease, and the applicant’s qualifications.

The deadline to submit Letters of Intent is June 15, 2018.

To learn more: https://www.vasculitisfoundation.org/research/research-program/

Teaching Medical Students About Vasculitis

Dr. Emily Brunner’s presentation “The Magic School Bus Human Body Venturesome Vessels of Vasculitis.”

Dr. Brunner explains to her fellow medical students how vasculitis is diagnosed based on the involvement of small, medium, and large vessels. Her presentation won the University of Pittsburgh's Fellows 2017 Teaching Video Competition.

https://www.residency.dom.pitt.edu/Videos/Brunner.html
Vasculitis Awareness Month Now A Year-Long Campaign, cont.

VF Awareness Twitter Event
On May 21, the VF and the Vasculitis Patient-Powered Research Network (V-PPRN) hosted a 24-hour Twitter event where members of the vasculitis and chronic disease community shared aspects of their life that the average person might not know. Participants used #KnowVasculitis and tag @VasculitisFound and @VPPRN to share what they wanted others to know about living with vasculitis.

VF Bob Awareness Month Checklist Competition
The VF Bob Campaign became an integral part of Awareness Month. Participants downloaded a new VF Bob Awareness Month Checklist from the VF’s VAM2018 web page. To participate, simply complete five of the eight tasks, shoot a photo holding the checklist, and email it to the VF at: vf@VasculitisFoundation.org to be eligible for a special random prize drawing on June 15.

Raising Awareness with Social Media Artwork and Memes
More than 1,200 people have swapped out their Facebook, and Twitter profiles with VAM2018 inspired artwork created by the VF. Moreover, the VF created a dozen new awareness month memes that can be circulated online. These memes (graphics) depict the impact of vasculitis in humorous and compelling images. The artwork can be found on the VAM2018 web page.

Raising Awareness Throughout the Year
Educating the public about vasculitis must be a year-long activity,” says Ed Becker, VF Director of Marketing and Communications. “We feel that once May ends that we still have to spread awareness throughout the year. We will be keeping the VAM2018 web page up throughout the rest of 2018. It will continue to be a go-to resource for tools and materials to raise awareness.”

VF Bob Continues to Grow Awareness Around the World
Now in its fourth month, the #VFBob Awareness Campaign continues to raise awareness across the globe.

You can see the entire collection of #VFBob photos here: https://www.vasculitisfoundation.org/vfbob/
VF Produces Three Videos for VAM2018

In past years the VF has produced a new video for vasculitis awareness month. These videos are a powerful way to spread awareness as thousands of people around the world view and share them. For VAM2018, the VF felt three videos would address the key issues of the VF Dream Big Campaign.

Connect the Dots

“Connect the Dots” was produced by VF Board President, Karen Hirsch, with the goal of raising awareness about the need for early diagnosis within the medical community. The video is built around the maxim, “When you hear hoofbeats you expect to see a horse, not a zebra”. Hirsch encourages patients to share the video with their physicians, and ask them to share it with their colleagues.

The One Thing I Wish People Knew About Vasculitis

The same phrase is repeated throughout this video: “The one thing I wish people knew about vasculitis.” However, that one thing is different for each of the patients featured in this montage of short video clips submitted from the international vasculitis community. “We wanted a video that quickly and powerfully communicated the impact of vasculitis on that patient,” said Joyce Kullman, Executive Director of the VF. “It’s much more effective to see and hear the message from the person who lives with the disease. We encourage patients to share the video with family, friends, and co-workers who may not fully appreciate the seriousness of the disease.”

Looking to the Future: Young Adults with Vasculitis

The message in this video is inspiring and optimistic. Each of the patients featured is pursuing their life goals despite having vasculitis. Produced by Ben Wilson and a team of peers, this is a video made by young adults for young adults. Wilson said it’s not only a video for patients in his age group, but also for the parents/caregivers who need to see that living life with vasculitis is possible.

These videos can be watched on the VAM2018 web page at: https://bit.ly/2HKenXW
Q: What benchmarks or highlights were most professionally rewarding or satisfying to you?

Without a doubt, the most rewarding thing in my career has been the privilege of working with patients. I have appreciated, and learned from every patient I have ever met. As well, it has been very important to me as I have advanced in my career to have had the chance to work with young physicians and young investigators, to help them in their careers and share the excitement of discovery, and curiosity with them.

Among the most rewarding aspects of my career are the relationships I have had with scientists and clinicians who have done so much to advance the field of vasculitis - people I have worked with, been inspired by and learned from - people like Gary Hoffman, Richard DeRemee, Ulrich Specks, Paul Bacon, Loic Guillevin, John Stone, Charles Pusey, Charles Jennette, Wolfgang Gross, Peter Merkel, Ronald Falk, David Jayne, Caes Kallenberg, Bhaskar Dasgupta, Alan Wik, Richard Watts, Carlo Salvarani, Raashid Luqmani, Gene Hunder and many, many more who have done so much for the field. In this regard, I also include the VF, because working with Marilyn, Joyce, Ed, many board members and volunteers has been a great pleasure and reward in itself.

Q: We are extremely fortunate that you chose to focus on GCA. Can you talk about advances and what gives you hope for patients with GCA over the coming years?

My principle research orientation has been as an epidemiologist, studying the occurrence of disease in populations. I have had the chance to study how frequent vasculitis is, and how it affects people. Our team brought out the first comprehensive survivorship data in GPA and GCA, and data on how often patients with giant cell arteritis develop large vessel disease. We were able for example to describe how often, and when, they develop complications from it such as aneurysms and stenoses and what the effect of these complications is on survivorship. I think the large study of features and classification of polymyalgia rheumatica was a highlight as well.

In the past year, we have seen approval of a new drug, tocilizumab, for the treatment of GCA, which holds promise for controlling the disease while substantially reducing the burden of glucocorticoids (steroids) required for treatment of the disease. I also think new diagnostic techniques like ultrasound are helping to identify affected blood vessels.

Perhaps in the grand scheme of things, the education efforts about vasculitis by workers in the field, and organizations like the Vasculitis Foundation, are increasing awareness of dreaded complications of GCA, like complete vision loss, which, while it still happens, appears today to be less frequent than in the past.

Q: What’s next for you?

I enjoy new experiences and new places, and have the opportunity to work in New Zealand through April of 2019. I’ll work as a rheumatologist in a couple of settings there, and my wife, Herta, and I will take the chance to travel there. A particular interest is in birds, and I plan to join the New Zealand Ornithological Society and participate in their activities. When we return to the US, Herta and I will continue with our interests in community involvement, birds, nature, and travel. I don’t think we’ll be bored!

THANK YOU!

On behalf of the VF Board of Directors, VF staff, and our entire vasculitis community, we thank Dr. Matteson for his many years of support and dedication to our patients and families and to the VF. We wish him a wonderful retirement and “happy birding”!
Vino for Vasculitis Fundraiser

On April 28, the 5th Annual Vino for Vasculitis 2018 brought together more than 90 guests, raising $13,000 for vasculitis research. View a photo album of pictures on Facebook: https://www.facebook.com/vinoforvasculitis

16th Annual Vasculitis Walk

› Sunday, June 3, 2018
› Registration starts at 11 a.m. Walk at Noon
› There is a $10 donation. No cost for patients.
› Ridley Creek State Park, #17
  1023 Sycamore Mills Road Media, PA 19063
› Learn more on the VF Events Calendar: https://bit.ly/2ItunOA

2018 KU Vasculitis Educational Conference

› August 4, 2018
› Registration: $30/person
› Register Now! http://ow.ly/hty130k35Fg

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**agenda**

9:15 a.m. - 10:00 a.m. Check In/Registration
Light Snacks

10:00 a.m. - 10:15 a.m. Opening Comments
Jason Springer, MD, MS
Director, KUMC Vasculitis Clinic
Division of Allergy, Clinical Immunology and Rheumatology
KU Medical Center

10:15 a.m. - 10:45 a.m. Tanaz A. Kermani, MD, MS
Rheumatology, Director
Vasculitis Center
UCLA Medical Center,
Santa Monica, California

12:00 p.m. - 12:30 p.m. Sinonasal Manifestations of Vasculitis
David Beahm, MD
Otolaryngology, Head & Neck
KU Medical Center

12:30 p.m. - 1:15 p.m. Lunch
Finding a New You
Suzanne DePaolis
VF Board of Directors

1:15 p.m. - 1:45 p.m. Bone Health
Rajib Bhattacharya, MD
Associate Professor
Endocrinology, Metabolism and Genetics
KU Medical Center

2:15 p.m. - 2:30 p.m. Closing Comments
Jason Springer, MD, MS

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**Breakout Session #1**
*The Immune System*
Selina Gierer, DO
Assistant Professor
Pediatric Allergy and Immunology
KU Medical Center

**Breakout Session #2**
*Large Vessel Vasculitis*
Tanaz A. Kermani, MD, MS
(for patients with Giant Cell Arteritis, Takayasu’s arteritis, and Polymyalgia rheumatica)
Kevin Byram, MD Reflects on Fellowship at Cleveland Clinic

by Kurt Ullman, Medical Writer

Kevin Byram, MD, graduated from the University of Alabama School of Medicine and completed his internal medicine and rheumatology training at Vanderbilt University Medical Center. Beginning in July 2017, he started a one-year vasculitis fellowship at the Cleveland Clinic Center for Vasculitis Care and Research. Dr. Byram’s fellowship has been supported by the Vasculitis Clinical Research Consortium (VCRC), the Vasculitis Foundation (VF) and Vanderbilt University Medical Center.

“Caring for patients with vasculitis has been a true pleasure,” says Dr. Byram. “The opportunity to guide someone and their family through a chronic disease with such devastating potential has been a humbling honor. With the advent of novel and repurposed therapies and treatment strategies, our ability to limit the serious nature of vasculitis has improved, but much still needs to be done.”

During his time as a vasculitis fellow, in addition to gaining advanced skills in the care of people with vasculitis, Dr. Byram has continued research that he began at Vanderbilt under the mentorship of Dr. Michelle Ormseth. His research project has focused on examining unique expression profiles of microRNA (mRNA) in patients with ANCA-associated vasculitis (AAV). mRNA is a molecule that silences certain genes.

“I am grateful for the financial support both the VF and VCRC have made available to me to pursue another year of training in the field of vasculitis,” says Dr. Byram. “The foundational, professional, and mentoring relationships I create will serve me well as I work toward my goals.”

At the end of his fellowship, Dr. Byram will be returning to Vanderbilt to establish a vasculitis clinic.

“This study could provide further information about how and why AAV occurs and relapses, which in turn could lead to more targets for treatment.”

MicroRNA is already being tested in diseases such as cancer. Small studies have identified several candidates that seem to be expressed at higher levels in patients with AAV.

Phase III ADVOCATE trial of Avacopan in the Treatment of ANCA-associated Vasculitis Exceeds 85% of Patient Enrollment

Phase III ADVOCATE trial of avacopan in treatment of ANCA vasculitis nears 85% of patient enrollment target as European Medicine Agency continues review process of Conditional Marketing Authorization application.

ChemoCentryx’s Phase III ADVOCATE pivotal trial of avacopan for the treatment of ANCA vasculitis has 200 sites activated and 220 patients enrolled to date. The trial will evaluate the safety and efficacy of avacopan following 52 weeks of treatment and will include approximately 300 patients. In addition to testing the effect of avacopan on improving active vasculitis, the ADVOCATE trial will also test avacopan’s efficacy in preventing the recurrence of vasculitis, one of the major limitations of the current standard of care for patients with ANCA vasculitis.

Learn more about this study in a webinar featuring Dr. Peter Merkel, principal investigator for the ADVOCATE Trial. View this webinar: [https://bit.ly/2pwXggh](https://bit.ly/2pwXggh)

Enrollment is still open.
Study Explores Illness and Morbidity Risks in GCA and GPA

by Kurt Ullman, RN

A few years ago Lin Li, PhD, a current postdoctoral research fellow at the Department of Quantitative Health Sciences in the University of Massachusetts Medical School in Worcester found out that her aunt had been diagnosed with vasculitis. Her aunt survived, but the experience changed both of their lives.

“Because vasculitis is such a rare condition with unknown causes, I wondered why my aunt had this disease,” she said. “I also wanted to know what are the health outcomes in this group.”

Dr. Li, working with Susan Jick, DSc, from the Boston Collaborative Drug Surveillance Program, received a two year grant from the Vasculitis Foundation to conduct a longitudinal study of morbidity and mortality in vasculitis patients. They used the Clinical Practice Research Datalink based in the United Kingdom, to identify both a population with vasculitis and another one without.

Different Types of Vasculitis

“There are many different types of vasculitis,” says Dr. Li. “Based on Dr. Tuhina Neogi’s suggestion, a rheumatologist and co-investigator, we focused on giant cell arteritis (GCA) and granulomatosis with polyangiitis (GPA). The first is the most common type of large vessel vasculitis and the second is the most commonly seen antineutrophil cytoplasmic antibody (ANCA) associated vasculitis.”

The researchers wanted to examine vascular disease morbidity as well as other conditions that are risk factors for vascular disease in patients with and without vasculitis. The major aims of the study included:

› Timing of the appearance of other diseases to separate those that were present before the diagnosis of vasculitis from those where the second health issue developed after the vasculitis.
› Estimating the rates of death in these vasculitis populations at 1, 3, 5 and 10 years and compare that to the rates in those without vasculitis.
› Identify risk factors for death in those with vasculitis.

Findings

They found that patients with GCA had more prior vascular diseases and other comorbidities than non-vasculitis patients. They also had increased risks for developing new vascular diseases (heart attacks, stroke, peripheral vascular disease, etc.) and other health problems (such as diabetes, depression, etc.), when compared to those without vasculitis. They found that GCA was associated with a higher risk of death in the first year following diagnosis, but the risk had gone away by year 5.

GPA patients had more prior hypothyroidism and increased risk for blood clots (thromboembolism) that can break off and travel to the brain or lungs. There were also increased risks for high blood pressure, high cholesterol, type 2 diabetes and depression within the first three years following diagnosis.

“Our study distinguished between pre-existing disease and post-diagnosis morbidity in these patients,” says Dr. Li. “The findings suggest that patients with both types of vasculitis suffer from a higher level of comorbidities, and vascular disease and its risk factors are already more common at the time of GCA diagnosis. Because this is a pilot study, I hope more research can be conducted to identify modifiable risk factors and cause-specific mortality with the hope of reducing morbidity and mortality in these patients.”
Athlete With Vasculitis Looking at Career in Medical Research

by Ben Wilson

With May signifying Vasculitis Awareness Month, it is as great a time as any to look at those in our community who are making a difference in raising awareness about vasculitis. In this young adult patient profile, I had the pleasure of meeting a bright college student well on his way to educating others about rare diseases.

Originally from the Dallas area, Jake Kula is a freshman at the University of Texas (UT) in Austin and was diagnosed with Microscopic polyangiitis (MPA) in his sophomore year of high school. Jake fought through the harsh side effects of prednisone and Rituximab. He also dealt with a hip replacement at the end of his junior year. While he was forced to quit playing basketball and struggled with sleep in the early aftermath of his diagnosis, he says the great treatment options available to him in a large city like Dallas, as well as the support of his family, made coping with the disease much easier. “My mom [Suzy] helped me get through everything throughout high school,” Jake adds.

Without any flare-ups after his junior year of high school and off of the prednisone, Jake began his college journey.

Jake Kula

Jake had a renewed level of energy, as well as a newfound desire to learn more about the disease that plagued him throughout his teenage years. Upon his arrival in Austin, Jake was admitted into the Dean’s Scholar Research Program, which will allow him to research different diseases while studying at UT. “I definitely want science to be a part of my future,” Jake says. “Getting diagnosed with vasculitis showed me how interested I am in research.”

In addition to his research opportunities, Jake is also involved in several organizations outside of the classroom. He tutors at a local high school for an hour or two each week and is a member of the school’s Sailing Club.

It is wonderful to see someone like Jake not only recover so quickly from a vasculitis diagnosis but also thrive in his environment and live freely as a college-aged student should. What is even more impressive is Jake’s willingness and desire to both give back to the local community and learn more about his disease so that he can help others in the future.

In keeping with the theme of Vasculitis Awareness Month and the Vasculitis Foundation’s mission to educate others about this rare disease, it is great to welcome in another young adult with a bright future like Jake into our rapidly growing community.

View a video about Jake’s story, produced by Gina Kwak: https://youtu.be/5Z86u6JL94E

To the Friends Who Offer ‘Cures’ for My Chronic Illness

By Suzanne DePaolis

Editor’s Note: This is an excerpt from an article which appeared in TheMighty.com, November 16, 2015. You can read the full article here: https://bit.ly/2rEhOFo

Sometimes, a simple chat with my friends and family can turn into a conversation about me defending my health choices. People will insist on telling me ways to boost my immune system. The problem is when you have an autoimmune illness, it’s usually because your immune system is overactive, and I take immunosuppressants to quiet it down so it stops attacking my blood vessels.

Many well-intentioned but insistent “friends” will spend hours talking to me about how I can boost my immune system. They don’t do this out of malice; they do it out of caring. They see me with constant colds or worry about me getting a cold or virus, but they don’t understand that boosting my immune system may put it into overdrive and begin a horrible cycle of flares. (A flare is a reactivation of my illness. I’m never cured — I just hope to keep things quiet throughout my life.) I know suppressing my immune system places me at greater risk for infections, but I live under a no-win situation and sometimes have to pick the lesser of two evils.

We need our friends to act as friends with open arms. We need people who will listen and won’t try to fix us or cure us. Just be our friends, and we will reward you with our unique sense of humor and newfound view of the world around us.
Former Fitness Professional Diagnosed with Cryoglobulinemia Now in Remission

by John Fries

In 1998, Marianne Vennitti, a Cherry Hill, New Jersey wife, mother, and fitness professional, suddenly started experiencing a rash of unusual symptoms—chronic fatigue, body pain, and even mental confusion. When she sought medical help, doctors considered a wide variety of possibilities including fibromyalgia and Lyme disease. Unfortunately, none of the treatments made a difference.

By 2009, Marianne’s problems had worsened. She developed severe anemia, numerous infections, and, eventually, kidney failure—which led to heart and lung complications.

Finally, in July 2010, after a year-long battery of biopsies and extensive tests at the Mayo Clinic, Marianne was conclusively diagnosed with mixed essential cryoglobulinemia (cryo), hemolytic anemia, leukocytoclastic vasculitis, and monoclonal gammopathy.

“At the time,” Marianne says, “I felt so alone and scared because there was so little information available about cryo.”

Her doctors recommended that she immediately begin a course of rituximab along with immunosuppressants and prednisone. “I experienced a bit of an improvement with the first course but not enough to improve my organ failure. Cyclophosphamide was added to my treatment protocol, and it slowly started to help with that.” Marianne was also told to stay warm because cryo patients are often adversely affected by changing temperatures.

In the years since her rituximab treatments continued. Then, about 18 months ago, there was a dramatic turning point.

“I’m crazy excited to say that I heard a word I never thought would be possible: remission,” Marianne says. “How long will it last? No one knows, but life for me has returned to what it used to be. No pain, fatigue, rash, or blood transfusions. No more endless hours alone in bed. No fear!”

Her experiences with the disease inspired her to establish the Alliance for Cryoglobulinemia (www.allianceforcryo.org), an online patient support resource, in 2012 with Eileen Propp, another person with cryo.

“You can heal both mentally and physically, but it starts with hope.”

Marianne notes her belief in the power of networking when faced with a rare disease. “The Vasculitis Foundation and I became good friends right from the beginning, both as a patient and as an advocate for cryoglobulinemia,” she says. “Like minds stick together, and I knew we had the same objectives in mind.”

“My big dream is a cure,” she says. “But until that time my little dreams are for faster diagnoses, continuing education in medical centers about vasculitis, and physicians being available and more transparent to patient community support groups.”

Marianne adds, “You can heal both mentally and physically, but it starts with hope. Educate yourself about vasculitis. Realize that research is taking place every day and that there are treatments that can greatly improve your life. Take part in making decisions regarding your treatments because it’s your life. And stop thinking you’re crazy. You’re not! Find people like yourself in the vasculitis discussion group on Facebook. You are rare, but you’re not alone.”
Introducing the Polymyalgia Rheumatica & Giant Cell Arteritis UK

PMRGCAuk is a user-led charity based in the United Kingdom, founded by a group of people with Polymyalgia rheumatica (PMR) and Giant cell arteritis (GCA). In the following interview, Kathryn Busby, director of PMRGCAuk, talks about the evolution of the organization.

VF: Your organization is celebrating an anniversary this year. Talk a little about the origin for your group and how it came together.

Yes, this year marks our tenth anniversary! On March 14, 2008, an inaugural meeting took place in London between representatives of all the known PMR and GCA support groups around the UK, plus several interested individuals. They were among the founders of what eventually became the three charities PMRGCAuk, PMR-GCA Scotland and PMR-GCA North East Region Support.

PMRGCAuk was registered as a charity in 2009. The charity is currently governed by five trustees and an honorary treasurer, working with two part-time staff and more than fifty brilliant volunteers across the country.

VF: How would you define the mission of PMRGCAuk?

We offer support, raise awareness, and promote research into these related auto-immune conditions, which affect older people and cause severe and debilitating pain and discomfort. We provide an information base for the public and medics through our printed resources, web and social media presence and press work. Of course, supporting research is a key part of our work. We have excellent working relationships with researchers in our field, e.g. providing pre-submission review of clinical research proposals, and patient representation on European League Against Rheumatism working groups to develop international recommendations for PMR and GCA.

VF: One of your events, the Rheuma Research Road Show sounds particularly interesting.

During 2017 we teamed up with top rheumatology departments and universities, to hold half-day workshops all around England and Wales. These workshops provided a chance to learn more about current and future research, raise awareness about new perspectives on these conditions, and gave researchers and patients the chance to put their heads together informally to share ideas and experiences. Along the way we have been collecting material to form the core of a free online course which will be offered in 2018.

For more information about PMRGCAuk visit their website: http://www.pmrgca.co.uk

“We offer support, raise awareness, and promote research into these related auto-immune conditions, which affect older people and cause severe and debilitating pain and discomfort.”
Dreaming Big for Vasculitis Research

by Kalen Young, Network Manager, Vasculitis Patient-Powered Research Network

In collaboration with the Vasculitis Foundation, the Vasculitis Patient-Powered Research Network (VPPRN) is excited to share how we are DREAMING BIG for vasculitis research. The aim of this year-long campaign is to fast track the advances about which every person impacted by vasculitis is dreaming: faster diagnosis; better treatments; and improved quality of life.

Working together, we have taken enormous strides toward achieving these goals, but we have a long way to go before our task is complete. The patients, investigators, care providers, other research networks, advocacy groups, and health systems that comprise the VPPRN choose to Dream Big! and are proud to share an innovative and robust research agenda for 2018!

Faster Diagnosis. Better Treatments. Improved Quality Of Life
Our patient-centered research network now has over 2,300 patients representing 13 different types of vasculitis in over 21 countries around the world all participating in vasculitis research. As our network continues to grow and more patients enroll to participate in research online, our dreams for vasculitis research flourish and forge novel methods for conducting research that is important to YOU.

BETTER TREATMENT

As a patient-centered research network, the VPPRN focuses on research that matters to you. One of the biggest concerns we’ve heard from patients is understanding how well and how quickly a treatment will work. That’s why we’re excited to Dream Big for vasculitis research and launch several new studies aimed at addressing these concerns.

Veritas: Vasculitis: Effects Of Remission Maintenance Therapies On Relapse And Side Effects On Patient Preferences
The VERITAS survey aims to answer the question: How much benefit does a maintenance medication need to provide a patient with vasculitis for its risks to be acceptable?

VERITAS is designed to provide information on patient values when clinicians and patients are faced with the decision of whether or not to discontinue maintenance therapies in patients with vasculitis in remission. The results of this survey will ultimately aid in the design of a large scale clinical trial. The research idea was generated by informal discussion with patients in clinic and through formal discussions regarding maintenance therapy discontinuation for patients at the time of remission.

VERITAS will assess how patients with vasculitis weigh the benefit of relapse risk reduction provided by maintenance therapy with the potential risk of adverse events.

The Comparative Health Outcomes In Immune-Mediated Disease Collaborative (Choice) Study
The VPPRN is excited to launch the CHOICE study in partnership with researchers at the University of Alabama at Birmingham. The goal of this study is to understand how different treatments work for different people. We hope that our findings help patients make better treatment decisions with their doctor.

IMPROVED QUALITY OF LIFE

Healthy Mind, Healthy You: A Study Of Mindfulness
Do you experience stress or anxiety? Are you interested in learning how to better cope with stress? The Healthy Mind, Healthy You study will look at the stress and well-being of individuals with chronic diseases and their caretakers and how mindfulness practices can help reduce stress related to more than 100 different conditions, including vasculitis.

The aim of this study is to examine what the briefest, least burdensome intervention is to effectively decrease stress and enhance one’s overall sense of well-being.

DREAM BIG! WITH THE VPPRN

The VPPRN is powered by patients like you. To all of our current members who take time out of their lives to participate in vasculitis research, we are sincerely grateful and thank you for all of your contributions.

If you are not currently a member of the VPPRN but would like to join us in conducting vasculitis research, please enroll today at www.vpprn.org!

BETTER RESEARCH, BETTER TREATMENTS, BECAUSE OF YOU!
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/](https://www.rarediseasesnetwork.org/cms/vcrc/)

---

**TAPIR Trial Now Open to Patients Taking Rituximab**

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:**

The TAPIR trial is a clinical trial for patients with GPA in remission-individuals who had a reduced number of symptoms or no change in GPA symptoms.

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](http://www.TAPIRTrial.org)
March and April 2018 Donors

Thank you for your gift of $50 or More!

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Researchers Study Behçet’s Disease in Midwest

Behçet’s disease (BD) is a chronic condition that is rare in the United States. Although better studied in areas where it is seen more often, not as much research has been done in North America. A group of researchers from the Division of Rheumatology at the University of Michigan in Ann Arbor analyzed the disease’s clinical characteristics among their patients and compared them to other cohorts outside the U.S.

Behçet’s Disease Understudied in U.S.
“Behçet’s disease is generally understudied in the U.S. because it isn’t a common disease compared to other parts of the world such as Eastern Asia, the Middle East, or North Africa where it is more common,” said lead author Amr H. Sawalha, MD, professor of Internal Medicine at the University. “This is a unique cohort describing the disease from the Midwest. It is important to know how patients in the US present and the differences in clinical features, what complications are expected, and what treatments work well. This knowledge helps us to better manage patients in this region and the US.”

A total of 114 patients who were seen by University physicians between October 2011 and June 2017 were included in the comparative study. All met the International Criteria for Behçet’s disease (ICBD), and most also met the International Study Group (ISG) standards for the diagnosis. Clinical indicators and current medications for BD were recorded.

Large Cohort for Better Understanding
“This is a large cohort for BD in North America,” says Dr. Sawalha. “That helps us better understand BD as it presents in Michigan and the US.”

According to the results, there was a nearly 4 to 1 ratio of women to men. Inflammation of the retina (retinitis) was 5.3 times more likely in men while joint pain was 3.3 times more likely in women. All patients had mouth ulcers. The (continued on Page 18)
Vasculitis Foundation Membership Campaign – JOIN!

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

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Researchers Study Behçet’s Disease in Midwest, cont.

majority also had genital ulcers, and other skin symptoms. Organ involvement does happen in a significant proportion of patients, including eye involvement.

BD is such a rare disease that there have not been many groups of patients studied in the United States. This is also one of the largest formed to look at BD in North America.

“This is a substantial group of patients and that helps us to better understand BD as it presents in the US,” said Dr. Sawalha. “This, in turn, gives us the information needed to better diagnose and treat our patients.”


Remember, the VF Newsletter is available both in hardcopy and digital format.

Yes, we will continue to offer the newsletter in hardcopy that is delivered to your postal mailbox.

But, if you’re ready to think outside of your mailbox let us know!

Contact the VF Office to change how you receive the VF newsletter at: vf@VasculitisFoundation.org

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  - VF logo on front, Dream Big! on back. Unisex.

- **2018 Vasculitis Awareness T-Shirt**
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- **Next Level Women's Jersey Tank**
  - Victory over Vasculitis. In red or white.

- **Golf Visor**
  - Keep cool while showing your support for the VF.

- **VF Tote Bag**
  - A durable carry-all to take anywhere!

- **Team Brandon T-Shirt**
  - In grey or red.

These and many other cool summer items are now available at [www.VFWebStore.com](http://www.VFWebStore.com)!

**Need a little Warm-Up?**

Deep discounts on cool weather gear are now available in the VF Web Store!

Jackets, hoodies, fleece, caps, and more! Save big while supporting the VF!
June 3, 2018
16th Annual W. NJ/E.PA Vasculitis Walk
› Registration begins at 11 a.m.  Walk at Noon.
› Ridley State Park, Site #17
   1023 Sycamore Mills Road, Media, PA 19063
› For more information contact:
   Sharon Sirman: 610-836-2455
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July 9, 2018
Sacramento Chapter Meeting
› 6:00 p.m. - 7:00 p.m.
› Hofbrau Restaurant, 2500 Watt Ave., Sacramento, CA
› For more information contact:
   Hedy Govenar, HGovenar@govadv.com

July 21, 2018
Victory over Vasculitis Basketball Tournament
› 12:00 p.m.
› Dugger Park, Mystic River Rd, Medford, MA
› Organizer: Patrick Lane 617.999.0113 or lanepd23@gmail.com

August 3, 2018
› VF Research Application Deadline
› www.VasculitisFoundation.org

August 4, 2018
KU Regional Vasculitis Conference
› 9:30 a.m. - 2:30 p.m.
› BEST Conference Center, Room 125
   University of Kansas Edwards Campus,
   12600 Quivira Road, Overland Park, KS 66213

August 25, 2018
Nick Pascente Memorial Golf Tournament
› Prairie Isle Golf Course
› Crystal Lake, Illinois
› Organizer: Craig Alshouse, 815.980.9870
calshouse10@yahoo.com

September 10, 2018
Sacramento Chapter Meeting
› 6:00 p.m. - 7:00 p.m.
› Hofbrau Restaurant, 2500 Watt Ave., Sacramento, CA
› For more information contact:
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November 10, 2018
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