The Race is On! Join us for Vasculitis Awareness Month 2020

By Nina Silberstein

Planning is underway for Vasculitis Awareness Month (VAM), May 1-31, 2020! From patients and family members, to medical professionals and the general public, it’s time to rally together to raise awareness and show support for all those affected by the disease.

“For me, Vasculitis Awareness Month is an opportunity to connect, educate, and encourage,” said VF board member Jacque Eidson, who is working with fellow board member Allison Ross on VAM planning. “This strategic outreach allows us to touch the lives of people all over the world, in both big cities and small communities,” she added.

“Making connections within the vasculitis community is easy when you see how many others are involved in VAM,” said Ross, who also serves as a VF Young Adult leader. “Even though there is much we patients can do every day, having an entire month to ourselves goes a long way toward education of symptoms, treatment, and quality of life with this disease.”

“This strategic outreach allows us to touch the lives of people all over the world, in both big cities and small communities.”

—Jacque Eidson, VF board member

This year’s highlights:

» “The Race is On!” is our theme for VAM and for our 2020 Spring Appeal campaign, which kicks off May 1. This campaign will support the second pillar of our Join Our Journey campaign for better treatments. We’ll offer a Matching Gift Challenge, and a special donor has already come forward with a $10,000 matching gift. Visit: vasculitisfoundation.org/the-race-is-on/.

» View and download the 2020 VAM interactive calendar. You’ll find a variety of vasculitis awareness activities and events to choose from for every day in the month of May. And it’s simple to use: Just click on the links in the calendar that interest you, and you’ll be directed to a web page for more information.

Continued on page 3

Dr. Stephanie Garner Named Recipient of 2020 VCRC-VF Fellowship Award

By Nina Silberstein

Stephanie Garner, MD, MSc, FRCPC, developed an interest in vasculitis as an internal medicine resident at the University of Calgary in Alberta, Canada, while admitting a patient to its nephrology service. The patient had pulmonary renal syndrome—respiratory failure that involves bleeding in the lungs and kidney failure—due to ANCA-associated vasculitis.

“It was a life-changing event for this previously healthy patient,” Dr. Garner explained. “And this was an area of medicine where I wanted to make a difference.” (ANCA vasculitis, or anti-neutrophil cytoplasmic antibody vasculitis, is a group of diseases that affect the small blood vessels of the body.)

Dr. Garner is one of two physicians who received the 2020 Vasculitis Clinical Research Consortium (VCRC)-Vasculitis Foundation (VF) Fellowship Award. The VCRC-VF Fellowship is a mentored training program of up to two years for physician-investigators who have a strong interest in vasculitis and wish to pursue specialized training in patient-oriented clinical investigation.

Continued on page 8
Dear friends,

I’ve always said you can raise awareness of vasculitis anywhere. I recently took the trip of a lifetime to Antarctica. Nina Adams, a VF member from the Chicago area, challenged me to take a VF banner with me. Nina always takes photos of herself with a VF banner on her trips, to raise awareness. My sister, Judy, and I posed with the banner on the Antarctic Peninsula. It was cold and raining, and the young penguin chicks were incredibly curious and completely dismissive of the rule about staying 15 feet away.

The next morning, one of the other passengers on the ship joined me for breakfast and asked about the VF. She shared that she had been diagnosed with giant cell arteritis in December 2018. We talked about the importance of a quick diagnosis (in her case, just three days), prednisone (the good and bad), and benefiting from newer treatments like Actemra®, also known as tocilizumab.

You just never know when you will meet someone who has been impacted by vasculitis.

At the VF, we are expanding our educational offerings this year and hope you will listen to one of our podcasts or watch one of our pre-recorded or live webinars. Our first regional conference will be held on Saturday, April 18, in the greater Washington, DC, area. Please plan to join us.

Vasculitis Awareness Month is celebrated during the month of May. We are planning lots of activities and hope you will help us raise awareness with your family, friends, co-workers, and local community.

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 grateful to authors who have shared their personal experiences with vasculitis in the newsletter. These contributions are personal reflections of the writer and do not represent medical scientific statements. VF’s materials are not intended to replace the counsel of a physician.
**Vasculitis Awareness Month, cont.**

» The Vasculitis Foundation’s 2020 Recognizing Excellence in Diagnostics (V-RED) award winners will be announced in May. The V-RED program calls on patients worldwide to nominate a medical professional for making a critical, early diagnosis of vasculitis. It’s not too late to make a nomination! The deadline has been extended to March 31. Visit: www.vasculitisfoundation.org/2020-v-red-program.

» International Vasculitis Day is May 15. It’s the day we collaborate with our international partners, patients, and families to raise awareness of vasculitis.

» The Vasculitis Patient-Powered Research Network (VPPRN) will present a webinar on international studies of vasculitis.

“Social media is perhaps the easiest tool we have, allowing the word to spread almost instantaneously.”

—Allison Ross, VF board member

Eidson said her life has been touched by vasculitis through her father-in-law, whom she adores. Living in a rural community with excellent health care but no specialists, he struggled for several years before being diagnosed. “It is an absolute pleasure to work with Allison, Joyce Kullman [VF Executive Director], and many other kind souls dedicated to planning a Vasculitis Awareness Month that touches as many lives as possible in the most meaningful way possible,” said Eidson.

“Social media is perhaps the easiest tool we have, allowing the word to spread almost instantaneously,” added Ross. “The platform to tell our stories makes us feel validated, and more importantly, shows those who are new to this journey that they have the support necessary to thrive even within a health struggle.”

There’s so much you can do during VAM to help raise awareness and make a difference. For more information and to get all the materials you need to help spread awareness during May, please visit: vasculitisfoundation.org/awareness/

**Awareness Month 2020 Sponsors:**

Register Now for Upcoming Vasculitis Patient & Family Conference in Greater DC Area

Join the VF for the 2020 Vasculitis Patient & Family Conference, scheduled for Saturday, April 18, from 9 am – 4 pm, at the Sheraton Silver Spring Hotel, Silver Spring, Maryland. Deadline for registration is April 14, 2020.

“Join Our Journey: The Race Is On” is the theme for the conference, which features numerous vasculitis experts discussing a wide range of topics of interest to patients and families. Fee is $40/person (lunch included).

Register at: https://bit.ly/2T8NeSN or call the VF office at 816-436-8211.

**Preliminary schedule:**

**Peter Grayson, MD, MSc**
Head, Vasculitis Translational Research Program, NIAMS
*Exciting Updates on Research from the NIH Vasculitis Program*

**Philip Seo, MD, PhD**
Johns Hopkins Medicine
*Update on Recent Clinical Trials in Vasculitis*

**Eric J. Gapud, MD, PhD**
Johns Hopkins Medicine
*(Topic to be announced)*

**Victoria Ruffing, RN-BC**
Johns Hopkins Medicine
*Medication Management: Tips and Tricks*

**Susanna Jeurling, MD**
Johns Hopkins Medicine
*CBD Oil Discussion*

**Brendan Antiochos, MD**
Johns Hopkins Medicine
*Steroids: The Good, The Bad, The Ugly*

**Dana DiRenzo, MD, MHS**
Johns Hopkins Medicine
*Mindfulness for the Patient*

**Marcela A. Ferrada, MD**
Lawrence Shulman Scholar/NIAMS, NIH
*Ear/Nose/Throat Management of Vasculitis*
The most common form of vasculitis in adults over the age of 50 is giant cell arteritis (GCA), an inflammation of the blood vessels that primarily affects the head—especially the temples and scalp—but also arteries in other parts of the body, including the aorta. Early diagnosis is critical in GCA to prevent vision loss and other serious complications. But unfortunately, GCA, which causes multiple symptoms and can mimic other diseases, is difficult to correctly diagnose, and treat.

Rheumatologist Marcia Friedman, MD, is trying to change all that through her work as the director of Oregon Health & Science University's (OHSU) Vasculitis Center in Portland, Oregon. Her primary area of research is in identifying new diagnostic tests for GCA. “Without treatment, [GCA] can lead to blindness, strokes, and death,” she said. “Treating this form of vasculitis requires long-term use of steroids, which have a lot of side effects. So, it is very important that we don’t miss cases and that we don’t overtreat.” Dr. Friedman is Assistant Professor of Medicine, Division of Arthritis and Rheumatic Diseases, School of Medicine, OHSU. She became director of the vasculitis center in 2018—the only vasculitis center in the Pacific Northwest.

Dr. Friedman’s role is to coordinate the care of its vasculitis patients with all of the other specialists. Most of the time, patients will meet first with the rheumatologist and will then be referred to other specialists as needed. Other times, patients are first seen by one of the specialists and then referred to the rheumatologist. “Since we opened, we have seen increasing demand for specialized multidisciplinary care,” Dr. Friedman said. “We hope to continue to expand to serve the needs of our patients.” Patients need a referral before they can be seen at the center.

“Vasculitides are multi-organ system diseases,” Dr. Friedman said. “The primary purpose of a vasculitis center is to have access to multiple specialists with expertise in vasculitis of various organ systems.” She said the clinic is lucky to have vasculitis experts in dermatology, ophthalmology, otolaryngology, nephrology, and pulmonology. All of the providers work collaboratively as a team to provide the best possible care.

Research also plays an important role at the OHSU Vasculitis Center. By partnering with organizations such as the Vasculitis Clinical Research Consortium, patients are offered opportunities to participate in OHSU, national, and international research studies, as well as in nonclinical trial research. Patients are often asked to donate blood and tissue samples, which are used to advance the clinic’s understanding of vasculitis.

“Vasculitis diagnosis and treatment can be challenging and we strongly believe that patients get better care from a team of doctors working together than they would from any one of us as an individual,” Dr. Friedman added. The ultimate goal of the center is to provide multidisciplinary care for patients with vasculitis, and advance vasculitis research leading to better diagnostic tests, and more effective, less toxic treatment.

**SPRING APPEAL 2020**

**Join Our Journey**

The Race is On! That’s the official theme of the VF’s Spring Appeal 2020, which kicks off May 1 and runs through May 31. The goal is to raise $50,000 in support of our Join Our Journey campaign for better treatments.

“The race for better treatments cannot happen with hope and good wishes alone,” said Beth Westbrook, VF Senior Director of Outreach. “We must pound the pavement and raise funds to work for better outcomes.”

Westbrook hopes supporters will make a donation, set up a fundraiser on behalf of the VF and/or participate in the activities planned during May. A special donor has already stepped up with a $10,000 matching gift challenge.

Learn more and support the Spring Appeal at: vasculitisfoundation.org/the-race-is-on/.
Penn’s Giant Cell Arteritis Fast-Track Program Provides Rapid Evaluation

By Nina Silberstein

The tricky part of giant cell arteritis (GCA) is the need for rapid evaluation, given the high risk of rapid vision loss and the importance of getting appropriate diagnostic tests, such as a temporal artery biopsy, soon after starting treatment. Unfortunately, there are not a lot of outpatient programs that handle urgent issues related to GCA—and within 48 hours.

To fulfill this need, the Penn Giant Cell Arteritis Fast-Track Program, which launched in January 2020, was created for patients with suspected or relapsing GCA who need rapid evaluation. The program provides rapid multi-disciplinary evaluation, initiates appropriate therapy promptly, and facilitates innovative research in GCA.

“Patients with high-risk features will be seen by a rheumatologist within 48 hours, as well as other appropriate specialists,” said Rennie Rhee, MD, MS, Assistant Professor in the Department of Medicine/Rheumatology at the Hospital of the University of Pennsylvania, Philadelphia. “Temporal artery biopsies will be done within one week; treatment may be initiated if suspicion for GCA is high and there is concern for visual impairment.”

The fast-track program, led by the Penn Vasculitis Center within Rheumatology, is located within outpatient practices at the Perelman Center for Advanced Medicine and the Penn Medicine University City locations in Philadelphia. Dr. Rhee had worked for several months to develop a pathway and collaborators for the program. The rheumatology team includes: Shubhasree Banerjee, MD, Assistant Professor of Clinical Medicine, Penn Medicine; Peter Merkel, MD, MPH, Chief, Division of Rheumatology, Penn Medicine; and Naomi Amudala, CRNP, MSN, Penn Medicine.

All members of the rheumatology team specialize in vasculitis and have been involved in clinical research in GCA. “We have a neuro-ophthalmologist with extensive experience in evaluating and managing patients with GCA,” said Dr. Rhee, “and a team of vascular surgeons who can see patients quickly to perform temporal artery biopsies in a timely fashion.”

The program provides a rigorous and standardized approach to processing and interpreting biopsy specimens, which will be reviewed by Franz Fogt, MD, PhD, MBA, Professor of Pathology and Laboratory Medicine at the Hospital of the University of Pennsylvania. Dr. Fogt specializes in ophthalmic pathology (including temporal artery biopsies). A neurologist is on board as well—Katherine Hamilton, MD, Assistant Professor of Clinical Neurology, Penn Medicine—and she specializes in headaches for patients who have them as a primary symptom but do not have GCA.

There will be a dedicated phone line for providers to call and discuss potential GCA cases with one of the program’s vasculitis specialists. “If appropriate, we will then schedule the patient within 48 hours and coordinate expedited care with other specialists when indicated. For providers within Penn, we also have a separate consult order, which facilitates the triaging process,” Dr. Rhee said. For now, providers can call the Penn Division of Rheumatology for scheduling: 215-662-4333.

“Patients with high-risk features will be seen by a rheumatologist within 48 hours, as well as other appropriate specialists.”

—Rennie Rhee, MD, MS

“Patients with high-risk features will be seen by a rheumatologist within 48 hours, as well as other appropriate specialists.”

—Rennie Rhee, MD, MS

Note that only providers can call and refer patients to the program. “This is to ensure appropriate work-up is done beforehand, in case the patient needs to be seen by other specialists and does not have GCA,” Dr. Rhee said.

Early diagnosis and prompt treatment of GCA is vital. “Vision loss is the most feared complication of GCA and it can occur incredibly fast—sometimes within a few hours from the onset of the first visual symptoms. There’s a very small window in which initiation of therapy can prevent a patient from going blind in one or both eyes,” Dr. Rhee explained. “At the same time, we need to be careful that we don’t unnecessarily expose patients to high doses of steroids, such as prednisone, which are associated with many side effects.”

The program will treat any symptom that is part of GCA (eg, polymyalgia rheumatica) and, if needed, partner with primary care providers as well. Some patients may need to see several specialists routinely, depending on their manifestations (eg, ophthalmology). The benefit of seeing a rheumatologist is that there is a growing number of steroid-sparing options for GCA, including the first-ever FDA-approved drug, tocilizumab, for GCA, Dr. Rhee said.

There are now multiple ongoing clinical trials of novel therapies for GCA, and patients who are interested can also learn more about these opportunities through the fast-track program.
VF Young Adults Group Spearheads New Vasculitis Visionaries Podcast Series

By Ben Wilson

As 2020 kicks into full gear, our VF Young Adults community has continued growing and coming up with new ways to build upon a successful 2019. Last November, we were fortunate enough to be honored in Kansas City for our efforts to raise awareness about vasculitis through a video featuring about a dozen young adults.

One of the young adults who starred in the video, Kaley Beins, joined me and several others in Kansas City to accept the award. While we pampered ourselves with Z-Man sandwiches from Oklahoma Joe's BBQ (which officially stole Kaley's BBQ-deprived heart, by the way), we also started brainstorming about potential new ventures that could take our mission of education and patient advocacy to greater heights.

With the help of VF Executive Director Joyce Kullman, we came up with a solution that we're incredibly excited to roll out over the next few months—the Vasculitis Visionaries Podcasts.

Our vision with this new podcast series is to better connect patients and physicians, while also providing further insight into some of the recent medical developments we've seen and their impact on different types of vasculitis.

If you've been to a VF International Symposium in the past and listened to any number of the doctor-led educational talks, you know how fortunate we, as a vasculitis community, are to have so many talented physicians who have a genuine passion for constantly learning more about the intricacies of such a rare disease.

Of course, our VF symposia only take place every other year, while just about all of our physicians are routinely working to better the lives of patients by launching new projects and research year-round. Our thinking is that this new podcast will allow us to speak one-on-one with many of these physicians to bring listeners the latest developments in their work, which in turn will allow patients and caregivers to stay informed.

This project also lets us further promote the concept of patient advocacy, as Kaley and I are both co-hosts of the podcast, and also fellow patients who have the desire to learn more in our own fights against the disease. (I was diagnosed with eosinophilic granulomatosis with polyangiitis [EGPA] in 2014, while Kaley got her granulomatosis with polyangiitis [GPA] diagnosis in 2015.)

I think Kaley is an especially great figure for listeners to look up to—she's someone who has taken her passion for advocacy to the next level, as she is now a public health practitioner studying chemical exposures and disease development in the Washington, DC, area. She even wrote her master's thesis on vasculitis! Our hope for this podcast is that our listeners come away from each episode feeling entertained, informed, and empowered to continue pushing forward through their respective involvement with vasculitis, whether as doctors, patients, or caregivers. With the guest list of physicians we have lined up, and working with a talented co-host like Kaley, I'm confident we'll meet that overarching goal. Thanks in advance for listening!

To hear the podcasts, visit: www.vasculitisfoundation.org/vascvisionpodcast.

VF Newsletter contributor Ben Wilson is a sports broadcaster currently based in Las Vegas, Nevada, and a VF Young Adult Group Leader.
Kathy Olevsky: Enjoying Life in Remission from MPA and Pursuing Her Passions

By Nina Silberstein

After Kathy Olevsky was diagnosed with ANCA-associated microscopic polyangiitis (MPA) in 2009, it took her about a year to realize that she would never be the same person she was before she became sick. But when you read her story, you’ll see that this determined 62-year-old is not only surviving, she’s thriving.

Kathy was a physically strong woman prior to developing vasculitis. She was an athlete and started training in martial arts right after college. The Raleigh, North Carolina, resident earned an eighth-degree black belt in karate, and she and her husband, Rob, had at one time owned five martial arts studios. The couple has two children, a 35-year-old son and a 27-year-old daughter.

While practicing karate, Kathy also taught and mentored other martial arts school owners. “I had loads of energy and worked 60 hours a week with no regrets,” Kathy said. But in the year before she was diagnosed, her health changed. She started having aches and pains at age 50. “But what pushed me over the edge was debilitating pain between my shoulder blades. It made me call 911 a few times.”

She was told repeatedly by specialists that she needed to learn to deal with stress better. Her primary care doctor, however, knew about the athlete and warrior living inside Kathy. “She continued to champion me,” said Kathy. “She knew me well, and if I was in her office, something was wrong.”

She was told repeatedly by specialists that she needed to learn to deal with stress better. Her primary care doctor, however, knew about the athlete and warrior living inside Kathy. “She continued to champion me,” said Kathy. “She knew me well, and if I was in her office, something was wrong.”

“I have never regained my strength, although I see a strength training coach twice per week and have been doing this for the last two years,” she said. “It took me four years after remission to start to understand that no matter how hard I tried, physically I was not the same person.” Kathy currently sees Ronald Falk, MD, at UNC every three months for lab work and to keep tabs on her disease.

“I miss the physical person I was before, but I’m a stronger leader than I was—even then,” she said. She has traveled and presented at conventions, and has visited places as far away as Australia to share her expertise. Once a week she teaches black belts in her organization—a group of about 130 children, teens and adults—and her role is now teaching instructors how to teach. “I’ve spent years working in an atmosphere of positive energy and great customer service. We treat everyone like family and we teach them why they need to help spread the good in the world.”

Kathy also hosts the Vasculitis Foundation’s 2020 Road to Wellness webinar series and thinks it will be the most important work that she will ever do. Visit: https://bit.ly/2HWvGTb.

“I definitely had my dark moments. I relied on friends and family to help me get through those,” Kathy said. “I know in my heart, that my life is limited. I will not live as long as I want to, but I intend to travel everywhere and then share what I’ve learned.”
Dr. Garner’s mentor is Nader A. Khalidi, MD, FRCPC, Professor of Medicine, McMaster University, and head of service, Rheumatology, St. Joseph’s Health Care System. “Dr. Garner has already brought her skills in rheumatology to vasculitis, and clinically has made a great impact on patient care, and has facilitated careful and urgent care for those in need,” he said.

During the one-year fellowship, which officially began in July 2019, Dr. Garner has been working on two research projects. “The first is looking at using large administrative databases to develop cohorts of vasculitis patients here in Canada,” she noted. “The second is a project describing a collaborative subspecialist clinic as a model of care for vasculitis patients.”

After completing her vasculitis fellowship, Dr. Garner plans to continue through McMaster University’s clinical educator track, pursuing a career as an academic rheumatologist.

V-PREG Registry Seeks 250 Enrollees for Pregnancy and Vasculitis Study

By Nina Silberstein

Women with vasculitis often ask, “How will this disease affect my ability to have children?” and if they have vasculitis, “How will it affect my pregnancy?” Fertility and reproductive health issues are areas of great concern for patients with vasculitis and their doctors.

In partnership with the Vasculitis Patient-Powered Research Network (VPPRN), the Vasculitis Pregnancy Registry (V-PREG) was created with the goal of understanding pregnancy in women with vasculitis, associated complications, outcomes, and how vasculitis treatment impacts pregnancy.

V-PREG is recruiting participants and is open to pregnant women, 18 years of age or older, who have been diagnosed with any form of vasculitis. The hope is to enroll 250 women in the registry.

V-PREG participants take online surveys to assess the severity of their vasculitis and pregnancy-related experiences throughout the duration of the pregnancy. Data collected can relate to pain, medication history, overall health, vasculitis disease activity, prior pregnancy history and outcomes, hospitalizations, and medication history.

To join V-PREG, participants must first be a member of the VPPRN. Visit www.vpprn.org for details.
EGPA Registry Available to Patients in Person and Online

By Nina Silberstein

Like many people living with a rare disease, patients with eosinophilic granulomatosis with polyangiitis (EGPA) may find it frustrating when they have questions about their disease that simply don’t have answers.

With the goal of improving the management and treatment of EGPA, the Vasculitis Patient-Powered Research Network (VPPRN) has partnered with the Vasculitis Clinical Research Consortium (VCRC) to conduct research and help address patients’ concerns.

Data collected through the EGPA Registry will be used to study genetics and causes of vasculitis; find new ways to track disease and predict responses; understand how different treatments work for patients, and more. “The registry can help us answer the questions that are most important to patients with EGPA,” said Kalen Young, MA, Director of Research Affairs at the VPPRN. EGPA, formerly called Churg-Strauss syndrome, is one of the rarest forms of vasculitis and primarily affects the small blood vessels.

The EGPA Registry is available to patients online or in person.

“We encourage patients to participate in both when possible,” Young added. The EGPA Registry online version is available to patients who want to self-enroll and respond electronically with personal and health-related information that is sent directly to the VPPRN. The in-person component is a longitudinal study (takes place over time) that requires patients to enroll at a VCRC location and participate on-site.

The VPPRN was formed through a partnership between the VCRC and the Vasculitis Foundation and conducts patient-centered clinical research. The VCRC is an integrated group of academic medical centers, patient support organizations, and clinical research resources dedicated to conducting clinical research in vasculitis as well.

The VCRC-VPPRN EGPA Registry is supported in part by GlaxoSmithKline.

For more information about the EGPA Registry, visit www.vpprn.org, or contact Kalen Young at kyoung@vasculitisfoundation.org.

‘Ghostbusters’ Group Raises Awareness, Honors Member with Vasculitis

By Nina Silberstein

Raising awareness of vasculitis can come in many forms. For a small group of “Ghostbusters” movie fans in Central Florida, it’s about getting the word out and honoring one of their members who was diagnosed with leukocytoclastic vasculitis.

The group, called the Lakeland Ghostbusters, was formed after the “Ghostbusters: Answer the Call” movie debuted in 2016. Most recently, they staged a table at the Central Florida Comic Con, January 18-19, in Lakeland, Florida.

“Initially, we just did it to hang out at Comic Cons in Ghostbusters uniforms and have fun,” said organizer Elexier Diaz. “One of our members had been sick with a mysterious [illness] since 2014 and was diagnosed with leukocytoclastic vasculitis later in 2016.” This form of vasculitis is an inflammation of small blood vessels and can be confined to the skin or affect other organs such as the heart, kidneys, lungs, central nervous system and gastrointestinal tract.

“It was a shock to us when we realized it was the same illness that affected actor Harold Ramis and took his life,” Elexier said. Ramis, who played the bespectacled ghost hunter Dr. Egon Spengler in the “Ghostbusters” movies, died in 2014 of complications from autoimmune inflammatory vasculitis.

Immediately, the group saw its purpose. It took almost two years for the member with vasculitis to get a clear diagnosis. “Most people are not in big rush at Comic Con and this allows us to explain vasculitis, talk to them and raise awareness,” Elexier said.


Elexier Diaz, organizer of Lakeland Ghostbusters, raises awareness about vasculitis at Central Florida Comic Con.
VF’s New ‘Road to Wellness’ Webinars Feature Vasculitis Medical Experts”

The VF has launched a new series of educational webinars called “Road to Wellness.” Live and archived webinars feature vasculitis medical experts sharing their knowledge so you can manage your disease more effectively. Vasculitis patient Kathy Olevsky serves as host. (See Patient Profile, page 7.)

The new library includes webinars on a variety of topics including: Vasculitis 101, Kidney Health and Vasculitis, and others. The series is supported by Genentech and GSK. Learn more about upcoming live webinars and register at: https://bit.ly/2HWvGTb.

Behçet’s Disease Videos Now Available

Interested in learning more about Behçet’s disease? The VF has posted four Behçet’s videos on its website, recorded during the 2019 Behçet’s Disease Patient Summit last November in Atlanta, Georgia.

The topics include: Understanding Behçet’s Disease; Patient Perspective: Living with Behçet’s Disease; Physician Perspective: Coordinating Behçet’s Disease Care; The Power of Your Story.

More than 100 patients and family members attended the 2019 Behçet’s Disease Patient Summit, co-hosted by the VF and the American Behçet’s Disease Association, with sponsorship from Celgene. The event drew another 100 people participating via livestream. View the videos here: https://bit.ly/2PoP2Vu.
January and February 2020 Donors

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VF Calendar of Events • 2020

vasculitisfoundation.org/events/

Tuesday, March 31, 2020
V-RED Nominations Deadline
www.vasculitisfoundation.org/2020-v-red-program

Saturday, April 4, 2020
Vasculitis Support Group Meeting
Inver Glen Library
8566 Blaine Avenue E, Inver Grove Heights, Minnesota
10 am – Noon

Saturday, April 18, 2020
Vasculitis Patient & Family Conference
Join Our Journey. The Race Is On
Sheraton Silver Spring Hotel
3773 Georgia Avenue, Silver Springs, Maryland
9 am – 4 pm
Register: https://bit.ly/2T8NeSN
VF office: 816-436-8211

Saturday, April 18, 2020
Kansas/Missouri VF Chapter Meeting
University of Kansas Edwards Campus
BEST Building, Room 125
12600 Quivira Road, Overland Park, Kansas
1 pm – 3 pm

Wednesday, April 29 – Friday, May 1, 2020
Cleveland Clinic Medical Dermatology Therapy Update Course
Global Center for Health Innovation
Cleveland, Ohio
www.ccfcme.org/DERM20

May 1 – 31, 2020
Vasculitis Awareness Month

Friday, August 7, 2020
VF / KU Vasculitis CME Course
Overland Park Kansas Conference Center
6000 College Blvd, Overland Park, Kansas
11:30 am – 1 pm (Registration/ lunch provided)
1 pm – 5 pm (Program)
For information: jakullman@vasculitisfoundation.org

Saturday, August 8, 2020
VF - KU Patient & Family Conference
University of Kansas Edwards Campus
BEST Building, Ballroom
12600 Quivira Road, Overland Park, Kansas
9 am – 3 pm
Registration to open on April 1, 2020

The VF thanks Genentech and Sanofi for their support of the VF bimonthly newsletter.