Annual Appeal 2019: Please Help Us Continue the Momentum!

Support our Campaign for Better Treatments and Hope for the Future

By Sharon DeBusk and Nina Silberstein

Hope has many faces for people living with vasculitis. It might be a patient or family member who feels better. Or a doctor who puzzles out a diagnosis. Mostly, hope looks like better treatment and a cure for vasculitis.

Vasculitis researchers and clinicians optimistically point to studies that promise better treatments—leading to less reliance on steroids—in the foreseeable future. But they also agree, there is more work to be done.

“Patients have helped bring vasculitis research to a new era where we have many more treatments,” said Amy Archer, MD, PhD, director of the Vasculitis Program at Northwestern University in Chicago. “However, we want to expand the treatment options, have medications with fewer side effects, and develop the ability to better tailor therapy to each individual.”

To that end, the VF has launched a call to action through our Annual Appeal 2019, built around the second pillar of our Join Our Journey—Better Treatments campaign. The fundraiser, which began October 1 and runs through December 31, is at

“Patients have helped bring vasculitis research to a new era where we have many more treatments.”

—Amy Archer, MD, PhD

Sam and Helen Dodge: Seeing Life through the Lens of MPA Vasculitis

By Nina Silberstein

Sam Dodge spent much of his working life as an ad cameraman, and he collects antique motion-picture cameras, so it’s not surprising that he thinks in terms of film metaphors.

Sam was diagnosed last year with microscopic polyangiitis (MPA), and he describes the experience like this: “Sometimes I feel as if we are all living a slow-motion British murder mystery and we patients are the potential victims,” Sam said. “The good news is that the researchers, clinics and the doctors are the detectives. They are so good at what they do, and they give all of us great hope.”

Continued on page 7

Continued on page 4
Welcome to our year-end issue! As 2019 rolls to a close, we have many accomplishments to celebrate. We have you to thank for one of our biggest milestones in 2019—we funded our 50th research study. The VF is proud to be a leader in vasculitis research support.

But our work is not done.

On October 1, we launched our Annual Appeal 2019, built around the second pillar of our three-year Join Our Journey—Better Treatments campaign. Our goal is to raise $250,000 by December 31.

We’ve set up a special fundraising web page, where you’ll find a link to MobileCause, an online fundraising platform that makes donating easy. To learn more, please visit vasculitisfoundation.org/annual-appeal-2019/.

You can also support the Annual Appeal by participating in our Matching Gift Challenge, held in conjunction with #GivingTuesday on December 3. For every individual who donates a minimum of $10, a special donor will contribute $25. (Offer limited to the first 400 gifts made on #GivingTuesday. Only one $25 match will be made per individual donor.) Please visit: igfn.us/form/yymPtA.

My dad had vasculitis, and I wish he were here to see what has been accomplished in research. I know that was important to him. So please help us keep the momentum going. When you support vasculitis research, you are doing your part to help improve the lives of those affected by vasculitis—and giving them hope for the future.

As always, thank you for being a caring member of the vasculitis community. We wish you a healthy and happy holiday season!

Sincerely,

Joyce A. Kullman
Executive Director
Looking Back on 2019: A Year of Accomplishments, Milestones for the VF

As we reflect back on 2019, the VF has many achievements to celebrate—made possible through your generous donations. Supporting Annual Appeal 2019 will enable us to continue this important work!

Visit: vasculitisfoundation.org/annual-appeal-2019/

Fundraising

» Raised $1.5 million in gifts through fundraising efforts; $200,000 was our largest gift of the year, with the median gift amount at $50.

» Numerous fundraisers by members of the vasculitis community including:
  • Brett Hack Vasculitis Charities 2019 Fundraiser
  • Celebrating a Life: Keesha Vessell Vasculitis Walk
  • Horseshoe Pitching Tournament—Awareness
  • Magic Charity Event
  • 2019 Move Over Mozart
  • Nick Pascente Golf Tournament
  • Spaghetti Western Dinner
  • Tony’s Celebration of Life
  • Vino for Vasculitis
  • Violins for Vasculitis (V4V)—four events sponsored by and featuring board member Allison (Lint) Ross in Illinois, Delaware, Alabama, and Tennessee
  • Brian Kilgarif’s VF4Steph fundraiser

Research

» Reached a milestone of 50 VF-funded research studies.

» Vasculitis Patient-Powered Research Network (VPPRN): 3,059 patients enrolled in the network with 12 forms of vasculitis represented.

Website and social media

» Launched our new website. Thanks to grant support from Genentech, GSK, and Sanofi, the new and improved vasculitisfoundation.org is a mobile-friendly platform that boasts a fresh, new look, is easier to navigate, provides critical information and updated resources, and more robust security.

» More than 9,000 visitors to the website!

» Gained nearly 400 new members to the VF Facebook page, bringing our total number of members to nearly 7,000.

Symposium and conferences

» Hosted the 2019 International Vasculitis Symposium in Bloomington, Minnesota, which drew more than 300 attendees, and 50 speakers, panelists and moderators.

» Hosted our first regional conferences in the Southwest (Phoenix) and the Pacific Northwest (Seattle).

Direct patient support

» Helped more than 1,000 patients by email and phone.

Volunteers

» More than 200 volunteers stepped up to the plate to help the VF, including conference and symposium volunteers, awareness advocates, fundraising champions, and area contacts.

V-RED nominations

» Received a record number of nominations—nearly 100—for the 2019 Vasculitis Recognizing Excellence in Diagnosis (V-RED) awards program, which recognizes medical professionals who make an early diagnosis.

Patient educational materials

» Distributed a record number of VF disease brochures. We offer the brochures online and in print format, free of charge.
Support Our Campaign, cont.
the halfway point, and more donations are needed to meet the VF’s campaign goal of $250,000.

How you can help
It’s easy to donate online, or even set up your own Annual Appeal fundraiser, using the MobileCause fundraising tool on the VF’s campaign web page at vasculitisfoundation.org/annual-appeal-2019/. If you’ve never used MobileCause, read the inspiring story on page 6 about Brian Kilgarif, who is successfully using the tool to raise funds for the VF.

“As new treatments are launched, there is no better time to support research,” said Beth Westbrook, VF director of development. “Over the coming weeks, we hope you will join us on our journey and give generously to support research and hope for tomorrow.”

Thanks to the generous support of the vasculitis community, the VF is one of the largest private funders of vasculitis research, said Joyce Kullman, VF executive director. “Supporting research efforts with your dollars is a powerful and tangible way to improve the lives of people living with vasculitis.”

Matching Gift Challenge

#GIVING TUESDAY

Contribute to the VF’s Annual Appeal campaign by participating in #GivingTuesday on December 3.

For every individual who donates $10 or more, a special donor will contribute $25. (Offer limited to the first 400 gifts made on #GivingTuesday. Only one $25 match will be made per donor.)

Please visit: igfn.us/form/yyymPtA.

Voices for Vasculitis Research

“It does cost money to fund research, especially for the robust agenda we want to have. I have personally benefited from the research coming out of the VF.”

—Sara Baird Amodio, MSW, EdD, VF Board member; patient with EGPA

“The VF is a critical organization for the entire international vasculitis community. I am quite proud to both be part of the VF and to support this great organization with my time and donations.”

—Peter Merkel, MD, MPH, rheumatologist and professor of medicine, University of Pennsylvania

“When you go on one of these biologicals that targets what needs to be targeted, it’s really fantastic. Better treatment is the road we’re on.”

—Meaghan Carpenter, young adult patient with EGPA

“I believe the vasculitis research community views the VF as a leader in research support, and we should continue to work toward our goal of finding the causes and cures for these devastating diseases.”

—Jason Springer, MD, MS, director, University of Kansas Vasculitis Center; VF Research Committee

“I encourage you to continue supporting research studies in vasculitis, as we work together toward finding better treatments and cures.”

—Peter Grayson, MD, head of vasculitis research, NIH/NIAMS; VF Research Committee

“I never thought I’d live long enough to see a medication approved for my disease.”

—Kate Tierney, young adult patient with EGPA
Loneliness is a common feeling among patients with vasculitis. When you find someone else on a similar path, it can help ease the isolation. That’s what happened to Dedra DeMarco and Devri Velazquez, when they met at the 2019 International Vasculitis Symposium in July and discovered they share a lot in common on their journey with Takayasu’s arteritis (TAK).

“IT was great to meet someone else with the same disease,” said Dedra, who along with Devri, appeared in a VF video (bit.ly/31KV0Ec) at the symposium, to talk about living with TAK. Neither had ever met another person with TAK until then. “What we have is so weird and random and painful,” Devri added. “I am so happy I met people like Dedra and other patients who uplifted me and made me feel less alone in my journey.”

“Research is important so we can find these breakthrough treatments.”
—Dedra DeMarco

She hopes researchers will develop better treatments that have minimal side effects and are more targeted to her specific disease. She takes the immunosuppressant tocilizumab, prednisone and blood pressure medications, but her disease is still active. “Taking one medication would be better than taking multiple medications,” she said. “Research is important so we can find these breakthrough treatments.”

Devri, now 30, was diagnosed with TAK in 2011. Along with significant and rapid weight loss, Devri’s symptoms included fatigue, migraines, heart palpitations, numbness and tingling in her limbs, and temporary vision loss. She was working and finishing school at the time so she was preoccupied. “I was scared for many years on and off, especially when I’d be in the hospital for weeks at a time and the doctors couldn’t clearly tell me what was going on,” Devri said. There have been many challenges with relationships, jobs, friendships and finances. “Having vasculitis while trying to manage these things independently is difficult, even to this day.”

Devri currently lives in New York City and doesn’t think her diagnosis was an accident. “I’m a writer by profession and I think this was the story I was meant to tell.”
Annual Appeal 2019

Brian Kilgarif: A Success Story in Using MobileCause to Raise Funds for Vasculitis

By Nina Silberstein

If you ever need a shot of motivation, just talk to Brian Kilgarif.

Brian is raising money for the VF on behalf of his wife, Steph, who was diagnosed with granulomatosis with polyangiitis (GPA) in 2002, when she was 16. His goals are to raise vasculitis awareness, and to honor the strength of his wife and all those fighting the disease.

Along the way, he became motivated to tackle a third goal, this one for himself: weight loss. Since January 2018, he’s shed an impressive 173 pounds.

But first, about his mission to raise money for vasculitis. Brian uses a fundraising tool called MobileCause, where he created his own donation page to share with his personal social network: app.mobilecause.com/vf/VF4Steph. The VF is using MobileCause for its Annual Appeal 2019/Join Our Journey fundraising campaign, and hopes Brian’s story will inspire others to try the platform. (Brian is also sharing his efforts on Instagram at: @insecure_2_confident.)

For the second year in a row, the VF is using MobileCause for its Annual Appeal because more people are using phones and mobile devices to make donations.

“It has not been an easy journey for Steph, especially with the flares she has had in the past two and a half years,” Brian explained. She has been in the emergency room more than 20 times and admitted to the hospital nine times, on top of chemotherapy treatments every six months. In addition to GPA, Steph also deals with fibromyalgia and has undergone multiple surgeries. Steph and Brian were married in September 2016, and the family, which includes Steph’s son, Drake, live in Downingtown, Pennsylvania. “While she is the one going through this, I try my best to be there for her,” he said.

Brian is committed to losing weight. His why is simple. “I was making excuses for being overweight and none of them were valid reasons.” One day he saw his profile in the mirror and thought, “What are you doing?” He instantly thought of Steph, who has no control of her situation. “I’m doing all these things simply because I can.”

In the future, Brian plans to complete a full marathon (he finished his first half-marathon this past September) and an Ironman 70.3 triathlon. He is inspired to try, even if he fails, because there are so many people like Steph who push themselves every day.

“I’ve gained confidence, self-belief and a very positive mindset,” he said. “I’ve been overweight my entire life and struggled with food. Now I look at any obstacle as a stepping stone to become a better person, husband, stepdad, son, brother and friend.”

His weight loss has given him a platform to further support Steph and her disease. “She is truly a warrior and is a big source for my strength,” he said.

To support the VF’s Annual Appeal, please visit: vasculitisfoundation.org/annual-appeal-2019/.

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Have You Tried Peer-to-Peer Fundraising? Please Help us Meet our Campaign Goal!

Create your own Annual Appeal fundraiser on Facebook! Over the past eight years, the VF has received over $96,000 in donations through Facebook fundraisers hosted by our supporters. Learn more at facebook.com/fundraisers.

You can also donate and create your own fundraiser through MobileCause. You can set up your own landing page to share your story and show your fundraising progress and goal at vasculitisfoundation.org/annual-appeal-2019/.
VF Launches New Video Collections from International Vasculitis Symposium

The VF is excited to present two new online video libraries, featuring educational lectures and interviews from the 2019 International Vasculitis Symposium held last July in Bloomington, Minnesota.

The 2019 Vasculitis Symposium Video Library

In September, the VF added 30 full-length video lectures presented at the symposium to its educational video library on the VF website. Viewers can also download the PowerPoint slides featured in those presentations. The video collection is available at: bit.ly/2kVIFwN.

Presentation topics include: the role of genetics in vasculitis; what’s new in vasculitis research; vasculitis treatment and your immune system; diet; and much more.

Vasculitis Voices

During the symposium, the VF transformed a room on the fourth floor of the Hyatt Regency Bloomington-Minneapolis hotel into a professional video recording studio. Over the course of three days, videographers captured 17 interviews with patients, researchers, physicians, and caregivers sharing their perspectives on a wide array of topics.

The new video collection is called “Vasculitis Voices.” While filming patient stories isn’t something new at VF symposia, the organization wanted to try something more ambitious.

“Instead of just simply recording patient stories, we wanted to take the idea to a new level since a symposium brings together a diverse group of individuals,” said Joyce Kullman, VF executive director. “We created a traditional interview format where patients, doctors, and researchers interviewed each other in different combinations. It was something new for us, and the results are wonderful.”

You can view the Vasculitis Voices video interviews at: vasculitisfoundation.org/mcm_webinar/vasculitis-voices/.

Sam and Helen Dodge: Seeing Life through the Lens of MPA, cont.

In April of 2018, Sam and his wife, Helen, set out to live on a barge and cruise the canals of England for six months. Life had different plans for them. “My first heavy, crippling symptoms showed up on Day 1 in England,” Sam explained. “It was soul-crushing fatigue and edema (swelling) in both my feet.”

He felt like his immune system was randomly attacking different parts of his body. “My right eye turned wonky. I had a chronic, mild cough and then blood in my urine. My nose ran and teeth hurt. Fatigue was always there.” But the doctors he saw overseas were unable to give him a diagnosis.

The Dodges returned to Washington state after their trip, and Sam, then 74, saw his regular doctor. “After several blood draws, heart checks, MRI and CT scans, my GP and his staff were completely stumped,” Sam said. He was referred to a rheumatologist and was diagnosed with MPA within four months of returning home. “I’m just really lucky that he was the first (rheumatologist), and he hit it right on,” Sam said.

Sam was prescribed prednisone, mycophenolate, and Rituxan®, a biologic drug. Except for extreme fatigue, he is managing his treatment well. “But MPA makes it a problem just to get out of the house and do simple things that I used to do,” he said.

“MPA makes it a problem just to get out of the house and do simple things that I used to do.”

—Sam Dodge

After 33 years of marriage and raising two sons together, Helen says her husband’s diagnosis has changed the dynamics of their relationship. “I’ve had to develop a lot of patience,” Helen said, but she likes that it has made her more tolerant.

“I am so blessed with good health, I feel like I can pick up the slack, no problem.

“For Sam, I think that’s going to help in the long run, this feeling of hopefulness and positiveness.”
Frank B. Cortazar, MD, has been named director of a new vasculitis center in the Albany, New York, area. Dr. Cortazar will oversee both clinical and research activities at the New York Nephrology Vasculitis and Glomerular Center, which opened August 1.

There has been a significant need for a vasculitis center in the Albany, New York, area, according to Dr. Cortazar, who is also a nephrologist with St. Peter’s Health Partners in Albany and a clinical research scientist for Massachusetts General Hospital in Boston.

“Given the rarity and complexity of these conditions, patients benefit greatly from being managed by experts at dedicated vasculitis centers,” said Dr. Cortazar. However, there are only a few such centers across the country, he added, and until now, there were none in this geographic region.

“I am privileged to be part of an excellent team,” Dr. Cortazar said. Jorge Cerda, MD, is a fellow nephrologist at the new center, with extensive experience in managing vasculitis patients in addition to being an international authority on acute kidney injury.

“He has been a tireless advocate for the center from the beginning and I am indebted to him for his continued support in making this a reality,” Dr. Cortazar explained. The two have assembled a multidisciplinary team, including specialists in ophthalmology, ENT and pulmonary medicine, which allows them to manage all aspects of care for vasculitis patients. Dr. Cortazar and his team’s goals include:

• Providing outstanding care to vasculitis patients and their families
• Advancing the care of patients by conducting patient-oriented research
• Educating local physicians with the intent of fostering the early diagnosis and referral of vasculitis patients
• Creating a local support group for vasculitis patients in the Albany area

“We are equipped to manage all aspects of care for patients with vasculitis,” Dr. Cortazar said. A prime focus is expedited evaluation/diagnosis and prompt implementation of a tailored immunosuppressive regimen when needed. In addition, research will be a key component of the center, which is in the process of starting the Albany Glomerulonephritis Registry. This is a prospective cohort study that longitudinally (data studied over a period of time) collects disease, treatment and outcome data on patients with vasculitis and glomerular disease.

“All patients treated at the New York Nephrology Vasculitis and Glomerular Center will be offered enrollment,” Dr. Cortazar concluded. “Combining data from the Albany Glomerulonephritis Registry with other registries will allow for rigorous analyses of these rare diseases.” There is also an interest in offering patients enrollment in clinical trials investigating promising novel therapeutics for ANCA-associated vasculitis.

Scientific Abstracts from ACR and ASN Meetings to be Posted Online Soon

The American College of Rheumatology (ACR) will hold its 2019 annual meeting November 8-13 in Atlanta, Georgia. Scientific abstracts from the meeting will be available for review online and will be published in a special online supplement of the scientific journal, Arthritis & Rheumatology. Visit: rheumatology.org/annual-meeting.

In addition, the 2019 American Society of Nephrology (ASN) Kidney Week meeting is November 5-10, in Washington, DC. Accepted Kidney Week 2019 research abstracts, with the exception of late-breaking clinical trials, are available online. Visit: asn-online.org/education/kidneyweek/2019/meeting-overview.aspx.

A research abstract is a synopsis of the most important information from a scientific study. It provides a brief account of science being reported, including the purpose, methods, primary results, and conclusions. The abstract is based on the study’s summary and conclusions.
Clinical Study: Evaluation of Efficacy and Safety of Sarilumab in Patients With Giant Cell Arteritis

*Now Enrolling Patients*

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

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

**Inclusion criteria:**
- Diagnosis of 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: [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**.

Clinical Study: Evaluation of Efficacy and Safety of Sarilumab in Patients with Polymyalgia Rheumatica

*Now Enrolling Patients*

**Primary Objective:**
To evaluate the efficacy of 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 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.
- Patient is 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).
- Patient 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: [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**.
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Thank you for your gift of $50 or more!

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IN MEMORIAM
Italian Family Expresses Gratitude to Doctor through 2019 V-RED Certificate

In March 2017, Cinzia Galimberti’s son Lorenzo, 11 years old at the time, fell ill. He was admitted to the De Marchi Pediatric Clinic of Milano, Italy, for a variety of symptoms including weight loss, vomiting, fatigue and pallor. Following an emergency kidney biopsy, nephrologist Antonio Mastrangelo, MD, diagnosed Lorenzo with microscopic polyangiitis (MPA).

“The vasculitis, in the doctor’s words, was very aggressive at first and Lorenzo had severe renal failure,” said Cinzia. “The first year was very hard for all of us, and there were two ER visits, but Dr. Mastrangelo knew how to explain what was happening to Lorenzo and to us.”

Cinzia was so grateful to Dr. Mastrangelo, she decided to nominate him for the VF’s 2019 Recognizing Excellence in Diagnostic (V-RED) award program, in which individuals nominate medical professionals who have made an early vasculitis diagnosis. Earlier this year, Dr. Mastrangelo received a V-RED Certificate of Appreciation.

Cinzia, whose family lives in Lissone, a town in Northern Italy, said she nominated Dr. Mastrangelo for the award for his “expertise and humanity.”

“We are able to say that Lorenzo, now 14, is well, has had no relapses and lives a completely normal life,” she said. He still has regular follow-ups and is on treatment, “but we feel more serene because we are in good hands.” She also expressed gratitude to clinic director Dr. Giovanni Montini and the entire medical team at the clinic.

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

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. rarediseasesnetwork.org/cms/vcrc/
VF Calendar of Events • 2019-2020

vasculitisfoundation.org/events/

Saturday, November 9, 2019
Behcet's Disease Patient Summit

» Renaissance Atlanta Midtown Hotel, 866 W Peachtree St. NW, Atlanta, Georgia
» 9 a.m. - 12:30 p.m. (breakfast and lunch provided)
» Free of charge
» Live stream will be available
» To receive updates, please email behcet's@dna-comms.com

Saturday, November 16, 2019
North Carolina Vasculitis Support Group Meeting

» University of North Carolina Wellness Center at Meadowmont, 100 Sprunt St., Chapel Hill, North Carolina
» 9:30 a.m. - 2 p.m. (includes lunch)
» Contact Brandon Hudgins at bdhudg@gmail.com

Saturday, February 29, 2020
Rare Disease Day

» The purpose of Rare Disease Day® is to harness the creativity and energy of the millions of people around the world with rare diseases—and the millions who care about and assist them—to raise awareness and generate action. Together we can accomplish that goal. rarediseases.org/rare-disease-day/

May 1-31, 2020
Vasculitis Awareness Month
(Stay tuned for details)