Welcome to Vasculitis Awareness Month! The Race is Still On!

Dear Readers:

We chose “The Race Is On!” for this year’s Vasculitis Awareness Month (VAM) theme before the coronavirus pandemic turned the world on its head. The Race Is On is even more fitting now as the scientific community works around the clock to find answers to COVID-19’s mysteries.

We believe the race is STILL on for more vasculitis research, better treatments, improved quality of life, and a cure. Now, the coronavirus gives us a unique opportunity to help the general public recognize that people with vasculitis are at a higher risk of infection due to immunosuppression. Social distancing is so important to help protect ourselves and loved ones. Conversely, immune-compromised vasculitis patients already know the drill of effective hand-washing, the proper way to cover a cough or sneeze, and how to cope with social isolation, so those skills can be used to help others who are getting used to this “new normal.”

Please join us in our vasculitis awareness and education activities this month as your own personal situation allows. Read on to see how you can raise awareness, right from your own home.

Wishing you good health and well-being during these trying times.

—Joyce A. Kullman, VF Executive Director

Vasculitis Awareness Month 2020 is here! The Race Is On, and we have a wide range of activities, events and initiatives to raise awareness.

VASCULITIS AWARENESS 2020
THE RACE IS ON!

“Races come in many forms—some are sprints and some are marathons,” said Suzanne DePaolis, President, VF Board of Directors. “Patients, physicians, and researchers are all part of the race to help vasculitis patients live a better, productive and fulfilling life. Won’t you join us as we race toward our goals?”

Except where noted below, please find information on all our activities at www.vasculitisfoundation.org/awareness/. This year’s VAM highlights:

» V-RED awards: The VF’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. Note: The coronavirus has caused

Continued on page 6

Collaborative COVID-19 Patient Project Launches, Enrolling Study Participants

When it comes to how the rapidly spreading coronavirus (COVID-19) is affecting people with vasculitis, medical experts agree there are more questions than answers—at least right now. To address that concern, the VF and the Vasculitis Patient-Powered Research Network (VPPRN) have teamed up with partners in the Autoimmune Research Collaborative (ARC) to launch a new vasculitis and autoimmune COVID-19 patient study.

The Vasculitis COVID-19 Patient Project will survey vasculitis patients in the United States and Canada in an effort to capture as much information as possible from those who have existing respiratory illness, those with respiratory involvement related to coronavirus, and those who may fall into both categories. The project is for anyone with vasculitis, not just those vasculitis patients who have tested positive for COVID-19. Broader international registration will be available soon.

“We are collecting data on how many vasculitis patients have it, how they were diagnosed if they do have it, how they are feeling

Continued on page 9
Dear friends,

“Life is what happens to you while you’re busy making other plans.”
—John Lennon

We’ve seen our world turned upside down by the COVID-19 pandemic over the past few months. Loved ones, friends, and colleagues are fighting the disease; some have recovered, others have lost the battle. Our thoughts go out to all of you.

Thank you to all the health care providers, support staff, and essential workers around the world for their extraordinary efforts during this pandemic. Thank you to the scientists working around the clock to learn as much as possible about the virus and how to treat and prevent it.

Many of you have watched Dr. Anthony Fauci’s daily medical briefings on COVID-19. Dr. Fauci is the director of the NIH’s National Institute of Allergy and Infectious Diseases, and began his career at the NIH studying Wegener’s granulomatosis, now granulomatosis with polyangiitis (GPA). Dr. Fauci and Dr. Sheldon Wolff developed the first effective treatment for Wegener’s, which combined prednisone with daily cyclophosphamide (Cytoxan®). Their findings were published in the 1973 edition of the journal, Medicine. While this was a major advancement, physicians and researchers quickly recognized the need to develop approaches that were effective and associated with fewer side effects.

May is Vasculitis Awareness Month, and we hope you’ll participate as your circumstances allow. Raising awareness of vasculitis and its impact on patients’ lives is even more important during these days of social isolation. It is apparent that many people do not know the challenge of living with an immune-compromised system, as most of our patients with vasculitis do. As one patient wrote, “I’ve been practicing social isolation for 15 years because of my GPA and immune-compromised system.”

Many thanks to all of you who continue to encourage and educate the general public about the importance of staying home during this pandemic. Together we can make a difference and continue to flatten the curve.

Sincerely,

Joyce A. Kullman
Executive Director
Please Join Us: The Race is Still On!

The coronavirus has changed the world as we know it. What hasn’t changed is the ongoing need for more vasculitis research for better treatments, improved quality of life, and a cure. And although we’re taking shelter in our homes during this pandemic, we believe the race is still on to help make life better for those living with vasculitis.

Our Spring Appeal 2020 is June 1–June 30. The goal is to raise $50,000 in support of our Join Our Journey campaign for better treatments.

“Together we are trying to resolve some of the biggest challenges we’ve had to face,” said Beth Westbrook, VF Senior Director of Outreach. “That’s why we are focused on raising funds with modest donations—the amount that is appropriate for you. It is critical to patients we keep research and programs in the pipeline.”

You can make a donation, and/or set up a fundraiser on behalf of the VF. Learn more at: www.vasculitisfoundation.org/awareness/.

VF Newsletter Converting from Print to All-Digital Format Going Forward

Dear Readers:

As an increasing number of our readers are getting their news and information on phones, tablets and computers, we have made the decision to stop printing the VF Newsletter. This issue—the May/June 2020 edition—is the last newsletter that will appear in print, as we move to an all-digital format.

We are in the process of redesigning our monthly VF E-News to share important information via email. We’ll continue to offer news, research updates and study enrollment announcements, conference and event information, patient stories, new webinar/podcast listings, and more.

In addition, we will continue to utilize videos, webinars, podcasts and other avenues on our website to deliver content designed to inform, educate, inspire, and connect. Check out our website at: www.vasculitisfoundation.org.

We want to thank our sponsor, Genentech, for generously helping fund the printed newsletter since 2010. And many thanks to you for being a loyal reader! Please contact me with any questions or concerns at: jakullman@vasculitisfoundation.org, or call 816.436.8211.

Sincerely,

Joyce A. Kullman
Executive Director

New Vasculitis Webinars and Podcasts Aim to Enlighten, Inform, and Educate

Webinars

The Power of Mindfulness and Meditation: This installment of the VF’s Road to Wellness webinar series addresses how stress can take a toll during the current COVID-19 health crisis. Psychotherapist Lynn Valencic, LCSW, talks about coping strategies in these times; how the pandemic is affecting us; surviving information overload, and more. Dr. Valencic also leads a guided meditation. Visit: https://bit.ly/2XdW5F4.

Adrenal Insufficiency and High-Dose Steroids: Lynnette Nieman, MD, FACP, of the National Institute of Diabetes and Digestive and Kidney Diseases/NIH, presents valuable information about adrenal issues and steroid therapy. She talks about clinical features and causes of adrenal insufficiency, what you need to know about taking steroids, and more. Visit: https://bit.ly/2xTVU7q.

Dispatch From Across the Pond: Living with Vasculitis in the UK: This is the latest episode in The Ride by Vasculitis Journey podcast series, created by Sara Amodio, VF Board Member and vasculitis patient. The series is available through Apple Podcasts and Spotify® and is an offshoot of her Facebook site, Vasculitis Journey.

In this episode, Sara talks with Jane Edwards about life in the UK as a vasculitis warrior and recently published author. They also chat about COVID-19, how to come to grips with the emotional effects of vasculitis, and share what we all have in common. To listen, visit: https://bit.ly/2XcQiiY.

Podcasts

PET Scans and Imaging Technology: This is the fourth episode of the Vasculitis Visionaries podcast series, co-hosted by Ben Wilson and Kaley Beins, VF young adult leaders and vasculitis patients. They join Kaitlin Quinn, MD, an NIH researcher and lead of the Medstar Georgetown University Hospital vasculitis clinic. Dr. Quinn talks about her interest in vasculitis and her research in large-vessel vasculitis. She also discusses her recent publication on PET scan timing and disease activity, and the implications for predicting flares. Tune in at: https://bit.ly/39LtPMP.
Three New Members Join VF Board of Directors; Bring New Skills, Perspectives

By Nina Silberstein

The VF welcomes three new members to the Board of Directors: Kevin Byram, MD, Anisha B. Dua, MD, MPH, and Brian Goldman.

“The VF board is always evolving and it’s exciting to add new members to the Board,” said Suzanne DePaolis, President, VF Board of Directors. “Kevin, Anisha, and Brian have the experience and talents needed as the VF moves into the future. We are looking forward to working with them now and for many years to come.”

Kevin Byram, MD, Director, Vanderbilt Vasculitis Clinic; Assistant Professor of Medicine, Division of Rheumatology, Vanderbilt University School of Medicine, Nashville, Tennessee

Dr. Kevin Byram has long held an interest in vasculitis. “Vasculitis syndromes are really interesting,” he said, “but the patients with these diseases are even more fascinating. I’m amazed by their resiliency.”

As Director of the Vanderbilt Vasculitis Clinic, Dr. Byram and his team are establishing cohorts of patients with vasculitis so that they can study disease-related outcomes. For the past few years, he has also been a member of the American College of Rheumatology’s (ACR) Vasculitis Guidelines Committee on the literature review team. Once the recommendations are published, the VF and ACR will team up to disseminate the guidelines this calendar year.

“The VF Board of Directors opportunity is exciting because it’s patient focused,” he said, “and it’s another way to positively impact vasculitis patients on a policy and fundraising level.”

In addition, having benefited from the support of the VF through his training, he wants to ensure those opportunities are present for other trainees and investigators interested in vasculitis.

Anisha B. Dua, MD, MPH, Director, Northwestern Vasculitis Center; Associate Professor of Medicine, Rheumatology, Director, Fellowship Program at Northwestern University Feinberg School of Medicine, Chicago, Illinois

Dr. Anisha Dua has been involved with the VF for many years, participating in patient symposia, reviewing grants, and leading the patient panel for the vasculitis guidelines in collaboration with the ACR. These opportunities have allowed her to fully engage with experts in vasculitis research and patient care, VF members, and a wide variety of patients.

“I am passionate about caring for patients with vasculitis and educating my patients and my peers in order to try and achieve earlier diagnoses, and targeted and comprehensive management,” she said.

As a VF board member, Dr. Dua would like to focus her efforts on the Research and Fellowship Committee. “I believe directing funding and support for viable and innovative projects will be critical in moving the field of vasculitis forward,” she said. “Encouraging research and educating our patients and providers, as well as collaborating with other subspecialists to pool our expertise, are central to consistently improving the landscape for vasculitis care and management.”

Brian Goldman, Chief Financial Officer, Sani-Tech West, Camarillo, California

Brian Goldman’s wife, Jen, was diagnosed with eosinophilic granulomatosis polyangiitis (formerly Churg-Strauss Syndrome) in 2010. Despite going to the best doctors and trying all available treatments, Jen passed away in November 2018, one week before her 47th birthday.

“I lost my wife, soulmate and best friend that afternoon,” he said. “I cannot think of a better cause that is closer to my heart that also honors Jen and her brave fight.”

Brian hopes to take everything he learned and experienced from those years and use it to help others. “I also hope to use my professional background to help the VF grow,” he said. Brian has 23 years’ experience working for nonprofits and more than half of his career has been at the executive level. He has also served on other boards, including the Make-A-Wish® Foundation for the Central (California) Valley, the Fresno Chaffee Zoo, and his son Brandon’s soccer club, and has volunteered for various organizations over the years.

“Add in that I was a spouse and caregiver to someone who lost her life to vasculitis, and I come in with the ability to be a board member from many perspectives. I have passion for the cause,” Brian said.
Vasculitis Awareness Month: Working Toward our Goals in the COVID-19 Era

By Beth Westbrook
VF Senior Director of Outreach

We are in this together. Whether it’s good times or challenging times, I’ve never felt such a coming together as I do with the vasculitis community. Last year was the first time I attended the VF’s International Vasculitis Symposium. The level of compassion and empathy for each other was inspiring. Even today, I know you are doing what you can to support each other during the COVID-19 pandemic.

We chose the theme, “The Race is On!” for this year’s Vasculitis Awareness Month (VAM) long before the coronavirus hit. The Race is On, as a rallying cry, may seem to contradict the “shelter in place” order many of us are now living under, but we think they can successfully co-exist.

To that end, we invite you to join us in the race for vasculitis awareness. From May 1 – May 31, we’ll have vasculitis awareness and education activities you can take part in right from your own home. Learn more at: www.vasculitisfoundation.org/awareness/.

Spring is also the time of year when we reach out and ask for your support so we can continue to provide resources to our community. Right now, it may appear insensitive to ask for donations—it’s a dilemma fundraisers all over the country are grappling with. But if we are to continue providing outstanding educational tools and programs, we need your help.

During VAM, we’re offering a matching gift fundraiser. With heartfelt gratitude to one of our generous donors, we will be able to match gifts up to $10,000. Every $1 will become $2 until we reach the $10,000 goal. Please consider participating as your resources allow.

Then in June, we will launch our Spring Appeal for donations. It is not about the size of the gift but the heart and soul with which the gift is given—and that’s the right amount for you.

The VF is here to help you, too. We’re updating our coronavirus web page with the latest information: www.vasculitisfoundation.org/coronavirus-covid-19/.

There are new educational webinars and podcasts as well: www.vasculitisfoundation.org/educational-videos/.

Isolation does not mean you are alone. We are a community of caring people. Together, we’ll make sure the coronavirus doesn’t stop us in our tracks as we work to support our mission.

Stay safe and healthy,

Beth Westbrook
Senior Director of Outreach

NORD’S RareAction Network:
Be an Advocate, Get Involved!

By Nina Silberstein

One thing you will probably learn as a patient with a rare disease like vasculitis is that you have to be your own advocate. Whether it’s learning about your medical condition, speaking up for yourself on matters that affect your health, or simply connecting with others, self-advocacy is not easy. But a little research can lead you to organizations like the RareAction Network® (RAN), that are working to improve the lives of patients with rare diseases.

An advocacy program of the National Organization of Rare Disorders (NORD®), RAN works to improve the lives of 30 million-plus Americans living with rare diseases, and includes patients and their families, caregivers and friends, as well as researchers, physicians, and academia. Members participate in regional and local events; develop relationships with key decision-makers and opinion leaders; share stories to help raise rare disease awareness, and receive news and information on what the network is taking action on. While working largely at the state level, RAN filters information up to NORD’s national federal policy team to help address issues of national concern.

Art Diaz, who was diagnosed with granulomatosis with polyangiitis in August 2017, was not familiar with RAN at the time. But after reading an article about it in an issue of the VF newsletter, he decided to look into it further. He then signed up on an email list for his home state of California. “It was exciting because I had not met any fellow vasculitis patients and this was my first opportunity to meet other rare disease patients, too,” he said.

In addition to those mentioned above, there are other ways to get involved with RAN, including leadership roles (known as ambassadors), for those interested in taking the lead in their state. For more information about RAN, visit: https://bit.ly/2UGM15Q.
Welcome to Vasculitis Awareness Month, cont.

some delays in this program. Get updates at: www.vasculitisfoundation.org/2020-v-red-program.

» 2020 VAM video: “The Race is On” is the theme of our 2020 awareness video, available on our VAM web page. Every year, the VF produces a new video that captures the spirit of raising awareness about vasculitis. This year’s video will stress the importance of racing toward developing better medications and improving the quality of life for patients worldwide.

» 2020 VAM engagement calendar: View our 2020 calendar (See page 7), then go to our VAM web page and download. You’ll find a variety of vasculitis awareness activities and events to choose from every day of the month.

» VAM matching gift fundraising challenge: A special donor is matching gifts up to $10,000 in support of VAM 2020. Make a donation in May and double your gift. Every $1 becomes $2. You can also start your own fundraiser on behalf of the VF during this time. https://app.mobilecause.com/form/D9_29w?vid=5ave5

» International Vasculitis Day—May 15: Join us for a live webinar with leading vasculitis researchers Tanaz A. Kermani, MD, Peter Grayson, MD, and patient-partner Jennifer Gordon, PhD. They’ll discuss the most impactful research studies of 2019 and the future of vasculitis research in a new world with the coronavirus. The Vasculitis Patient-Powered Research Network (VPPRN) presents the webinar, with hosts Kalen Young, MA, Director of Research Affairs for the VPPRN, and Dianne Shaw, patient-partner. Sign up on our VAM web page.

» Life hacks: Promote self-care by submitting your own short video describing the “life hacks” you use to improve your daily life with vasculitis. For example, vasculitis patient Kate Tierney wears purple on days when she doesn’t feel well to let her family/friends know it’s not a good day. Another patient keeps gloves by the refrigerator to handle cold things. Post your video here: www.facebook.com/VasculitisFoundation/.

» Buy your #VAM2020 T-Shirt and spread vasculitis awareness! Visit the VAM web page.

» Say it like you meme it: Spread awareness by sharing our memes on your social media channels.

» New podcasts:
  • Join Ben Wilson and Kaley Beins for their Vasculitis Visionaries series. (See VAM web page).
  • Check out Sara Amodio’s series, The Ride by Vasculitis Journey: www.facebook.com/vasculitisjourney/.

» We want to thank our sponsors Amgen, ChemoCentryx, Genentech, and GSK, for their generous support of Vasculitis Awareness Month 2020, and the V-RED awards program.

2020 VF-KU Patient & Family Vasculitis Regional Conference Slated for Saturday, August 8

Note: At this time we are planning to hold the conference. We are monitoring the COVID-19 pandemic and will make a decision about the meeting in June. We will open registration once we know more. Thank you for your patience.

Please join us for the VF-KU 2020 Vasculitis Patient & Family Regional Conference on Saturday, August 8, at the University of Kansas in Overland Park, Kansas. Medical experts will come together to discuss a wide range of topics of interest to patients and families. Please stay tuned for more details. If you have questions about this event, please call the VF office at 816.436.8211.

Preliminary schedule:

2020 VF-KU Regional Patient & Family Vasculitis Regional Conference
Saturday, August 8, 2020
9 am – 3:45 pm
University of Kansas Edwards Campus
BEST Building
12600 Quivira Road, Overland Park, Kansas

9:30 am – 10 am Registration
10 am – 10:10 am Welcome and Introductions
  Jason Springer, MD, MS
  University of Kansas Medical Center

10:10 am – 10:40 am Emerging Management and Treatments in Systemic Vasculitis
  Sharon Chung, MD, MAS, UCSF Vasculitis Center

10:45 am – 11:15 am Special Considerations of the Lungs and Airways in Systemic Vasculitis
  Ulrich Specks, MD, Mayo Clinic

11:20 am – 11:50 am Roundtable Discussion
  Moderator: Allison Ross, Violin for Vasculitis, VF Board Member

11:55 am – 12:15 pm Stay Connected: Kansas City Local Support Group
  Denny and Ruth Hale, Chapter Leaders

12:15 pm – 1 pm Lunch
Patient discussion groups

1 pm – 1:30 pm Focus on the Kidneys
  Reem Mustafa, MBBS, MPH, PhD
  University of Kansas Medical Center

1:30 pm – 2 pm Focus on the Large Arteries
  Mehrdad Maz, MD, University of Kansas Medical Center

2 pm – 2:30 pm Social Break

2:30 pm – 3 pm The Horizon for Steroid Replacement/Minimization in Systemic Vasculitis
To be announced

3 pm – 3:30 pm Alternative Medicine
  Jonathan Smitz, MD

3:30 pm – 3:45 pm Closing Comments
  Allison Ross
# Vasculitis Awareness Month Interactive Calendar

You’ll find this downloadable VAM calendar at: [www.vasculitisfoundation.org/awareness/](http://www.vasculitisfoundation.org/awareness/)

<table>
<thead>
<tr>
<th>SUNDAY</th>
<th>MONDAY</th>
<th>TUESDAY</th>
<th>WEDNESDAY</th>
<th>THURSDAY</th>
<th>FRIDAY</th>
<th>SATURDAY</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>03</strong> Buy a VF #VAM2020 T-Shirt! Share your story and educate people about vasculitis!</td>
<td><strong>04</strong> Share Your Life Hack for Living with Vasculitis!</td>
<td><strong>05</strong> Make a Quick $5 Donation.</td>
<td><strong>06</strong> Celebrate National Nurses Day 2020. Thank a Nurse in Your Life!</td>
<td><strong>07</strong> Violin for Vasculitis (V4V) Live Request Hour on Facebook!</td>
<td><strong>08</strong> Listen! Vasculitis Visionaries Podcasts</td>
<td><strong>09</strong> Share Information about the V-PREG Registry! Encourage women in childbearing years to sign up.</td>
</tr>
<tr>
<td><strong>10</strong> Make a Gift in Honor or Memory of a Special Mom!</td>
<td><strong>11</strong> Enroll in the Vasculitis COVID-19 Patient Project.</td>
<td><strong>12</strong> Listen to The Ride by Vasculitis Journey Podcast Series.</td>
<td><strong>13</strong> Learn about the VPPRN!</td>
<td><strong>14</strong> Watch a Webinar on Self-Publishing!</td>
<td><strong>15</strong> International Vasculitis Awareness Day Breaking research webinar with our vasculitis experts!</td>
<td><strong>16</strong> Make a Short Video about Your Vasculitis Journey. Post on Social Media and Tag the VF!</td>
</tr>
<tr>
<td><strong>17</strong> Celebrate Caregivers Day!</td>
<td><strong>18</strong> The VF is Hosting a Pajama Party on Saturday, June 20! Our first-ever virtual fundraising and awareness event!</td>
<td><strong>19</strong> Going the Distance Live with Brandon Hudgins!</td>
<td><strong>20</strong> Behçet’s Awareness Day</td>
<td><strong>21</strong> Road to Wellness Webinar: &quot;Mindfulness and Meditation&quot;</td>
<td><strong>22</strong> Take a Walk with Friends and Family!</td>
<td><strong>23</strong> Share Your Life Hack for Living with Vasculitis!</td>
</tr>
<tr>
<td><strong>31</strong> Complete Your Bingo Card and Enter Drawing to Receive a VAM T-Shirt!</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

## Thank You to the Following VAM Sponsors!

- **AMGEN**
- **ChemoCentryx**
- **Genentech**
- **GSK**

---

VF News
**Vasculitis Experts Answer Your Questions about Vasculitis and the COVID-19 Virus**

By Kalen Young, MA  
Director of Research Affairs, VPPRN

This is an exceptionally challenging time for patients and our community as the COVID-19 virus continues to spread. Isolation, fear, and anxiety are common and valid feelings, especially when the unknowns about the virus are far greater than what is known for certain.

The VF has received a wealth of questions from our community about the virus and its specific implications for vasculitis patients. Our vasculitis medical experts have answered the most commonly asked questions below—to the best of their current medical knowledge. We thank these passionate and dedicated medical professionals for sharing their expertise in a rapid manner.

The VF and our medical experts cannot provide individualized medical advice. If you have concerns about your health or treatment, please contact your physician directly.

This Q&A was prepared and published on our website in early April. Responses were provided by Tanaz A. Kermani, MD, Director of the Vasculitis Program, University of California – Los Angeles (UCLA), and Jason M. Springer, MD, MS, Director, University of Kansas Vasculitis Clinic, Kansas City, Kansas.

---

**Q:** What are the risks of COVID-19 to people with vasculitis?  

**A:** The specific risks for people with vasculitis are yet to be determined. We suspect our patients are at higher risk of infection due to immunosuppressive drugs used to manage vasculitis. So far, we do not know whether the risk differs based on the type of immune-suppressing medication someone is taking. We also do not yet have data on the clinical course of patients with vasculitis who develop infection with COVID-19.

**Bottom line:** All patients with vasculitis (especially those on treatment) should consider themselves at high risk. They should take all the precautions recommended by the Centers for Disease Control (CDC) to minimize exposure.

**Q:** What should I do if I feel sick? How can I tell the difference between my vasculitis symptoms and potential COVID-19 symptoms?  

**A:** The symptoms of COVID-19 are fever, signs of a cold (cough, runny nose, shortness of breath), and, in some cases, diarrhea. Keep in mind our patients may not have a high fever because of medications they are taking. Anyone who develops these symptoms should contact their doctor for advice on evaluation and testing. Given the highly contagious nature of COVID-19, we ask patients with symptoms of infection to call their doctor’s office before going in, so the office can prepare and take appropriate precautions. However, if you have symptoms like worsening shortness of breath/difficulty breathing, seek medical attention immediately in the ER.

Even under normal circumstances, it can be challenging to distinguish infection from inflammation. Usually symptoms that get better on their own within a few days are more likely to be infection (than inflammation). Sometimes, vasculitis can also flare with infection. If patients have symptoms, they should contact their doctor to assist in evaluation. The burden of determining whether this is vasculitis or infection should not be placed on the patient.

**Q:** Should I stop taking my medications if I have vasculitis and am concerned about COVID-19?  

**A:** Please do not stop any medications before contacting your doctor. If you are concerned about your medications and the risk of infection, you should discuss this with your doctor. They can advise you on what is best for you because they know your vasculitis history. If you are on infusion medications and are scheduled for an infusion, check with your doctor about whether you should proceed.

While we are all concerned about the risk of this infection, we are also concerned about relapses or flares of vasculitis from stopping or lowering medications. If this occurs, you will be at risk for complications from active vasculitis and your doctor may need to put you on more immune-suppressing medications like high-dose steroids to manage the vasculitis.

**Q:** What would you like to say to our patient community during this crisis?  

**A:** Be calm, but also take the warnings seriously. It is important for you to take care of yourself and ask for help if needed.

---

Continued on page 9
The Vasculitis COVID-19 Project, cont.

about coronavirus, regardless of whether they have it or not, and more,” said Kalen Young, MA, Director of Research Affairs for the VF and VPPRN. “This study will help researchers and clinicians better understand how patients with autoimmune, rheumatic, or related conditions, are dealing with and feel about COVID-19 coronavirus.”

The Autoimmune Research Collaborative includes the ArthritisPower/Global Healthy Living Foundation, IBD Partners/ Crohn's & Colitis Foundation, and iConquerMS, along with the VF and VPPRN.

A series of surveys will be sent out over a one-year period—every two weeks for the next two months and then again at six months and 12 months. The project opened for enrollment in April and is currently accepting patients to participate. Each survey will take about 10 minutes to complete online.

Survey questions include topics such as: level of concern about the coronavirus; medications being taken or stopped, and why; existence of respiratory illness, symptoms and severity; exposure to others who had the coronavirus or might have been exposed; testing for the coronavirus; diagnosis of coronavirus; avoidance of activities due to concerns about the virus, and more.

This survey is for anyone who has an autoimmune or related disease and is 19 years or older (21 years or older in Puerto Rico). All participants’ information will be private. No participant will be personally identified in any publications.

The VF and VPPRN will contact potential survey participants from existing patient databases. In addition, you can enroll in the survey at https://bit.ly/3cmSkBt. Scientists from ARC will analyze and share out the survey results with the vasculitis community as they become available.

For up-to-date coronavirus information and resources, visit our coronavirus web page at https://bit.ly/2KcvQXL.

“We are committed to providing you updates over time about the rapidly changing situation around the coronavirus, as a way of supporting the community of people living with, or affected by, autoimmune and related conditions,” said Young.

International COVID-19 Rheumatology Registry Launched for Providers

The COVID-19 Global Rheumatology Alliance, an international registry for reporting cases of COVID-19 in patients with rheumatic diseases, has been launched.

Clinicians are asked to use the site to report all cases of COVID-19 in rheumatology patients, including those with only mild or no symptoms.

The VF is among more than 100 organizations supporting the registry, along with the American College of Rheumatology, the Lupus Foundation of America, the European League Against Rheumatism, journals, charities, and others. The alliance’s goal is to “provide an open platform for data collection, sharing, and dissemination which is transparent, inclusive, and non-competitive.” The website provides information on data sharing, and on institutional review board and patient consent requirements for entering data into the registry.

For more information, visit: https://rheum-covid.org. Please let your physicians know they can register their patients.

COVID-19 Q&A, cont.

Please follow the precautions recommended by the CDC, as well as recommendations from your individual state/region.

• Practice social distancing, avoid public places, and practice good hand hygiene.

• Avoid sick people and contact your doctor immediately if you are sick.

• Follow your local guidelines about being outdoors around other people.

• Seek support and reach out to your doctor/mental health professional if you are having symptoms of depression or anxiety.

• Be patient with the changes that may be occurring in your doctor’s offices (eg, appointment cancellations, changing in-person visits over to phone or video visits and, in some cases, delays).
Q&A with Brandon Hudgins: Thoughts on Olympics Postponement and COVID-19

By Sharon DeBusk

In our January/February newsletter, we featured professional distance runner Brandon Hudgins as he prepared for the 2020 US Olympic Team Trials in Track & Field in June. Hudgins, a vasculitis patient, VF Ambassador, and founder of the Victory over Vasculitis campaign, had been training hard in hopes of qualifying for the 2020 Tokyo Summer Olympics.

VF: The Tokyo 2020 Summer Olympics were postponed in March due to the coronavirus. How are you feeling about that?
BH: I was initially worried that they would try to forge ahead and host the games. So when they finally announced they would be postponed, it was a sigh of relief. For several weeks, as things with the coronavirus got more serious, I had to stop my intense training and put my season on hold. In talking with my team (my partner, doctors, family) it wasn’t worth the health risk. I’ve been in this sport since I was 10 and have had to put racing on the back burner for years at a time with my vasculitis, so waiting one more year doesn’t faze me at all. These problems all pale in comparison to the health issues that every high-risk person is dealing with right now. Because ultimately, being healthy and alive is far more important than any job or sport.

VF: How long have you been training for these Olympic games?
BH: I’ve been training for this moment since I was 13. It’s all I’ve dreamed about. But from a physical sense, I’ve been training hard since my last Rituxan® infusion in October 2018. A month or so after that infusion I was declared in remission. From that point on it’s been about building for this year. I’ve had some minor injuries, but before I shut it down in March, I was doing workouts on par with what I was doing in 2016. I know I was on track to be ready. If it’s 2021, then so be it.

VF: How is the coronavirus affecting your running and exercise regime now?
BH: I’ve reduced my training by about 20-30 percent. I’m still getting out and running every day—more for sanity and routine than for race training. By staying at 70-80 percent I can hang on to most of the fitness I’ve gathered over the last 18 months but not put myself at risk of infection.

VF: How are you coping with COVID-19?
BH: Luckily, life as a distance runner and vasculitis patient has prepared me for the isolation. I’ve been stressed and anxious, but that is more fear of getting sick than being down in the dumps. I’ve needed to get back on a regular routine of meditating and practicing mindfulness. With too many hours on social media and reading the news, my stress levels are at an all-time high. Relaxing and focusing on my breathing are incredibly helpful for reducing stress levels.

VF: What do you do to keep your spirits up?
BH: I’m enjoying more time with my partner, Ryanna. I’ve had more time to catch up on writing, playing music and doing things that I never have the time or energy to pursue. I learned long ago to pour my energy into things other than running. When I don’t, I fall into those dark depressions, so when I see things like this happen, I immediately start figuring out what’s next. And I’m constantly inspired by the stories I hear from other patients.

VF: You are such an inspirational voice, what would you say to encourage others during this time?
BH: I’ve learned it’s best to take things one day at a time. At some point things will return to normal. Best to find things to occupy your time that are productive: Get out and walk or exercise, read books that you’ve put aside, pick up the guitar that hasn’t been played, and develop a routine each day.

VF: As VF ambassador, what would you like to communicate to the vasculitis community?
BH: Right now we have a unique opportunity to help others. Most of us have been immunocompromised, so we know the wash-your-hands-and-cover-your-cough-drill. As patients, we’ve had to suffer in silence very often, and we developed skills to help ourselves in times of trouble. Those skills now can be used to help others.

“Ultimately, being healthy and alive is far more important than any job or sport.”
—Brandon Hudgins, distance runner
Dr. Rebecca Manno: Bringing Rheumatology Expertise to the US Virgin Islands

By Nina Silberstein

The US Virgin Islands (USVI) have always been a special place for rheumatologist Rebecca Manno, MD, MHS, because she and her husband, Nick Hoyt, have vacationed in the territory for the past 20 years. But after the two devastating Category 5 hurricanes in 2017 (Irma and Maria), Dr. Manno began learning more about the health care needs in the region. It was important for her to help and be of service to the community—which was without stable rheumatologic care prior to the storms. And the aftermath left an even larger gap in care for patients with rheumatic disease.

“There were zero full-time rheumatologists residing in the USVI. Most patients had to travel to the continental US or Puerto Rico for rheumatologic care,” Dr. Manno explained. “Traveling off-island for health care became financially prohibitive for many patients due to extremely high costs and limited resources. I wanted to be part of the solution.”

The USVI is a limited resource territory, Dr. Manno added. “Although there has been a great deal of recovery from these natural disasters, there’s still a lot of work that needs to be done. Unfortunately, many health care providers left the territory following these events.”

Dr. Manno relocated with her husband to the USVI in August 2019. Prior to that, she had been Assistant Professor of Medicine, and Assistant Director of the Vasculitis Center at Johns Hopkins University, where she completed her fellowship training in rheumatology and joined the faculty in 2011. She has maintained her faculty status as Adjunct Assistant Professor of Medicine in the Division of Rheumatology at Johns Hopkins.

For Dr. Manno, vasculitis encompasses everything that is great about being a rheumatologist. “It’s a group of heterogenous [diverse] diseases, which on the surface, appear very different. But as you look more closely, they share many features—the hallmark feature—inflammation of blood vessels,” she noted. “It requires attention to every aspect of the patient, not just a single organ system. The systemic vasculitides are challenging but rewarding diseases to research and care for.”

Dr. Manno joined a group practice in the USVI—Comprehensive Orthopaedic Global (COG)—which is an orthopedic (and now rheumatologic) private practice with offices located on St. Thomas and St. Croix. COG employs three full-time general orthopedists, a part-time pediatric orthopedic specialist, a part-time orthopedic pediatric spine specialist, and Dr. Manno. “As the only full-time rheumatologist in the territory, I see patients predominately in St. Thomas and travel to St. Croix for patient care at least once per week,” she said.

While practicing general rheumatology and caring for patients with all of the rheumatic diseases, Dr. Manno sees plenty of inflammatory arthritis, ie, rheumatoid arthritis, spondyloarthritis, psoriatic arthritis, and lupus. “I have seen and diagnosed several cases of vasculitis since relocating here as well,” Dr. Manno said.

“The biggest challenge with rural medicine is limited resources and the limited access to advanced technology, although there are improvements being made every day. For example, obtaining an MRI to look for large vessel vasculitis or a CT scan with 3D reconstruction to look for polyarteritis nodosa is not so easy here,” Dr. Manno said.

But she sees this as a positive. “There’s an opportunity to build things in partnership with the community and endless opportunity for growth,” she said. “Working in a small community also allows for personalization, both for patient and physician interactions.”

For Dr. Manno, vasculitis encompasses everything that is great about being a rheumatologist. “It’s a group of heterogenous diseases, which on the surface, appear very different. But as you look more closely, they share many features—the hallmark feature—inflammation of blood vessels,” she noted. “It requires attention to every aspect of the patient, not just a single organ system. The systemic vasculitides are challenging but rewarding diseases to research and care for.”

Dr. Manno joined a group practice in the USVI—Comprehensive Orthopaedic Global (COG)—which is an orthopedic (and now rheumatologic) private practice with offices located on St. Thomas and St. Croix. COG employs three full-time general orthopedists, a part-time pediatric orthopedic specialist, a part-time orthopedic pediatric spine specialist, and Dr. Manno. “As the only full-time rheumatologist in the territory, I see patients predominately in St. Thomas and travel to St. Croix for patient care at least once per week,” she said.

While practicing general rheumatology and caring for patients with all of the rheumatic diseases, Dr. Manno sees plenty of inflammatory arthritis, ie, rheumatoid arthritis, spondyloarthritis, psoriatic arthritis, and lupus. “I have seen and diagnosed several cases of vasculitis since relocating here as well,” Dr. Manno said.

“The biggest challenge with rural medicine is limited resources and the limited access to advanced technology, although there are improvements being made every day. For example, obtaining an MRI to look for large vessel vasculitis or a CT scan with 3D reconstruction to look for polyarteritis nodosa is not so easy here,” Dr. Manno said.

But she sees this as a positive. “There’s an opportunity to build things in partnership with the community and endless opportunity for growth,” she said. “Working in a small community also allows for personalization, both for patient and physician interactions.

“There are some incredible doctors in the USVI and I very much enjoy sharing patients with them, and working to grow programs and resources for health care,” she said.

“I enjoy being engaged with the community. It allows me to really understand the culture and the community of my patients,” Dr. Manno said. “And it’s a beautiful, caring, family-oriented, and joyful community that is a privilege to be a part of.”

Rebecca Manno, MD, MHS

Medical Degree: University of Maryland School of Medicine
Residency: Internal Medicine, University of Maryland Medical Center and Baltimore VA Medical Center
Fellowship: Rheumatology, Johns Hopkins University
Patient Profile

Fran Crotty Finds that Faith and Positivity Fuel Her Personal Transformation

By Nina Silberstein

Back in November 2013, the VF ran an article written by Fran Crotty, who was diagnosed in 1996 with granulomatosis with polyangiitis (GPA) and Crohn’s disease. In her own words, she “has come back from her challenges, only slightly worse for wear, yet filled with optimism, strength in her faith and a greater appreciation of the life that can still be found in the old, tattered and forgotten.” You can read Fran’s personal account of her medical journey, “The Power of Transformation – Fran’s Story” at: www.vasculitisfoundation.org/frans-story/.

Fran has managed to stay in remission for almost two decades. We reconnected with her in March 2020 to see how she’s doing.

The road to Fran Crotty’s transformation first started with her diet. A neighbor who had overcome ovarian cancer suggested she start reading labels, tackling one diet goal at a time because trying to do it all at once would be overwhelming and make her feel deprived.

Fran read books and online articles, attended lectures, watched documentaries, and listened to podcasts. Based on her learnings, she tweaked her diet, exercise, and lifestyle, carefully noting what worked and what didn’t. She says her body and mind have continued to grow stronger as a result. Fran maintains a special diet that she has adjusted over the years, eliminating gluten and most dairy products, caffeine, alcohol, and diet soda. She limits her sugar intake and red meat, and tries to eat a whole-foods-based organic diet, heavy on fruit and vegetables.

After prednisone took a toll on her body, Fran began investigating alternative treatments. She met a medical doctor who studied Chinese medicine and acupuncture; someone she’s worked with for years. “I'm convinced his treatments are a primary reason my GPA has been in remission for close to 20 years,” she says. “Possessing strong faith and a very determined purpose for living (my family) have been essential.” Daily prayer, meditation, affirmations, a positive attitude, Reiki (channeling energy into a patient using touch), massage, morning walks, pool exercises, creative hobbies, positivity, loving people, and a healthy diet—all have played a part in her healing journey, she says.

Fran says she and her siblings were brought up by her parents to look for the silver lining in everything. “I've always had a positive attitude and it has helped me through some challenging times. I have read a lot about the power of intention, positive thinking and my ability to choose my thoughts. Most importantly, my faith keeps me positive.”

Fran’s hard-earned comeback is why the idea of transformation has become so important to her. “I'm a living example of how what was sickly, bent-over, bloated and brittle, can be transformed and renewed with a lot of love and attention.” As an example, when Fran saw a 1910 Victorian home that was plain and drab—one called the ugliest house on the block—she knew she could rescue it. The same thing seems to happen each time she sees something tattered, bumped or bruised, seeing beyond what someone might consider as junk or a neglected, forgotten “something.”

Fran has a knack for repurposing those things—in any condition—and giving them a new life. If a piece needs a little reworking, a coat of paint, sun bleaching or just a good wash, she’ll clean up the exterior, and then for her, “its soul shines through. Its history, the story of finding it, the love from its previous life become part of its energy.”

Today, 58-year-old Fran lives in that same Victorian home in Glenside, Pennsylvania, a suburb of Philadelphia. She still tackles rehab projects and has many in the works, but is currently a color consultant for a residential painting company. “I like to think of my job as helping customers bring color into their lives,” she adds.

Fran recommends patients be kind and loving to themselves, fully digesting the gravity of their diagnosis and spending quality time reflecting on lifestyle, habits, diet, and the ways stress and sleep are managed. “When committed to living your healthiest life, you should decide which area you’re going to work on,” Fran says. “From there you should start getting educated to determine what baby steps you can take to move into a positive direction.”
**Dr. Eric Gapud: Giving Back by Furthering his Medical Training in Vasculitis**

By Nina Silberstein

When Eric Gapud, MD, PhD, was in medical school, he was diagnosed with an autoimmune disease. As you might expect, he can empathize with the experiences of his patients, particularly those with vasculitis and anyone who has been diagnosed with a rare disease. A physician-scientist, Dr. Gapud is also an instructor of medicine on the junior faculty at the Johns Hopkins University School of Medicine in Baltimore, Maryland. His area of clinical expertise is rheumatology with a sub-specialty in vasculitis.

“I've been very fortunate as a patient in that my condition has been stabilized with a biologic,” Dr. Gapud said. “I had a smart doctor who took care of me, who I’ve always admired.” Wanting to do the same for others, Dr. Gapud is taking the opportunity as a clinician and researcher to give back.

“Vasculitis is among the rarest and probably the least understood condition that rheumatology, as a whole, deals with,” Dr. Gapud noted. “I've always been captivated by that.” His interests include mechanisms and patient outcomes for antineutrophil cytoplasmic antibody (ANCA)-associated vasculitis, giant cell arteritis, Behcet's disease, and Takayasu's arteritis.

Dr. Gapud's training is partially funded by the Vasculitis Foundation. “The VF is pleased to support Dr. Gapud’s training through the Dr. Darwin James Liao Memorial Fund,” said Joyce Kullman, VF Executive Director. “We must encourage the next generation of physician-researchers to choose the field of vasculitis to ensure that our patients receive the care they need.”

“**We anticipate that Dr. Gapud’s work will be impactful, from breakthroughs in vasculitis research to acceleration of improvements in patient care.**”

—Dahlia Mak

Dr. Liao was an ophthalmologist, entrepreneur, and inventor in the Seattle, Washington, area. He passed away from complications of eosinophilic granulomatosis polyangiitis (EGPA) in December 2013. Dahlia Mak is the family representative for her brother's memorial fund held at the VF.

“Darwin’s sudden passing from EGPA was absolutely heartbreaking,” said Mak. “It is why improving vasculitis research, awareness and treatment continues to be critically important to our family. We believe that helping clinicians and patients learn more about vasculitis and best practices in treatment will facilitate more timely diagnosis and care.”

Dr. Gapud divides his time between seeing patients in the Johns Hopkins Vasculitis Center, while conducting molecular immunology research on rheumatic disease mechanisms.

Through his current research he has found that most researchers have thought that the function of the molecules involved in the immune system’s response was to kill cells, causing tissues to function abnormally. Using kidney disease in ANCA-associated vasculitis as a model, Dr. Gapud’s research suggests that there may be another side to this that has been underrecognized.

“We think by understanding this different set of immune functions that we may be able to further subtype patients and then eventually correlate this with greater precision, like a diagnosis or what a person’s chances are, for example, of progressing to having lung or kidney issues,” he said. “Or if we treat you with agent X over agent Y, will you be more or less likely to do better?”

Dr. Gapud earned both his MD and PhD in molecular immunology through the Medical Scientist Training Program at Washington University in St. Louis, Missouri. He then completed his internship and residency in internal medicine at Washington University at St. Louis/Barnes Jewish Hospital followed by a fellowship in rheumatology at the Johns Hopkins University.

“There's something about vasculitis, the way it manifests in such a nonspecific way,” Dr. Gapud said. “That means a lot of detective work for the clinician.” Even though progress has been made, Dr. Gapud said he is struck by how little we know: Where do these diseases come from? Why do some of the things we prescribe, like rituximab, work? How do we better predict outcomes? Who's going to flare and who's not? Who really needs the high-intensity suppression and for how long?

Dr. Gapud said his research will continue indefinitely, as these are important questions that need answers. “We're finding what we think might be important lessons that could be extrapolated

**Continued on page 15**
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: [https://clinicaltrials.gov/ct2/show/NCT03600818](https://clinicaltrials.gov/ct2/show/NCT03600818).

If you do not have internet access, please contact the VF office for a study flyer: 816.436.8211.

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: [https://clinicaltrials.gov/ct2/show/NCT03600805](https://clinicaltrials.gov/ct2/show/NCT03600805).

If you do not have internet access, please contact the VF office for a study flyer: 816.436.8211.

**Rituximab Gets Expanded Approval for Use in Pediatric Patients**

The U.S. Food and Drug Administration expanded the approval of rituximab (Rituxan®) injection last fall to include the treatment of children ≥2 years of age who have the rare diseases granulomatosis with polyangiitis (GPA) and microscopic polyangiitis (MPA), in combination with glucocorticoids.

The safety profile was found to be consistent in that of adult GPA and MPA patients. The most common side effects in the pediatric study were infections, infusion-related reactions and nausea. Rituximab was first approved in 1997 to treat Non-Hodgkin’s lymphoma and is now approved for multiple indications in adults, including for the treatment of GPA and MPA.

March 2020 Donors

Amgen Inc.
Karen and Joseph Anderson
Shannon Aust
Louann and William Barnwell
Berkshire United Way, Inc.
Kenneth Bevry
Scott Brunton and Maxine Cordell-Brunton
Cynthia Burrichter
Mary and Shayne Busby
Tracie Caplinger
Chemocentryx, Inc.
Michael Chesonis
Sarah Cody
Margaret Cook
Crown Power & Equipment
Trina Cutshaw
Dianne Dennis
Lindsay Douglas
W. and Jane H. Douglas
Susan Drew
Catherine Elliazar
Frontier League Middle & Jr. High Schools
G. Rabun Frost
Claudene Galbreath
GlaxoSmithKline
Tina Hansen
Kathleen Haslett
Ken Kiernan and Brian Hemann
Victor and Brenda James
Janet Kelk
Carmen Kidd
Jennifer Kush
Lincoln Baptist Church
John and Michele Martin
Lynn Mawhorr-Fortman
Margery McBride
Thorvard McKiearnan
M.D. Electric Inc.
Judi Medaglia
Christine Mellusi
Leann Miller
Myrtle and Robert Morrison
Diana Pasquarella
Carlie Pierson
Bozana Radenkovic-Hadzic
Jennifer and Leman Renner
Della Ribordy
Karen Rundquist
Stacie Shaffer
Bridget Sosaya
Jason Springer, MD, and Athena Springer
Carol and Myrna Swart
Thrivent Funds
United Way—California Capital Region
United Way of Miami Dade
Leonard and Alberte Wadler
Mary Welton
Rich Westhoff
Reginald Wickham
Peter Williams
Joann and Ronald Wojnar

IN MEMORIAM

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

Donald Christie
Karen Colletti-Pacilli
Anthony W. Cvelbar
Gudrun Hanson
Mark Hibpshmaun
Nancy Lavin
Patti Sue Massa
Don Medaglia
Suzanne Reedy
James Springer
Janet Westhoff

Dr. Eric Gapud, cont.

broadly to study autoimmunity and immune function in general," he said. With the ability to subtype disease, there’s the hope of finding key elements of these pathways that might actually represent novel therapeutic strategies. “It could suggest ways in which certain biologics or other drugs could be used in unexpected ways to treat disease with potentially fewer side effects. Ultimately that is the goal.”

“The hope is that with the help of resources like what I’ve been fortunate to have received from the Vasculitis Foundation, that we can continue this work and use it as a springboard for additional research,” Dr. Gapud said.

Dahlia Mak said her family is excited to support Dr. Gapud’s work at the Vasculitis Center at Johns Hopkins. “We anticipate that Dr. Gapud’s work will be impactful, from breakthroughs in vasculitis research to acceleration of improvements in patient care,” she said.

VF Calendar of Events • 2020

Note: Due to the rapidly changing situation with the coronavirus, some items in our calendar may be out of date by the time the newsletter is printed and delivered. Please check with the respective organizations to confirm schedules.

April 6, 2020 – May 29, 2020
Virtual Lecture Series for Fellowship Trainees
Virtual Rheumatology Learning Collaborative
American College of Rheumatology,
Committee on Training and Workforce
Lectures will be held Mondays, Wednesdays, Fridays
9 am – 10 am
https://bit.ly/2JUQ34d

May 1 – 31, 2020
Vasculitis Awareness Month
Visit www.vasculitisfoundation.org/awareness/

RESCHEDULED DUE TO CORONAVIRUS!
The Cleveland Clinic Medical Dermatology Therapy Update CME course has been rescheduled for September 3 – 5, 2020.
The location and content materials remain the same.
Global Center for Health Innovation
1 St. Clair Avenue NE, Cleveland, Ohio

Saturday, August 8, 2020
VF – KU Patient & Family Vasculitis Regional Conference
University of Kansas Edwards Campus
BEST Building
12600 Quivira Road, Overland Park, Kansas
9 am – 3:45 pm
For more information, please call the VF: 816.436.8211.

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