Recent advances in the field of vasculitis have exposed problems with the classification criteria that have been used for ANCA-associated vasculitis since 1990. GPA/Wegener’s, EGPA/Churg-Strauss, and microscopic polyangiitis are considered to be ANCA-associated. Classification criteria are used to group patients into different types of vasculitis, once a diagnosis of vasculitis has been made, and are useful for studying patients in clinical trials with similar or identical diseases.

To address the classification problems, in 2010, the Vasculitis Foundation provided $100,000 in funding and partnered with the American College of Rheumatology (ACR) and the European League Against Rheumatism (EULAR) to establish the Diagnostic and Classification Criteria in Vasculitis Study (DCVAS). The multi-year study has recruited more than 6,000 patients from 130 vasculitis research sites/centers and enlisted hundreds of investigators worldwide to work on the project. DCVAS will also develop classification and diagnostic criteria for giant cell arteritis, polyarteritis nodosa, and Takayasu’s arteritis.

Speaking on behalf of the committee, presenter Ravi Suppiah, MBChB, MD, FRACP, said it was important to update the classification criteria for vasculitis because the 1990 criteria are no longer consistent with current disease definitions. “For example, microscopic polyangiitis, which is one of the major forms of ANCA-associated vasculitis, was not even recognized in the previous criteria,” he said.

“In addition, tests for ANCA were not in routine use when the previous classification criteria were developed, and now patients are more often identified earlier in their disease course. Furthermore, the use of advanced cross-sectional imaging, especially CT scans, has become routine compared to 30 years ago.”

In developing the new criteria, Dr. Suppiah, who presented the section of the session titled “New Classification Criteria for ANCA-Associated Vasculitis: Why and How?” said it was important to get the global vasculitis research community to help. “We collected detailed clinical, radiological, and laboratory information about each patient and their presenting illness, which was captured in an online database,” said Dr. Suppiah, who has worked on the DCVAS study since its inception when he was a fellow at the University of Oxford, England. “A vignette of each...”

Nominate Your Health Care Professional For The 2017 VF RED Award

Often, one of the greatest challenges a patient with vasculitis faces is receiving a definitive diagnosis. Patients often spend months, or even years seeking a diagnosis or worse, living with a misdiagnosis and ineffective treatment.

The Vasculitis Foundation also recognizes that there are many health care professionals who have MADE the diagnosis of vasculitis and we want to honor them for their efforts to care for our patients.

We are pleased to announce that nominations are open for the 2017 VF Recognizing Excellence in Diagnostics (RED) Award. The VF RED Award is presented annually to a medical professional (general practitioner, registered nurse, physician’s assistant, nurse practitioner, physical therapist, etc.) who made a quick diagnosis of vasculitis, thus enabling the patient to receive timely and appropriate treatment, potentially sparing the patient permanent and ongoing health complications.

If you or a loved one received an early diagnosis, we invite you to nominate your deserving health care professional for the 2017 VF RED Award. All of the submissions will be reviewed and we will announce the winner during Vasculitis Awareness Month in May.
Dear Friends,

Happy New Year!

Thank you for your generous support of the 2016 VF Annual Appeal. Your donations fund our awareness, education, research and fellowship programs and make it possible for us to achieve our mission. We are grateful for your generosity and support.

This year we hope you will be the best advocate for yourself and your loved ones.

Advocate for yourself and for all patients with rare diseases. The Vasculitis Foundation will partner with the National Organization of Rare Diseases (NORD) and the American Autoimmune Diseases Related Association (AARDA) to keep abreast of the many health-related issues facing our community. Celebrate Rare Diseases Day on February 28th!

Learn as much as possible about vasculitis! Assemble an experienced medical team. Connect with other patients and family members either in person or online.

Participate in one of our online webinars, regional conferences or even better, attend our 2017 International Vasculitis Symposium in June in Chicago! The symposium is a wonderful opportunity to learn from our vasculitis experts and meet other patients and family members during the three-day weekend. You will gain knowledge and hope!

Join the Vasculitis Patient-Powered Research Network (V-PPRN) and be an active member in research. We have several studies in the planning stages. Please contact Kalen Young, the V-PPRN Network Manager, to learn more. kyoung@vasculitisfoundation.org.

Organize a virtual or “real” awareness/fundraising event for our 2017 Vasculitis Awareness Month in May. If you are interested in organizing an event please contact me.

Finally, I’d like to thank Morgan Richards, Elizabeth Rodriguez, and Travis Akins for organizing the 2016 Victory over Vasculitis 5K Run/Walk as a school project. They planned the event in less than three months and did a great job!

Sincerely,

Joyce A. Kullman
Executive Director
PCORI Approves $2.3 Million for Kawasaki Disease Research

In December 2016, the PCORI Board of Governors announced a $2.3 million award for a study to determine whether established treatment or a newer drug is more effective against treatment-resistant cases of Kawasaki disease, which can cause heart problems in children. The principal investigator is Dr. Jane Burns and the co-investigator is Dr. Katherine K. Kim, both at the University of California San Diego.

Kawasaki disease, a form of vasculitis, is a self-limited illness that affects the heart blood vessels (coronary arteries) of infants and children, and is now the most common cause of acquired heart disease in children. Intravenous immunoglobulin (IVIG) is a treatment which reduces the rate of aneurysms, a major complication of KD. However, 10 percent to 20 percent of children are resistant to IVIG treatment and the fever returns. These children have the highest rates of aneurysm formation and thus should be treated aggressively. Unfortunately, because the problem has never been adequately studied, there are no guidelines for the best secondary treatment for these resistant patients. Most physicians choose either a second infusion of IVIG or infliximab, which inactivates a molecule that promotes inflammation.

The Kawasaki award was one of 19 new patient-centered research projects approved by PCORI.

“We are pleased to add this latest round of projects to our expanding portfolio of patient-centered research,” said PCORI Executive Director Joe Selby, MD, MPH. “We look forward to following the studies’ progress in producing evidence that could lead to changes in practice and, eventually, better outcomes for patients and their families.”

The V-PPRN is a member of The National Patient-Centered Clinical Research Network (PCORnet) which is also funded by PCORI.

Survey Says: Focus on Education, Support, and Communication  | Ed Becker

The beginning of a new year typically involves writing out resolutions, or laying out a set of goals to be achieved. However, to make the process work it’s important to first understand the highest priorities that carry the most value.

For the Vasculitis Foundation, a membership survey conducted in 2016 yielded a list of what you—the VF member—believed were the most important goals of the organization. Where should we be investing our time, energy, and resources to ensure we’re accomplishing the basic tenants in our mission—supporting and empowering our community through education, awareness and research.

Survey Says........

95%
Provide education for medical professionals

91%
Fund more research and train more vasculitis specialists

89%
Focus on educating about the individual vasculitides

60%
Hold more regional conferences and symposia

How the VF is Responding........

The Vasculitis Foundation is partnering with the Cleveland Clinic Center for Vasculitis Care and Research to host the CME course “Primary Vasculitides: Best Practices and Future Practices” on April 5, 2017.

The VF Research program broke the $2,000,000 mark in funding in February 2016. This year the VF expects we should be funding two new VCRC-VF Fellows to begin their training in July 2017.

In 2017 the VF will be updating its disease-specific web pages, providing more webinars focused on the types of vasculitis, and engaging with disease-specific patient advocacy groups.

In June the VF will hold its International Vasculitis Symposium in Chicago. The VF will host regional conferences in Bethesda, Maryland on February 4th and Cleveland, Ohio on April 4, 2017.


The Victory over Vasculitis 5K Run/Walk with the theme “Ugliest-Sweater-Ever” was held on Saturday, December 3, 2016. Over 100 runners and walkers braved very cold weather to participate. Brandon Hudgins, 2016 Olympic long distance runner, shared his story and reminded the audience to “never give up and keep going.” The event raised $2,800 for the Vasculitis Foundation. Many thanks to Morgan Richards, Elizabeth Rodriguez, and Troy Akins for organizing the event and many thanks to Liberty North High School and to their running coach, David Chatlos, and the Northland CAPPS Program for their tremendous support of the event.
Participate in EGPA (Churg Strauss Syndrome) Survey

The Vasculitis Foundation is helping a marketing health care consulting firm learn more about the management of patients with EGPA/Churg Strauss Syndrome, specifically the patient journey and the needs of patients. The company would like to interview patients across a wide spectrum of EGPA disease presentation and experiences during a one-on-one, 60-minute interview via telephone. The conversation will be anonymous and confidential and no personal information will be shared outside that of the interviewer. They are offering an honorarium for each patient’s participation.

Participate in Giant Cell Arteritis Patient Engagement

The Vasculitis Foundation is collaborating with the biopharmaceutical company Bristol-Myers Squibb (BMS) to facilitate a virtual meeting bringing together patients with Giant cell arteritis (GCA) and their caregivers, with a team from BMS, as they plan a phase 3 clinical study for GCA.

BMS is pioneering this patient/caregiver/company interface, called a ‘Patient Engagement Network’ PEN, which has the goal of forming a collaboration with patients, caregivers and study site professionals.

The objective of the PEN meeting is for BMS to share aspects of the study design, and to receive feedback on specific questions regarding how the GCA patient and caregiver might consider the experience of the clinical trial. The BMS team is highly motivated to understand the patient journey and the perspectives of patients and caregivers, and to take these into consideration as they begin the planning to put this clinical study into practice.

The VF is partnering with BMS and will participate in the PEN meeting. The VF is recruiting 5-7 GCA patients and 2-3 caregivers to take part in the PEN. The meeting itself will take place in February 2017 via teleconference and webinar format.

Please contact me if you have any questions or would be interested in participating as a patient or a caregiver. We hope you will consider participating in this opportunity.

If you are interested in participating in either research opportunity, please contact:

Joyce Kullman, VF Executive Director, with your full name, phone number and email.

jakullman@vasculitisfoundation.org ✆

www.VasculitisFoundation.org

Rare disease research is crucial to providing patients with the answers and solutions they need, whether it’s a treatment, cure or improved care.

Celebrate Rare Disease Day
February 28, 2017
Patient Involvement in Research is Crucial

What is Rare Disease Day?

Launched by EURORDIS and its Council of National Alliances in 2008, Rare Disease Day has and continues to collaborate with organizations globally in order to put on events, create media coverage, and ultimately raise awareness amongst the general public and policy-makers about rare diseases and their impact on patients’ lives.

The primary drivers and beneficiaries of the international campaign are the millions of people around the world living with a rare disease, their families, and patient advocacy organizations who support them.

Rare Disease Day 2017

Rare disease research is crucial to providing patients with the answers and solutions they need, whether it’s a treatment, cure or improved care.

On February 28, 2017, the tenth edition of Rare Disease Day will see thousands of people from all over the world come together to advocate for more research on rare diseases. Over the last few decades, funds dedicated to rare disease research have increased. But it can't stop there.

Rare Disease Day 2017 is therefore an opportunity to call upon researchers, universities, students, companies, policy makers and clinicians to do more research and to make them aware of the importance of research for the rare disease community.

Rare disease patients and families, patient organizations, politicians, care-givers, medical professionals, researchers and industry will come together to raise awareness of rare diseases through thousands of events all over the world.

Rare Disease Day 2017 is also an opportunity to recognize the crucial role that patients play in research. Patient involvement in research has resulted in more research, which is better targeted to the needs of patients. Patients no longer solely reap the benefits of research; they are empowered and valued partners from the beginning to the end of the research process. Patients:

- Advocate for research on a specific disease or across diseases.
  They know where research is needed and work to influence research bodies and companies to prioritize these areas in their research.
- Fund research. Individuals or patient organizations often raise money for clinical trials or research projects, on their own or in partnership with private funding initiatives.
- Partner in research projects and are included in the governance of research.
- Participate as subjects in clinical trials and also in the design of clinical trials. They therefore help to ensure that the development of a medicine takes into account their real needs, so that the patient perspective is not overlooked.

Learn more about how you can become involved at http://www.rarediseaseday.org ✆
individual case was created and then reviewed by an independent expert. The expert was asked to make a diagnosis based on the information provided. If the expert came to the same diagnosis as the submitting physician, this was considered the reference diagnosis for that patient. If there was discrepancy, then that case was reviewed by another expert. A case was only included if two people concurred with the diagnosis.”

Several thousand data elements — clinical, radiological, and laboratory — were captured for each patient.

“This information was then reduced using statistical methods by excluding items where the prevalence was quite low or where there was no difference between the groups, and by combining items that made clinical sense. We then used a variety of standard and novel statistical approaches to develop the relevant criteria.”

The methodology used to establish classification criteria for other diseases such as rheumatoid arthritis or gout is not directly transferable. “Developing classification criteria for multiple different forms of vasculitis is complex,” Dr. Suppiah said. “We are dealing with several heterogeneous, multi-organ diseases rather than a single disorder. We also had to contend with the inherent circularity of defining the reference diagnosis as a starting point.”

To address these issues, researchers used a composite of several methodological approaches, including data-driven methods, expert opinion, and standard statistical methods such as multivariable regression.

Other investigators also presented lectures during the symposium, including Joanna Robson, BSc, PhD, MRCP, who is Consultant Senior Lecturer in Rheumatology and Faculty of Health and Applied Sciences at the University of the West of England, Bristol. Dr. Robson compared the differences between the drafted 2016 criteria and the published 1990 criteria.

Raashid A. Luqmani, DM, FRCP, FRCPE, who is one of the three co-principal investigators of the DCVAS study, presented “Clinical Implications of the 2016 Classification Criteria for ANCA-associated Vasculitis.” He is Professor of Rheumatology and Consultant Rheumatologist, Nuffield Department of Orthopaedics, Rheumatology and Musculoskeletal Science, at the University of Oxford, Oxford, England.

Dr. Luqmani’s fellow co-principal investigators of the DCVAS study, Peter A. Merkel, MD, MPH, Chief of Rheumatology and Professor of Medicine and Epidemiology at the University of Pennsylvania in Philadelphia, and Richard A. Watts, MD, Senior Lecturer in Rheumatology at the University of East Anglia, Norwich, England, also presented during the session.

Other speakers included investigators Peter Grayson, MD, PhD, who leads the Vasculitis Translational Research Program at the National Institutes of Health and co-chairs the ACR Subcommittee, and PhD candidate Cristina Ponte, MD, a rheumatologist at Hospital de Santa Maria, Lisbon, Portugal.

Source: http://www.acrdailynewslive.org/anca-associated-vasculitis-criteria-revised/
2017 Vasculitis Foundation Patient & Family Vasculitis Regional Conference
In Partnership with The Johns Hopkins Vasculitis Center and the NIAMS Vasculitis Translational Research Program

2017 Vasculitis Foundation Patient & Family Vasculitis Regional Conference
SATURDAY, FEBRUARY 4, 2017 | 8:00 a.m. - 4:30 p.m. (Program starts at 9:00 a.m.)
Bethesda North Marriott Hotel, 5701 Marinelli Road, North Bethesda, MD  20852
Registration: $30/person | Registration Deadline: January 31, 2017

PRELIMINARY CONFERENCE SCHEDULE

8:00 a.m. - 9:00 a.m.  Check in/Registration
Continental Breakfast

9:00 a.m. - 9:15 a.m.  Welcome and Introductions
Peter Grayson, MD, MSc
VF Board Member
Head, Vasculitis Translational Research Program, NIAMS

9:15 a.m. - 9:45 a.m.  Pathogenesis of Vasculitis - Why Did I Get Vasculitis?
Eric Gapud, MD, PhD
Johns Hopkins Rheumatology

9:45 a.m. - 10:15 a.m. Management of Upper Airway Symptoms in Vasculitis
Marcela Ferrada, MD
NIAMS Rheumatology Training Program

10:15 a.m. - 10:45 a.m. Morning Break

10:45 a.m. - 11:15 a.m. Steroids in Vasculitis: A User’s Guide
Kaitlin Quinn, MD
Georgetown University Hospital, Department of Rheumatology

11:15 a.m. - 11:45 a.m. Role of Exercise/Management of a Chronic Illness
Rebecca Manno, MD, MHS
Assistant Director, The Johns Hopkins Vasculitis Center

11:45 a.m. - 12:00 noon Vasculitis Patient-Powered Research Network (V-PPRN) Update
Kalani Young
Network Manager, Vasculitis Foundation

12:00 noon - 1:15 p.m. Lunch

1:15 p.m. - 2:00 p.m. Unmet Needs in Small and Large Vessel Vasculitis: One size Does not Fit All
Peter Grayson, MD, MSc
VF Board Member
Head, Vasculitis Translational Research Program, NIAMS

2:00 p.m. - 2:30 p.m. Recognition and Management of Kidney Disease
Geetha Duvuru, MD
Division of Nephrology, The Johns Hopkins Vasculitis Center

2:30 p.m. - 3:00 p.m. Vasculitis Around the World
Sree Banarjee, MD
Vasculitis Translational Research Program, NIAMS

3:00 p.m. - 3:15 p.m. Afternoon Break

3:15 p.m. - 3:45 p.m. What Matters to Patients with Vasculitis
Elaine Novakovich, BSN, RN
Vasculitis Translational Research Program, NIAMS

3:45 p.m. - 4:00 p.m. Break

3:45 p.m. - 4:30 p.m. Not-for-ready for Primetime: Therapies for Vasculitis
Phil Seo
Director, The Johns Hopkins Vasculitis Center

4:30 p.m. Wrap-up and Goodbye

Registration Form PLEASE PRINT CLEARLY
MAIL TO:  Vasculitis Foundation  .  PO Box 28660  .  Kansas City, MO 64188-8660  .  USA

Last Name ____________________________  First Name ____________________________
Last Name ____________________________  First Name ____________________________
Address______________________________ ______________________________________
City ____________________________  State ____________  Zip ____________
Phone ( ) ____________________________ Cell ( ) ____________________________ E-mail ____________________________
Diagnosed with ____________________________

PAYMENT METHOD:
____ Check (payable to Vasculitis Foundation) Amount $________
____ Credit Card ______ Visa ______ MasterCard ______ Discover ______ American Express
Credit Card Number: ____________________________
Exp. Date ____________________________  Amount $________
Name on Card ____________________________
Authorized Signature ____________________________

www.VasculitisFoundation.org
Biomarkers Not Helpful in EGPA Treatment Decisions | Kurt Ullman, RN

Eosinophilic granulomatosis with polyangiitis (EGPA) is a disease that can be hard to manage. Certain blood tests (also known as biomarkers) have been used to follow disease activity and predict relapse. How well these markers actually work in patients hasn’t been rigorously tested.

Paul A. Monach, MD, from the section of Rheumatology at the Boston University School of Medicine, and others studied the performance characteristics of absolute eosinophil counts (AEC), IgE antibodies in the blood, erythrocyte sedimentation rates (ESR), and C-reactive protein (CRP). The research was published in the November 2014 edition of Rheumatology.

Lacking Indicators of What to do Next

“We have all these tests that help tell us a person has the disease,” said Dr. Monach. “What we are lacking now are indicators that suggest what we should do next. It is hard to know when a person needs their medications changed or if we can safely decrease them.”

Patients were enrolled from the Vasculitis Clinical Research Consortium (VCRC) Longitudinal Study of EGPA, an observational group composed of people from North America. The patients are seen at eight centers specializing in vasculitis.

They underwent a standardized clinical assessment that included obtaining the biomarkers. Their physicians also recorded information on treatment status and medications they were prescribed. The visits were scheduled either quarterly, annually, or as needed for disease flare-ups.

Seventy-four percent of the 892 visits by 141 patients took place while they were on treatment. Most of them were deemed to be in remission or having only mild disease activity. Correlation between the various biomarkers and disease state were either very low or not significant. They found a few weak correlations between disease activity and eosinophil count. ESR and AEC were able to weakly predict flares.

Results Show No Clinical Significance

The results have shown some statistically significant associations with active disease based on the expert opinion of the doctors. But they found no clinical significance. There were differences in test results, but not enough of a difference in outcomes to reliably guide treatment decisions.

“We always talk to our patients about how they are feeling and use our clinical experience in making treatment decisions,” said Dr. Monach. “We are doing these tests already and assume they are good, but they aren’t. This doesn’t mean we shouldn’t do them, but just take them with a big grain of salt.”

Patients Should Know Limits

Those being treated for EGPA should also realize the limitations of the biomarkers in their treatment.

“Some get really caught up in their AEC or other lab values and become worried that they are going to be sick,” noted Dr. Monach. “Patients shouldn’t focus on these numbers alone. How they feel is a much better guide to treatment and their disease state.”

Value of commonly measured laboratory tests as biomarkers of disease activity and predictors of relapse in eosinophilic granulomatosis with polyangiitis.


Inaugural International Conference on Deficiency of ADA2

On November 11, 2016, physicians and researchers from around the world met in Bethesda, Maryland to discuss the mechanisms, diagnosis, and treatment of Deficiency of ADA2 and to chart a path forward for research. At the same time, patients and their families gathered to share their experiences living with DADA2, and to discuss plans to further the work of the DADA2 Foundation. A joint session at the end of the day brought the two groups together for a review of the day and what was learned.

DADA2 — deficiency of the enzyme ADA2 (Adenosine Deaminase 2) — is a recently discovered and extremely rare genetic disease that usually starts in childhood. It can cause recurrent strokes, severe systemic inflammation, immune deficiency, and damage to many of the body’s tissues and organs. Researchers at the National Institutes of Health (NIH) have discovered that some patients diagnosed with Polyarteritis nodosa (PAN), a form of vasculitis, have been found to have DADA2 instead of PAN.

Joyce Kullman, executive director of the VF, Ed Becker, director of marketing, and Kalen Young, V-PPRN Network Manager, were invited to attend the conference to learn more about DADA2, and to meet the families and researchers studying the disease. The VF will work with the NIH investigators, the DADA2 Foundation, and the PAN Support Network, to identify patients with PAN for additional testing and participation in research studies.
A Near-death Experience can be a Life-changing Event

Nina Adams, a 71-year-old patient with vasculitis, understands that no one should ever take life for granted because it can change dramatically without warning. She believes her diagnosis has been both a curse and a blessing, but she prefers to focus on the positive. In the following interview, she shared her story of being diagnosed with vasculitis.

My husband, Olaf, and I live in Western Springs, a suburb of Chicago. I grew up in the Bronx, went to college in upstate New York, and moved to Los Angeles right after college. I lived awhile in Iowa and then moved to Chicago around 1978.

My odyssey with vasculitis began in October 2015. I spent almost the entire month in bed with terrible back pain. I could barely walk. The MRI's showed bulging discs and stenosis, and I figured I would need back surgery, but I planned on getting a pain shot first. As I waited for the doctor's appointment for the shot, I took lots of painkillers, which caused a stomach ulcer. My doctor had me admitted to the hospital, which probably saved my life.

Ten Days, Ten Doctors

It took ten days and ten doctors to diagnose me with necrotizing vasculitis and Polymyalgia nodosa (PAN) around November 10th. With 20-20 hindsight, I realize I had been having symptoms of vasculitis including sinus issues and hearing loss for almost a year. I was diagnosed with PAN, but my current rheumatologist, Dr. Carol Langford, director of the Cleveland Clinic Center for Vasculitis Care and Research, believes it is more likely that I have GPA/Wegener's.

I'm currently taking vitamins, thyroid and cholesterol medications, prednisone and Imuran (azathioprine) and I'm on Protonix which helps with upset stomach. I started at 60 mg of prednisone which caused terrible side-effects. Prednisone was my "Botox" because my face puffed out so much that my skin was perfectly smooth and I had "chipmunk cheeks." If I bumped my arm, I would bleed. I only slept four hours a night and then had to take a nap during the day. And, I had the "shakes." Now that I'm down to 7 mg/daily of prednisone, my arms and fingers don't shake, and I don't bruise as easily, and I sleep most of the night.

I know prednisone makes a difference because when I dropped my dosage too quickly, I had a flare and we had to up my dose again.

I had a wonderful support system throughout my illness. Olaf was amazing through this adventure and provided 24-hour care and support, only taking time for meals and showers. He answered phone calls, greeted the many visitors, questioned doctors, and tracked all of my tests.

My friends, Jeanne and Nancy, also helped and the three of them kept a log of every doctor visit, blood test, and medication.

I learned a lot during my extended hospital stay. Some people don't visit because they think the patient should rest. Some people don't visit because they can't handle "watching me die." And, some people find it best to visit to provide support and companionship. Some wanted to see me one more time before I died.

My day-to-day life has changed. I've lost a lot of energy due to the vasculitis. I still get tired and have some difficulty walking up stairs. I have to rest to rest each day, but my strength is coming back much more quickly than the doctors expected. I've cut back on my volunteer activities significantly, but still work out at the health club five days a week. I play Mahjong twice a week, and I still doesn't seem to have enough time to do everything I want to do.

Take the Trip

My husband and I love to travel and try to take a major trip every year. Now that we realize how short life can be (no matter how old you are), we've increased our travel plans. I went on a Mississippi River cruise and took a trip to Canada. In July, we went to the Norwegian Arctic. And, in November we saw friends and family across Colorado. My doctors weren't thrilled to hear about my travel plans, but we think taking calculated risks, and enjoying ourselves, is better than getting into bed and pulling blankets over our heads.

Being diagnosed with vasculitis has made our relationship stronger than it has ever been. We figure that dealing with adversity either strengthens a relationship or tears it apart. We're fortunate; it has brought us together. We look at each other's positive traits rather than the negative. (OK… we're not perfect. Sometimes the negatives slip in, but mostly we look at the positive!)

We still hope for peace in the world but take pleasure in beautiful scenery, blue skies, interesting adventures, and good friends.

Beer Tasting –Fundraiser for Vasculitis Foundation

Sunday, March 12, 2017
3:00 p.m. - 6:00 p.m.
Imperial Oak Brewery,
501 Willow Blvd., Willow Springs, Illinois 60480
Organizer: Nina Adams: 708.246.0766; Nina@s3wests.com

Enjoy samples of four craft beers of your choosing from Imperial Oak's current weekly selection while listening to music, enjoying light snacks, and getting to know some new people. A small table of handmade jewelry and pottery will be available for purchase with all sale proceeds going to the Vasculitis Foundation. Note: Other drinks and additional beers will also be available for purchase.

Cost: $30.00 per person
https://www.eventbrite.com/e/beer-tasting-fundraiser-for-the-vasculitis-foundation-tickets-30964978083
2017 INTERNATIONAL VASCULITIS SYMPOSIUM
June 23-25, 2017
Chicago Marriott O’Hare
8535 West Higgins Road, Chicago, Illinois  60631
www.vasculitisfoundation.org/2017symposium

Join us for our 2017 International Vasculitis Symposium! The symposium is a three-day opportunity to learn about new treatments and research advances from our vasculitis medical experts. Learn about new research opportunities to participate in! Connect with other patients and family members! Enjoy Chicago in the summer!

DO YOU HAVE?
- Behcet’s
- CNS vasculitis
- Cryoglobulinemia
- EGPA/Churg-Strauss Syndrome
- Giant cell arteritis/Polymyalgia rheumatica
- GPA/Wegener’s
- Henoch-Schönlein purpura
- Kawasaki disease
- Leukocytoclastic/Hypersensitivity vasculitis
- Microscopic polyangiitis
- Polyanteritis nodosa
- Takayasu’s arteritis
- Urticarial vasculitis

VASCULITIS AND ISSUES IN:
- Dermatology
- Ear/Nose/Throat
- Gastroenterology
- Nephrology
- Neurology
- Nutrition, Exercise and Fatigue
- Ophthalmology
- Organizing Your Medical Team
- Pain Management in Vasculitis
- Pulmonology

UPDATES ON VF-FUNDED RESEARCH
- Aramis Dermatology Study
- Diagnostic and Classification Criteria Update
- Impact of Healthcare Utilization and Informal Caregiving for Primary Systemic Vasculitis
- Longitudinal Study of patients with Vasculitis
- Reports from the Fellows
- Vasculitis Patient-Powered Research Network (V-PPRN) Update
- VascWorks: Impact of Vasculitis on Employment and Work Ability
- AAV-PRO: Quality of Life Study for Patients with ANCA-associated Vasculitis
- V-PREG Study: Pregnancy and Vasculitis

SPECIAL SESSIONS
- Fertility Issues for Male & Female Vasculitis Patients
- Introducing Mindfulness into Your Life
- Introducing the Northwestern University Chicago Vasculitis Center
- Joys and Challenges of Caregiving
- Sunrise Yoga by the Pool
- VF Team Brandon: Get Your Moving!
- Wellness: Creating a Positive Lifestyle

WATCH FOR MORE INFORMATION COMING SOON ON THIS EVENT!
Visit www.VasculitisFoundation.org

SAVE the DATE!
6|23-25|2017
2017 INTERNATIONAL VASCULITIS SYMPOSIUM
Chicago Illinois USA
LEARN. CONNECT. ENGAGE. BE EMPOWERED.
Kristalyn | VF Team Brandon Member Spotlight

Through my involvement with Victory Over Vasculitis: VF Team Brandon, I am continually impressed with the stories of the people whose lives have been turned upside down by vasculitis.

Often, their stories begin the same way as mine - they’re in peak physical condition when the unthinkable happens.

This is what happened to Kristalyn, who had to face the reality of being diagnosed with a rare disease just when everything seemed to be going right for her. We are pleased that her involvement with VF Team Brandon has been a source of inspiration and support. Brandon Hudgins

Kristalyn: Vasculitis Warrior

Before her diagnosis of vasculitis, Kristalyn was in the best shape that she had been in many years. She had one health concern - for two years before her diagnosis, she got sick each October with debilitating pain, swelling, rash on her legs, and severely limited mobility which lasted for a month or two at a time. Physicians were unable to diagnose the mystery illness, however, with medication to manage the symptoms, and with time, she would eventually recover.

Healthy again, Kristalyn became immersed in her happy, hectic lifestyle and forgot about the mystery illness until the next attack when she had such a severe medical crisis and wound up in the emergency room with life-threatening issues.

She was diagnosed with IgA vasculitis (Henoch-Schonlein purpura), and although she finally had a name, there was still uncertainty on how best to manage the disease and if it would be a chronic illness or not. As a single mother of elementary school-age children, a self-employed business owner, and an active person, Kristalyn desired a clear plan that would quickly put her back at 100%. She realized it would be a journey of trial and error in finding which medicine would work best for recovering and keeping flare-ups at bay.

Her spiritual faith provided her the greatest well of daily strength and forgot about the mystery illness until the next attack when she had such a severe medical crisis and wound up in the emergency room with life-threatening issues.

Kristalyn wrote, “I am so inspired by the authentic stories shared by the members of VF Team Brandon. I’ve learned the struggle is just as real for others, as for myself. The success of getting back to a full life is very real and has provided me hope and inspiration time after time. To hear that others have felt the same moments of feeling alone, challenged, depressed or overwhelmed helps form a bond. We then watch these same people transform into runners, Olympic Trial Qualifiers or even who just gets back to walking again after weeks of being immobilize. All of this reassures me the storm clouds will part, and there will be a ray of sunshine again. The sense of community of other like-minded people has been invaluable. I felt very alone in my disease before I became connected with VF #TeamBrandon. Now I enjoy the shared health tips, stories, encouragement and medical news in this community.”

As Kristalyn shared, “It has been amazing to see the support from my family and friends. Brandon and my local running community inspire and strengthen me. Even when I can’t race, watching my circle of runners compete, and being able to cheer them on, keeps my adrenaline going and keeps me feeling connected to a healthy lifestyle.”

When she was first diagnosed, she sought out information on the disease. A long-time friend/old co-worker had a son with another form of vasculitis and referred Kristalyn to the Vasculitis Foundation. Finding the right education and support resources early in the diagnosis was crucial to expectation-setting and disease management and brought a sense of relief during the chaotic months after her diagnosis. She also learned so much from the real-time dialogues on the VF Facebook page as well.

Kristalyn wrote, “I am so inspired by the authentic stories shared by the members of VF Team Brandon. I’ve learned the struggle is just as real for others, as for myself. The success of getting back to a full life is very real and has provided me hope and inspiration time after time. To hear that others have felt the same moments of feeling alone, challenged, depressed or overwhelmed helps form a bond. We then watch these same people transform into runners, Olympic Trial Qualifiers or even who just gets back to walking again after weeks of being immobilize. All of this reassures me the storm clouds will part, and there will be a ray of sunshine again. The sense of community of other like-minded people has been invaluable. I felt very alone in my disease before I became connected with VF #TeamBrandon. Now I enjoy the shared health tips, stories, encouragement and medical news in this community.”

What would you tell a newly diagnosed patient?

It will not always be this way. I spent the majority of 2015 in a painful battle to calm my disease with half the year in a hospital bed, in a wheelchair, or on crutches. Today, I still experience smaller, occasional flares, but I have persevered to rebuild my strength, return to running, and I completed the 2016 Peachtree Road Race, the world’s largest 10K race, in Atlanta, Georgia. I am returning to the things I love. I may not be the same as I was before, but I am happy, and I feel strong. You, too, will have a chance to return to the things you love, and you will feel strong again. It may take time, but it can happen. And most of all, in this journey of vasculitis, know you are not alone.

Kristalyn ●
2016 Flashback for the V-PPRN | A Year in Review | Kalen Young, V-PPRN Network Manager

The V-PPRN is a team of patients with vasculitis, caregivers, researchers, data specialists, and providers on a daily mission to share and learn from one another with a vision for the future in clinical vasculitis research. We are working to transform how clinical research in vasculitis is conducted by directly engaging patients, investigators, care providers, and health systems to develop research methods to electronically collect health records and patient-reported data on a large number of patients with various forms of vasculitis.

Our vision is to improve the health of vasculitis patients by developing early-diagnosis methods, discovering more effective treatments, and finding cures. Our Network launched in the fall of 2014 and since then we have forged full speed ahead advancing vasculitis research and working to improve the lives of patients.

HOW WE’VE GROWN:
Since December 2014 we have grown to over 1,700 participants!

What does that really mean? That means over 1,700 patients living with vasculitis are willing to participate in research and provide much needed data to researchers and care providers to help improve the lives of patients.

OUR NETWORK AT A GLANCE:

Is your disease group well represented? Join the V-PPRN and help advance the knowledge and understanding of your specific form of vasculitis. We are seeking to enroll at least 100 patients with each form of vasculitis.

AGE BREAKDOWN

STUDIES CONDUCTED:
Since our launch, the V-PPRN has conducted three studies and continues to collect longitudinal data.

- **VASCWORK - Completed**

  Work disability associated with rheumatic diseases accounts for an important part of the costs of these conditions, in addition to direct treatment costs, especially with biological agents. Interest has been growing in studying work disability associated with rheumatoid arthritis, but only a few studies have investigated vasculitis.

- **ANCA-ASSOCIATED VASCULITIS PATIENT REPORTED OUTCOMES (AAV-PRO) - Completed**

  The aim of this project was to develop a disease specific quality of life survey for patients with ANCA-associated vasculitis. We know that patients with ANCA-Associated Vasculitis (AAV) have inflammation in the small blood vessels leading to involvement of a range of organs. Patients can also often suffer from ongoing disease activity or treatment side effects. Quality of life can be measured by questionnaires called patient-reported outcome measures (PROMs), and this is considered an important outcome for clinical trials of new medications.

continued on page 13
The 21st Century Cures Act, and Perspectives from NIH | Posted on December 14, 2016

Dr. Michael Lauer is NIH’s Deputy Director for Extramural Research, serving as the principal scientific leader and advisor to the NIH Director on the NIH extramural research program.

You may have been following news of the 21st Century Cures Act, a landmark piece of legislation with provisions for healthcare, medicine, and research. Republican and Democratic lawmakers supported this bill through its development and eventual passage, and on December 13, 2016, President Obama signed the bill into law.

The Act establishes a multitude of important changes to our nation’s approach to supporting and funding health care, medical interventions, and research. Readers of this blog may be particularly interested in the many changes directly relevant to NIH’s mission. A New England Journal of Medicine Perspective essay by NIH Director Francis Collins and NIH Deputy Director Kathy Hudson highlights those changes, and I encourage you to read it. Drs. Collins and Hudson draw attention to support for certain ongoing high-priority initiatives, enhancement of the biomedical research workforce, improved clinical research, better privacy protection for patients who participate in clinical research, greater transparency in science, and reduced red tape.

- High-priority initiatives: The Act includes support for major ongoing NIH scientific initiatives, such as BRAIN, the Precision Medicine Initiative (“All of Us”), and the Cancer Moonshot.
- Biomedical research workforce: A number of provisions focus on early career researchers, who continue to be the subject of much interest. Studies carried out by the National Academies committee referenced in the law will look at factors within NIH – and beyond – that impact the future workforce. Other provisions will enable NIH to develop and promote policies that will attract and sustain support for diverse groups of outstanding young and new investigators.
- Clinical research, transparency, and privacy: The Act contains measures to assess, report, and improve inclusion of key demographic groups, groups that reflect diversity of sex, age, and minority status. NIH is encouraged to further efforts in understanding health disparities between different demographic groups. Other measures enhance the impact of “big data” through data sharing, while also protecting private information of research volunteers. For example, certificates of confidentiality – formerly provided upon request to researchers collecting sensitive information about research participants – will now be provided to all NIH-funded scientists, with strong protections against involuntary disclosure.
- Red tape: The Act exempts NIH–supported or NIH–conducted research from the “ironically titled” Paperwork Reduction Act, making it possible to launch projects in faster time and without fulfilling paperwork requirements that have rarely yielded substantive change. The Act also strikes barriers that have made it difficult for NIH extramural staff to engage in outreach efforts to the research community through attendance at and participation in scientific conferences.

We are greatly appreciative of the hard work that went into making this bill become law. The consideration of these biomedical research topics in the scope of the 21st Century Cures Act is a huge vote of confidence in what we as a nation can accomplish, and improve, through supporting a robust and dynamic scientific enterprise.

Source: https://nexus.od.nih.gov/all/2016/12/14/21st-century-cures-perspectives-fro

Flashback | continued from page 12

CURRENT STUDY - ENROLLING PATIENTS NOW

- VASCULITIS PREGNANCY REGISTRY | Finding Answers, Finding Hope.

One of the most common questions women with vasculitis ask is how this disease will affect their ability to have children. Unfortunately, there is very limited reliable information regarding pregnancy and women with vasculitis. This is a great concern for both patients and physicians.

The purpose of this study is to learn about the experience of women with vasculitis who become pregnant. In particular, the study will consist of several online surveys to assess a) each woman’s vasculitis severity and pregnancy-related experiences, and b) pregnancy outcomes.

DO YOU HAVE A RESEARCH QUESTION?

The V-PPRN accepts research questions from patient participants and to date, we have collected over 400 questions!

JOIN! Help make 2017 even more productive in vasculitis research by joining the V-PPRN at www.vpprn.org!
Giant cell arteritis (GCA) is a chronic condition with frequent relapses. A better understanding of why relapses occur might help identify patients who would benefit from longer treatment duration.

Tanaz A. Kermani, MD, MS, Director of the Vasculitis Program at UCLA and others from the Vasculitis Clinical Research Consortium (VCRC) studied the frequency, timing, and clinical features of relapses seen in GCA. Their results were published in the July 2015 edition of the Journal of Rheumatology.

“Many of the previous studies on this issue evaluated relapses retrospectively using a review of records,” said Dr. Kermani. “The VCRC was well suited to answer many questions about relapses in GCA because the data was gathered systematically and patients were followed over time. This enabled us to obtain very useful data on relapses in giant cell arteritis.”

One hundred and twenty eight people were included from across the United States. All were diagnosed using American College of Rheumatology classification criteria. The patients underwent standardized clinical assessments every quarter. These included asking them about symptoms, and gathering physical exam findings and laboratory test results. They were followed for a mean of 21.4 months.

**Study Unique**

“Many previous studies evaluated relapses using a review of records which can miss important data or give us biased data,” said Dr. Kermani. “We know in recent years that GCA not only affects the temporal arteries but also other large vessels. Most previous studies on relapses included patients with involvement mainly of the temporal arteries. This study was unique because it also to gathered data on patients with GCA and large vessel involvement such as the arteries in the arm which has not been well studied in the past.”

During follow-up, 59 relapses were seen in 44 patients (34%). Ten of these experienced 2 or more relapses.

**Symptoms of Relapse**

The most common symptoms in relapses included headache and muscle pain and stiffness from polymyalgia rheumatica (PMR).

There was increased claudication or cramping from too little blood flow to the muscles (ischemia). Most of the ischemic incidents were short-lived.

Roughly three out of four relapses happened while the person was still on glucocorticoid medications (steroids). Among the 69 people with newly diagnosed disease, 24% relapsed within the first year of diagnosis and half by 24 months.

“The study showed that GCA frequently relapses with headaches and PMR symptoms such as pain and stiffness in the shoulders or hip,” said Dr. Kermani. “The good news is that loss of vision was rare after starting treatment even during relapse.”

**Disease Relapses among Patients with Giant Cell Arteritis: A Prospective, Longitudinal Cohort Study.**


**Connect with Us!**

We are collecting members’ email and cell phone numbers to enable us to quicker communication and to help reduce postage costs! Do we have your correct mailing address? Phone number? Please send us your contact information and we will update your record!

**Vasculitis Foundation. Providing Support. Awareness. Research**

**Subscribe to our e-newsletter!**

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**VSP Newsletter Sign-Up**

**www.vasculitisfoundation.org**
Ways to Donate

United Way Donors
If your company participates in the United Way Campaign, you can often designate the Vasculitis Foundation as your recipient for United Way funds. Please contact your local United Way office to find out if the VF is eligible. We are grateful for your support. UW pledges will be acknowledged according to the instructions on your pledge form.

Combined Federal Campaign
The Vasculitis Foundation has been accepted to participate in the 2017 Combined Federal Campaign. If you are an employee of the federal government, postal service, or a member of the United States armed forces, you can now designate your gifts and pledges during the Combined Federal Campaign (CFC) to the Vasculitis Foundation. Our national code is 64445.

Matching Gift Programs
Many businesses have charitable programs that will match gifts made by their employees to the Vasculitis Foundation. If you would like the VF to provide information to your employer about our programs and services please contact the VF office.

Honorarium and Memorial Gifts
Gifts may be made to the Vasculitis Foundation in honor or memory of a loved one by designating that wish on the donate form. Please include the name and mailing address of those you would like to receive acknowledgement, and the VF office will notify them of your contribution. Honor gifts are also a great way to celebrate a birthday, wedding, anniversary, or other special holiday!

Monthly Giving Program
Enroll in the Vasculitis Foundation's Monthly Giving Program, and you will help bring our community one step closer to the cause of and cure for vasculitis. Once enrolled, you will automatically become a Vasculitis Foundation member — as a thank you for your on-going commitment. Choose the amount that you wish to give monthly and your credit card will automatically be charged once a month. You may cancel your monthly donation at any time by contacting the VF office.

Planned Giving
Predetermined philanthropic plans benefit the Vasculitis Foundation's mission, and leave a legacy gift that will assist others for years to come. In coordination with the Greater Kansas City Community Foundation, the VF can assist you with your planned giving needs and tailor a giving method that specifically meets your desired giving outcomes.

For more information:
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816.436.8211

2016 Vasculitis Foundation Research Report Published
The Vasculitis Foundation is pleased to announce the publication of its 2016 VF Research Report, which provides a comprehensive overview of the research studies funded by the VF, the physician-investigators trained through the VF Fellowship Program, and an excellent glossary of terms commonly used in the study of vasculitis.

The VF Research Program broke the $2,000,000 mark in funding in February 2016. Since 2002, the Vasculitis Foundation has funded 42 studies in Australia, Austria, Canada, England, Germany, Ireland, Italy, The Netherlands, and the United States. We have funded six fellowships at the Cleveland Clinic, McMaster University, University of North Carolina, University of Pennsylvania, and the University of Toronto.

The VF Research and Fellowship Programs are made possible through the generous donations of you, our members, and extended vasculitis community. Thank you for your support. The report is available in print format or can be viewed online: https://goo.gl/O9D9yi

Support the VF through AmazonSmile Program
AmazonSmile is a simple and automatic way for you to support the Vasculitis Foundation every time you shop, at no cost to you. When you shop at smile.amazon.com, you’ll find the exact same low prices, vast selection and convenient shopping experience as Amazon.com, with the added bonus that Amazon will donate a portion of the purchase price to the Vasculitis Foundation.

Please recycle this newsletter to your physician's office! Contact the VF office if you’d like brochures to distribute.

For more information:
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Please recycle this newsletter to your physician’s office! Contact the VF office if you’d like brochures to distribute.
VCRC Update | Are you a member of the VCRC Patient Contact Registry?

The Vasculitis Foundation encourages patients to participate in research whenever possible. Your participation will help researchers find better treatments and the cause and cure for vasculitis.

The Vasculitis Clinical Research Consortium (VCRC) is an integrated group of academic medical centers, patient support organizations, and clinical research resources dedicated to conducting clinical research in different forms of vasculitis and improving the care of patients with vasculitis. Funded by the National Institutes of Health, the VCRC is part of the Rare Diseases Clinical Research Network.

When you join the VCRC Patient Contact Registry, you will be contacted whenever new VCRC studies are launched. While some of the studies require patients to go to a participating VCRC center, over the past year the VCRC has launched several successful online studies that allowed 1,000s of patients around the world to participate in research via the Internet.

Over 3,000 patients are registered with the VCRC. Are you registered? The Registry is free of charge and anonymous. Patients can register via paper form, by calling a toll-free number (866.313.9879) or online by clicking “Join the VCRC Contact Registry” at http://rarediseasesnetwork.org/vcrc. This is your opportunity to participate in studies and to help researchers learn more about vasculitis.

If you are already signed up, please make sure the Registry has your updated information:
http://rarediseasesnetwork.epi.usf.edu/vcrc/beta/registry/update/index.htm

You must be enrolled in the Registry to participate in the following studies:

**EOSINOPHILIC GRANULOMATOSIS WITH POLYANGIITIS**
- 5506: Longitudinal Protocol for Churg-Strauss Syndrome

**GIANT CELL (TEMPORAL) ARTERITIS**
- 5523: Concurrent Pilot Studies in Giant Cell Arteritis and Takayasu’s Arteritis to Examine the Safety, Efficacy, and Immunologic Effects of Abatacept (CTLA4-Ig) in Large Vessel Vasculitis (AGATA)
- 5502: Longitudinal Protocol for Giant Cell Arteritis

**GRANULOMATOSIS WITH POLYANGIITIS (GPA/WEGENER’S)**
- 5505: Longitudinal Protocol for Wegener’s Granulomatosis and Microscopic Polyangiitis

**MICROSCOPIC POLYANGIITIS**
- 5505: Longitudinal Protocol for Wegener’s Granulomatosis and Microscopic Polyangiitis

**POLYARTERITIS NODOSA**
- 5504: Longitudinal Protocol for Polyarteritis Nodosa

**TAKAYASU’S ARTERITIS**
- 5523: Concurrent Pilot Studies in Giant Cell Arteritis and Takayasu’s Arteritis to Examine the Safety, Efficacy, and Immunologic Effects of Abatacept (CTLA4-Ig) in Large Vessel Vasculitis (AGATA)
- 5503: Longitudinal Protocol for Takayasu’s Arteritis
- 5515: VCRC Imaging Protocol for Magnetic Resonance and Positron Emission Tomography in Large-Vessel Vasculitis (Takayasu’s Arteritis): Development as Clinical Trial Outcome Measures

**5510: VCRC GENETIC REPOSITORY ONE-TIME DNA STUDY**

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Cleveland Clinic Regional Conference

The Vasculitis Foundation and the Cleveland Clinic Center for Vasculitis and Care Research is pleased to present the following educational symposium for patients, family members and caregivers.

Tuesday, April 4, 2017
InterContinental Hotel
9801 Carnegie Avenue, Cleveland, Ohio 44106
Program: 1:00 p.m. - 5:00 p.m.
Registration fee: $20/person  Registration deadline: March 27, 2017
On-line: www.vasculitisfoundation.org
By phone: 816.436.8211  Mail: Vasculitis Foundation, PO Box 28660 Kansas City, MO 64188-8660

Registration Form PLEASE PRINT CLEARLY
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Primary Vasculitides: Best Practices and Future Advances
(A pre-symposium to the Biologic Therapies VII Summit: Precision Medicine in the Biologic Era)

Date: April 5, 2017
Location: InterContinental Hotel, Cleveland, Ohio
Hosted by the R.J. Fasenmyer Center for Clinical Immunology
Register: https://goo.gl/g9KdjI

If you are unable to attend in person, register for the LIVE broadcast. Available from the convenience of your personal computer, the broadcast will stream all presentations.

The Vasculitis Foundation is pleased to help sponsor this one-day symposium for rheumatologists, nephrologists, pulmonologists, dermatologists, neurologists, allergists, immunologists, and advanced practice clinicians interested in vasculitis.

Overview
This symposium features an update on the current standard of care and management of patients with primary vasculitides. Advances and future development in the treatment of primary vasculitides will be shared by the experts in this field.

Learning Objectives
• Recognize the signs and symptoms of systemic vasculitic diseases in patients presenting with immunologic-associated conditions.
• Summarize efficacy and side effect data on use of conventional immunosuppressive agents to treat systemic vasculitis.
• Critically appraise the efficacy and side effect profiles, indications, and patient selection criteria for biologics in patients with systemic vasculitis.
• Provide an analytical review of the presentation, diagnosis, and treatment of CNS vasculitis.
November | December 2016 Donors | Thank You For Your Gift of $50 or More!

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Sondra Schmidt

continued on page 19
The VF Road Map to Wellness Webinars Continues to Grow and Evolve to meet Patient Needs

One of the most successful educational resources produced by the Vasculitis Foundation has been the monthly webinars. Since 2014, the VF has held more than 25 live webinars featuring vasculitis experts throughout the world.

Each webinar typically attracts between 15-70 attendees; however, the webinars get a second life as they are archived and made available for viewing on the VF’s Educational YouTube Channel. Thousands of viewers have watched and shared links to these recorded videos reinforcing their value as an educational tool.

“These webinars are popular because it provides a rare opportunity for patients to experience a live presentation by some of the most prominent specialists in the world,” says Ed Becker, VF Director of Marketing and Communications. “We also provide ample time for attendees to ask questions and interact with the presenter. Based on the feedback, patients love this opportunity to engage with an expert in vasculitis.”

Looking forward to the New Year, Joyce Kullman, VF Executive Director, says the VF will be offering more disease-specific webinars because there is an audience eager to learn more about their form of vasculitis. “We create these webinars to address those issues most important to all vasculitis patients. However, we discovered that our disease-specific webinars such as the ones focusing on Takayasu’s arteritis, Behcet’s, CNS, and Polyarteritis nodosa attracted the most attendees. You can expect to see more disease-specific webinars in the coming months.”

Visit the VF Webinar Library at:
http://www.vasculitisfoundation.org/education/the-road-map-to-wellness-educational-webinar-series/
IN MEMORIAM

THANK YOU to all those who made donations to the VF in memory of a loved one or as a year-end contribution. Your gifts are much appreciated.

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Note: Due to space constraints, we are no longer listing area contacts. Area contacts are listed on the VF website or call the VF office for assistance.
Biologic Therapies VII Summit

Date: April 6-7, 2017
Location: InterContinental Hotel, Cleveland, Ohio
Hosted by the R.J. Fasenmyer Center for Clinical Immunology
Register: https://goo.gl/VoOWTb

The Biologic Therapies VII Summit is an advanced course that brings together world leaders in immune-based therapies and addresses cutting-edge translational immunology and the latest data on biologic therapeutics. This year’s Summit will focus on precision medicine and kicks off with a fundamental immunologic plenary session, reviewing recent basic laboratory breakthroughs in terms of their potential clinical implications. The Biologic Crossfire session will provide critical insights into new pathways and shared challenges for multiple disciplines engaged in the use of biologic therapies.

Why attend?
- Network with world leaders in immune-based therapies
- Join experts in discussions of recent and future therapeutic targets
- Learn from diverse perspectives of the many disciplines utilizing biologic therapies
- Expand and enhance decision-making skills for appropriate use of biologic therapies in highly complex clinical situations
- Be a part of the conversation on genetics and personalized medicine in rheumatic diseases and immune-mediated inflammatory diseases

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2017 · calendar of events · 2017

February 4, 2017
VF Regional Patient & Family Conference
Baltimore/Washington DC/Bethesda
See page 7 for more information

February 4th, 2017
Tampa VF Support Group Meeting
11:00 a.m. - 1:30 p.m.
78th Street Library
7625 Palm River
Tampa, Florida 33619
Guest Speakers: Dr. Evelisse Capo, Nutritionist
Dr. Yih-Chang Lin, Vasculitis Center at USF Health Group and Jesus Perez

February 28, 2017
Rare Diseases Day

March 2017
Autoimmune Diseases Month
www.aarda.org

March 11, 2017
Kansas/Missouri Chapter Meeting
1:00 p.m. - 3:00 p.m.
BEST Conference Center, Rm 125
University of Kansas
Edwards Campus
12600 Quivira Road
Overland Park, Kansas 66213
Denny and Ruth Hale
dhale3@kc.rr.com or 913.764.7557

April 4, 2017
Cleveland Clinic Regional Conference
InterContinental Hotel
9801 Carnegie Avenue, Cleveland, Ohio 44106
Program: 1:00 p.m. - 5:00 p.m.
Registration fee: $20/person
Registration deadline: March 27, 2017
Online: www.vasculitisfoundation.org
By phone: 816.436.8211
Mail: Vasculitis Foundation, PO Box 28660
Kansas City, MO 64188-8660

April 1, 2017
NC/Raleigh Vasculitis Support Group Meeting
UNC Wellness Center at Meadowmont
Chapel Hill, NC 27517
Speaker: Will Pendergraft, III, MD, PhD
Mary Zimmerman
maryzim0206@gmail.com

April 29, 2017
Vino For Vasculitis
7:00 p.m. - 11:00 p.m.
The Junction Salon & Bar
327 W. Davie St., Ste 114
Raleigh, North Carolina 27601
Jessica Foster
jessica.n.foster@gmail.com
See page 6 for more information

May 1-31, 2017
VASCULITIS AWARENESS MONTH
vf@vasculitisfoundation.org

June 23-25, 2017
2017 INTERNATIONAL VASCULITIS SYMPOSIUM
Marriott Chicago O’Hare
8535 West Higgins Road
Chicago Illinois

August 30, 2017
Chicagoland Golf Open ✪

To submit items for the calendar, please contact the VF office.

The Vasculitis Foundation acknowledges an educational grant for support of this newsletter from Genentech, Inc. and Biogen, Idec.