Three Ways the VF Impacted Patients with Vasculitis in 2017

How did the Vasculitis Foundation (VF) positively and powerfully affect the lives of patients and their caregivers over the last year? What VF programs and initiatives helped support research studies and doctors? Although we have dozens of examples here’s a brief retrospective demonstrating why the VF is a worldwide leader in patient support and education.

The 2017 International Vasculitis Symposium
June 23 – 25, Chicago

In June, 300 people from the patient and medical community came together at the 2017 International Symposium in Chicago. By all measures, it was one of the largest VF symposia in recent history. There were 48 sessions surpassing the number of presentations at the 2013, and the 2015 symposia.

VF Research Program

A core mission of the VF is funding and supporting vasculitis researchers and their studies through the VF Research Program. In the fall of 2016 the VF Research Committee screened 27 applications from researchers throughout the world to determine which ones met the established criteria set by the VF Research Committee. Four studies were chosen and funded in January 2017. For more information on these four studies, visit: http://www.vasculitisfoundation.org/researchers/

2017 Recognizing Early Diagnosis Award

In March, the Vasculitis Foundation honored one physician with its 2017 Recognizing Excellence in Diagnostics (RED) Award. The VF presents the V-RED Award annually to a medical professional who made a quick diagnosis of vasculitis, thus enabling the patient to receive timely and appropriate treatment. The 2017 V-RED Award was presented to Jennifer L. Nansteel, MD from Main Line HealthCare Primary Care (MLHC) in Wynnewood, Pennsylvania. Cheryl Petersohn, from Bryn Mawr, Pennsylvania nominated Dr. Nansteel. The 2018 V-RED Award competition will open in early January.
Dear Friends,

Welcome to our final issue of the VF newsletter for 2017. Thank you!

First, on behalf of the VF Board and staff, we wish you a wonderful holiday season. This is a perfect time for us to say Thank You to everyone who has supported the Vasculitis Foundation this past year. It has only been through the generous donations of financial contributions, volunteering time or talents that we’ve been able to achieve our mission.

Dream Big
In this issue we are rolling out a new and exciting campaign called Dream Big. Inspired by a rousing presentation by Dr. Peter Merkel at the 2017 Symposium, our Dream Big theme will become a central part of our organization throughout the next year.

New and Improved—The VF Newsletter
I’ve been with the VF long enough to remember our first newsletters which were cranked out on an ancient mimeograph machine by volunteers who also added the address labels and postage. That’s why I’m especially excited to debut the new, and we believe, improved VF Newsletter.

Finally, as we celebrate the season of giving, we ask you to invest with us, so that together, we can take another giant step closer to achieving our Mission.

Thank You for Your Board Service
The VF would like to recognize two of our directors who retired from the Board in October.

Chris Cox-Marinelli, MD joined the VF Board in 2011 and brought a unique perspective as a neurosurgeon and individual living with Takayasu’s since 2001. As a member of the VF Research Committee, Dr. Cox guided the annual review of applications and ongoing studies, and liaised between the committee and board. She provided annual updates on VF-funded studies to members and helped write the 2016 VF Research Report and worked on the VF Fellowship Program.

Robert Lebovics, MD, FACS joined the VF Board in October 2010 and served as secretary for many years. He is a nationally known otolaryngologist with expertise in infectious and inflammatory disorders. The board members greatly appreciated Dr. Lebovic’s and Dr. Cox’s tremendous dedication to our patients, researchers, and clinicians.

Thank you to both of these long-standing members for your many years of service in support of vasculitis awareness and treatment.

Mission Statement | The Vasculitis Foundation supports and empowers our community through education, awareness and research.

The Vasculitis Foundation is most grateful to authors who have shared their personal experiences with vasculitis in the newsletter. The reader should be aware that these contributions are personal reflections by the writer and do not represent medical scientific statements. Therefore, such information while being accurate perceptions of the writer, may not be scientifically accurate and may not apply to other patients.
Survey Captures Challenges Between Treatment Benefits and Risks for Patients with Chronic Illness

Kurt Ullman, Medical Writer

Chronic illnesses such as vasculitis include the burden of the disease itself, but also the various burdens associated with treatment. Those with more than one condition find the problems multiplied.

"There is a struggle to balance benefits and risks of multiple recommended treatments," said Viet-Thi Tran, from the Department of General Medicine at Paris Diderot University in Paris, France. "A physician following clinical practice guidelines could prescribe up to 12 medications for patients with osteoporosis, osteoarthritis, diabetes mellitus, hypertension and chronic obstructive pulmonary disease."

The "work of being a patient" includes such things as drug management, self-monitoring, visits to the doctor, and lifestyle changes.

"This is a real problem for patients that is largely overlooked both in research and practice," said Dr. Tran. "There is a need to take the patient's context into account. Care must be integrated in the patient's lives (and not the contrary), so as to improve patient's adherence to care and quality of life with their chronic conditions."

To address these issue, Dr. Tran and others developed an online survey that included English-, French- and Spanish-speaking participants with many chronic conditions. Between 2013 and 2014, 1053 participants from 34 different countries answered the survey. The responses analyze using both manual and automatic methods.

The patients described tasks imposed on them by both the disease and the healthcare system (medication management, lifestyle impacts, etc.) They also chronicled financial factors, structural factors (access to care, coordination of providers), and patient-reported consequences of the disease burden such as impact on family, professional and social life, financial burdens and lifestyle impacts, etc. They also chronicled financial factors, structural factors (access to care, coordination of providers), and patient-reported consequences of the disease burden such as impact on family, professional and social life, financial burdens and lifestyle impacts, etc.

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Study: Treatment for Antibody-Associated Vasculitis is Shifting from Cyclophosphamide to Rituximab

By Jennifer Byrne

Children hospitalized with severe antineutrophil cytoplasmic antibody-associated vasculitis are increasingly treated with rituximab rather than cyclophosphamide, and these patients frequently continue to need dialysis, mechanical ventilation and prolonged hospitalization, according to recently published findings.

In the retrospective cohort study, researchers evaluated 1,290 hospital admissions for 393 children with antibody-associated vasculitis (AAV) treated during an 11-year period. All patients had a charge for glucocorticoid medications and billing data were used to document receipt of treatment.

The researchers used mixed-effects logistic regression to assess factors linked to the likelihood of receiving each of the three glucocorticoid treatment regimens (cyclophosphamide, rituximab or both) patients, 16% required dialysis and 17% required mechanical ventilation. Median hospital length of stay was 9 days. Overall, 57% of children received cyclophosphamide; 21% received rituximab; and 10% received both treatments.

Plasma exchange was administered to 22% of the children. An association was seen between mechanical ventilation and receipt of cyclophosphamide and plasma exchange. This link was not seen with rituximab. Investigators found an increasing trend in the use of rituximab during the study period, while a decreasing trend was seen in the use of cyclophosphamide. Significant disparity was seen in the treatments used between hospitals, particularly in terms of plasma exchange.

“Our results show that children with AAV are ill at presentation, more than one-quarter require ventilator or dialysis support, morbidity is high and readmissions are common,” the researchers wrote. “There is a vital need for pediatric-specific studies to evaluate the effectiveness and efficacy of cyclophosphamide, rituximab and plasma exchange in this population.”


Scientists Focus on Gut Flora for Future Treatments of Autoimmune Diseases

By Linda Hagen-Miller

Volunteers are being sought for a major study to help determine how the gut microbiome can be used to treat multiple sclerosis, lupus, and other diseases.

What if your gut flora was actually a healing agent capable of doing battle with autoimmune diseases like multiple sclerosis, lupus, and rheumatoid arthritis?

According to researchers, it just might be.

And a major multiple sclerosis organization is looking for volunteers to help prove it. Gut flora, technically known as gastrointestinal microbiota, is the complex community of microorganisms that live in your digestive tract. These microorganisms are a critical part of your health.

Bacteria line your intestine and help you digest food. They also send signals to the immune system and make small molecules that can help your brain function.

You get gut flora at birth from your mother, but after that it’s heavily influenced by lifestyle and eating habits.

Researchers have determined that people with certain diseases often have a different mix of bacteria in their intestines compared to healthier people.

There are more than 80 autoimmune diseases in which the body turns on itself. In response to an unknown trigger, the immune system begins producing antibodies that instead of fighting infections, attack the body’s own tissues.

Since more women are affected than men, some physicians believe hormones may play a role.

The American Autoimmune Related Diseases Association (AARD) calls these ailments a major health problem. It’s estimated that at least 23 million Americans have these chronic and sometimes life-threatening diseases.

But help may be on the way.

Looking to the gut

In a recent study funded by the U.S. Department of Defense and the National Multiple Sclerosis Society, researchers from the Mayo Clinic and University of Iowa concluded that the human gut microbe may help treat autoimmune diseases such as multiple sclerosis (MS).

“This is an early discovery but an avenue that bears further study,” said Dr. Joseph Murray, a Mayo Clinic gastroenterologist and senior author of the article. “If we can use the microbes already in the human body to treat human disease beyond the gut itself, we may be onto a new era of medicine. We are talking about bugs as drugs.”

Read the entire article at: http://tinyurl.com/yckdtkhw • August 16, 2017

Giant Cell Arteritis Fund: Copayment and Premium Assistance Now Available

The HealthWell Foundation®, an independent non-profit that provides a financial lifeline for inadequately insured Americans, has opened a Giant Cell Arteritis Fund to provide copayment and premium assistance to eligible Medicare patients. Through the fund, HealthWell will provide up to $6,000 in copayment or premium assistance to individuals who have annual household incomes up to 400% of the federal poverty level. The new fund will assist these patients in accessing critical medications for treatment of their disease.

“The launch of the GCA fund represents our commitment to expanding our programs to reach as many patients in as many disease areas as possible,” said Krista Zodet, HealthWell Foundation President. “People living with giant cell arteritis, or temporal arteritis, can require treatment for years. Out-of-pocket costs associated with treating their condition often present a financial challenge and can be an added source of anxiety. Thanks to our dedicated donors, we are now able to offer GCA patients financial relief in the cost of their treatment.”

To determine eligibility and apply for financial assistance, visit HealthWell’s Giant Cell Arteritis (Temporal Arteritis) Fund page.

To learn how you can support this or other HealthWell programs, visit www.HealthWellFoundation.org

NOTE: The VF thanks Bruce Marks for providing the VF with information about the GCA HealthWell Foundation® fund.

The HealthWell Foundation also has an ANCA-associated Vasculitis GPA ( Wegener’s) Assistance Fund available to patients who qualify. Please visit their website for more information or contact them at 800.675.8416.
What is the road ahead in Vasculitis research? I believe we need to THINK BIG! A cure for Vasculitis? I say, why not. Am I right? Why not?"  
Dr. Peter Merkel, University of Pennsylvania

The Vasculitis Foundation is pleased to announce its Dream Big! campaign. The aim of this year-long campaign is to fast track the advances about which every person impacted by vasculitis is dreaming: faster diagnosis; better, less invasive treatments; and, ultimately, a cure for all forms of the disease.

Working together, we have taken enormous strides toward achieving these goals, but we have a long way to go before our task is complete. Please join our efforts to make this the breakthrough year for everyone impacted by vasculitis.

Please Dream Big! with us so that we can, together, take a giant step to achieving our dreams. Whatever you do will make an enormous difference. By working together, we can assure that people with vasculitis get diagnosed sooner, gain the support they need to best manage their disease, and live longer, healthier lives.

The Vasculitis Foundation is not just dreaming about a world without vasculitis, we are working hard to make the dream a reality. Over the last year, with your support, the Vasculitis Foundation:

- Funded a series of research projects through which we gained further understanding of the causes of vasculitis, diagnostic techniques, and more effective therapies.
- Collaborated with the pharmaceutical industry to assist in the development of treatments for GPA (Wegener’s), Giant cell arteritis and EGPA (Churg-Strauss Syndrome).
- Provided state-of-the-art information to individuals impacted by vasculitis, empowering them to more effectively partner with their doctors to develop customized therapies.
- Continued to train promising young physicians in our effort to make certain that specialty care for individuals with vasculitis is available throughout the world.

Next year, we intend to build upon that momentum and continue to serve the needs of the vasculitis community at unprecedented levels. We want to fund more research, increase our engagement with industry, offer a broader range of professional development opportunities, and continue to develop life-changing initiatives for individuals like you.

"If we can identify these causes and their pathophysiological pathways, we can provide prophylaxis against these diseases like vasculitis. One consequence would be that vaccination, or interruption of the trigger, could block the development of autoimmunity and diseases.”

Eric L. Matteson, M.D., Mayo Clinic

"My dream — and it’s likely shared by the Behcet’s community—is not only a cure, but affordable and accessible treatment for vasculitis.”

Beth Howe, administrator for the Behcet’s: We Are Not Alone Facebook Group

"No words hit home stronger than a diagnosis of a disease deemed incurable. Whether the diagnosis is for you, or worse, a loved one, the dreams of returning to normalcy and getting back something that was lost are strong and vivid. Dreaming of having easier and better treatments and for a cure, are deep in our hearts. So together, let's DREAM BIG!“

Karen Hirsch, VF Board President
Kris Kelbrant's Poignant Journey with CNS Vasculitis  
By Ed Becker

Kris Kelbrants was by every measure a successful young woman. In 1993, she graduated Cum Laude from the University of St. Thomas in Minnesota with a business degree and a minor in French. She was athletic, outgoing, and clearly on an upward arc in her career. However, her journey took an abrupt and unexpected detour with the onset of Central nervous system vasculitis. The long-lasting impact of the illness left her having to relearn how to walk, talk, and do the most basic cognitive tasks. Her journey is chronicled in a book, “Maze of Thorns” written by Kris and her mother, Sherry Shuss. The book details Kris’ frightening account of the early manifestation of the illness. In addition to headaches and extreme fatigue, Kris suddenly found herself unable to comprehend sentences, or simple instructions. Her parents knew something was clearly wrong when Kris became confused, unfocused, and withdrawn.

“Although we didn’t know exactly what happened, we knew something serious was affecting Kris,” said Sherry. “Her condition grew worse and eventually led to many visits to the ER, and the psych unit for evaluation. The experts were totally in the dark as to what was happening to her.” Eventually Kris, a brain biopsy and the results came back from Mayo Clinic with a diagnosis of CNS vasculitis. David Ridley, MD a rheumatologist from St. Paul Rheumatology in St. Paul, Minnesota who Kris’s family had been trying to see, arrived and came to the hospital.

“Maze of Thorns” is aptly titled because her journey back was full of setbacks and dead-ends. Prednisone and Cytoxan helped bring Kris’ vasculitis under control, but her family and medical team feared the diagnosis came too late as the vasculitis had already taken hold of Kris’ internal organs causing her heart to stop more than once. As miracles happen, Kris rallied. Her greatest challenge was regaining her physical and emotional health. “Everything I knew and everything I was as a person was mostly erased,” said Kris. “I had to use math flash cards to learn simple arithmetic. I had to be taught how to read. I also took piano and French lessons to help my brain relearn. I retreated socially as my twenty-something friends were all enjoying the prime of their lives. I had gone backwards and had to start over.”

Also erased was Kris’ memory spanning nearly the entire summer of 1997. Fortunately, those long months were not “lost” because during that time Sherry kept a detailed, day-by-day journal of her daughter’s challenging recovery. A few years ago, Kris and Sherry decided to take the notes and journal entries and turn them into a book they hope will help others going through a similar experience. After two years working together, the mother and daughter published "Maze of Thorns".

"We never wrote this book to win a literary prize, or make lots of money,” says Kris. “We just felt my story could be a road map to help others who go through a serious health crisis. The book ultimately shows that you can get through the worst experience and come out on the other side with valuable life lessons.”

By all accounts, the BrainWorks project (which features an easy-to-navigate website) is a model for patient education and it has already produced great results. Dr. Twilt explains the effectiveness of BrainWorks, saying, “It makes many aspects of the disease easier for patients and their parents to understand.”

The website guides families to locations offering the treatment options for their situations, and produces treatment regimens for the patients. The BrainWorks project isn’t just limited to patients, though. It also helps doctors, especially those who haven’t seen CNS vasculitis before. With diagnosis sometimes being complicated, BrainWorks guides doctors in ways to expedite the diagnosis process. Formed by Dr. Susanne Benseler at The Hospital for Sick Children in Toronto (now at the University of Calgary), BrainWorks has grown its database around the world, with collaborating centers from Uruguay to India to Australia and many countries in between, including the United States.

As the project continues to expand, Dr. Twilt is helping to get the word out. In her first presentation to the VF community in June, she spoke at the International Vasculitis Symposium in Chicago, leading a session on pediatric vasculitis with several other rheumatologists. “It came away really impressed with the symposium, and I was happy to see so many people speak up in our session,” Dr. Twilt noted. “Some of the questions pediatric patients have are very personal and difficult to ask to their primary care doctors. With the pediatric population relatively small in the vasculitis community, it is essential to give them and their families support.”

In this era of great technology, there’s no reason why we can’t have a thorough database for every sector of vasculitis. Dr. Twilt and the BrainWorks project are ahead of the curve in this regard, and hopefully the VF community will continue to see more resources like theirs developed soon.

Check out the BrainWorks website at: http://tinyurl.com/yoost6pl
Welcome to our newest section of the VF Newsletter highlighting how the VF connects with the vasculitis community through social media.

Here are just some of the discussions currently trending on the VF social media channels:

Is there a connection between shingles and vasculitis?
Where can I find a vasculitis specialist in Florida?
How does vasculitis affect vision?

JOIN: Vasculitis Foundation Facebook Discussion Group
More than 5,100 people belong to the VF’s Facebook Discussion Group. It’s a wonderful online forum where you ask questions and get answers about all aspects of vasculitis, and managing the illness on a day-to-day basis.

Request membership at: https://www.facebook.com/groups/vasculitisfoundation/
Editor’s Note: Joining the VF Facebook Discussion Group is not the same thing as being a member of the Vasculitis Foundation. To learn more about our VF Membership visit: http://www.vasculitisfoundation.org/membership/

LIKE: The VF News and Information Facebook Page
What’s the best way to learn online about upcoming VF webinars, regional conferences, fundraising events, or important VF news?
Simply LIKE the VF News and Information Facebook Page at: https://www.facebook.com/VasculitisFoundation/

FOLLOW: The VF Twitter Channel
With more than 1,500 followers, the VF Twitter feed continues to be one of the best places to tap into the latest news about vasculitis research, advocacy, and relevant medical news stories.

Follow us at: https://twitter.com/VasculitisFound

Here is a partial list of disease-specific vasculitis Facebook Groups. Editor’s Note: The following groups are not affiliated or endorsed by the VF. Always research any Facebook group before joining.
To find a complete list of vasculitis specific groups go the the Facebook Searchbox and enter vasculitis, or a form of vasculitis.

Alliance For Cryoglobulinemia
Behcet’s: You Are Not Alone
The CNS (Facebook) Group
Henoch Schonlein Purpura (HSP) (Facebook Group)
Microscopic Polyangiitis (MPA) Community
PMR-Polymyalgia Rheumatica on Facebook
Takayasu’s Arteritis (Facebook Group)
Urticarial Vasculitis (Facebook Group)
Vasculitis Foundation Canada
Vasculitis 2017: News and Information
Women with Polyarteritis Nodosa

Julie Power Supports Patients Through the Vasculitis Ireland Awareness (VIA) Organization

In 2010, Julie Power, a patient with Granulomatosis with polyangiitis GPA (Wegener’s) saw a need to create a support group for patients with vasculitis in Ireland. Funded by donations from a biking fundraiser led by her husband and sons, the Vasculitis Ireland Awareness (VIA) was born.

Over the last 17 years the VIA has grown from seven members to more than 300 patients and healthcare professionals throughout Ireland. Since 2011, the VIA has held an annual vasculitis conference featuring presentations by vasculitis and health care specialists. Hundreds of patients wanting to learn about the latest research and developments in their country and worldwide attended these conferences.

For Julie, collaborating with other organizations is the key to ultimately improving choices and options for the patient community. “We have always worked closely with local and national organizations who share issues with us,” says Julie. “Through the Irish Platform for Patient Organizations, Science and Industry (IPPOSI), we have become more aware of the Irish Health system and how we as patients can have a voice. I undertook a 14-month intense course with EUPATI (European Patient Academy in Therapeutic Intervention) in Research and Development. Through this program, I have been able to become more actively involved in this area and to make contact with other European patient support groups.”

Julie believes that being a patient with vasculitis allows her to share her valuable perspective and experience with medical professionals and vasculitis researchers. “Since doing the EUPATI course, I have given many talks on the patient experience. For me the question is: How can we impact research from the design stage and generally raise awareness of vasculitis? This year I talked to first and final year medical students about living with vasculitis, which was brilliant as I strongly feel if we can get involved at the training stage, they will remember something about this disease.”

For more information about the Vasculitis Ireland Awareness group, visit their website at http://vasculitis-ia.org

Granulomatosis With Polyangiitis (GPA) and Microscopic polyangiitis (MPA): Your Questions, Expert Answers.
By Dr. Jonathan Scott Coblyn, Director, Clinical Fheumatology, Brigham and Women’s Hospital Boston
This is the first book written specifically for GPA and MPA patients and cover signs, symptoms, diagnosis, treatment options, complications, relapse and remission. The book also discusses how to communicate effectively with your health care providers. If you would like a free copy of the book, please email the VF at vf@vasculitisfoundation.org or call 816.436.8211
A Year in Review: The Impact of Participation

The Vasculitis Patient-Powered Research Network just had our third anniversary. Thank you for your support and participation! In three years our Network has grown to over 2,000 participants in 29 different countries representing 13 of the vasculitides. There is strength in numbers. Each participant in the V-PPRN helps to make our data become stronger and our community becomes healthier.

Collaborating To Find Answers:
The V-PPRN is a longitudinal cohort study (a study capturing patient data over a long period of time) that provides us the opportunity to follow patients with many forms of vasculitis over numerous years. By asking patients questions regularly about their health, disease flares, and other patient-reported data, we can understand how people's health and lives change over time. Collecting patient data over time helps us better understand vasculitis and how to combat these diseases.

Dreaming Big
In 2013 the idea of a research network for vasculitis in which patients partner with investigators to create a network and develop research protocols was a dream. In 2014, that dream came true with the launch of the Vasculitis Patient-Powered Research Network. The dream of the V-PPRN in 2014-15 was to launch one study and enroll 500 patients. In 2015, we launched three studies and had enrolled over 1,000 patients.

It is time to really DREAM BIG! With 2,000 patients enrolled from over 29 countries and an extensive research portfolio, we are ready to dream bigger, push harder, and achieve more! If you are already a member of the V-PPRN, we thank you for dreaming big and participating in something that will improve the lives of patients with vasculitis. If you haven't joined the V-PPRN but you want to contribute to a bigger dream and brighter future for patients with vasculitis, join us today!

For more information about V-PPRN, please contact Kaleen Young, V-PPRN Network, Manager, kyoung@vasculitisfoundation.org

V-PPRN: Our Completed Studies

AAV-PRO (Completed)
The aim of this project was to develop a disease specific quality of life survey for patients with ANCA-associated vasculitis. 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.

Vasculitis Work Disability Study (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.

Healthy Mind, Healthy You
The purpose of the Healthy Mind, Healthy You study is to examine the effectiveness of mindfulness-based cognitive therapy on well-being in patients with vasculitis.

Comparative Effectiveness/Safety of Biologics (CHOICE)
The first aim of this study is to evaluate the comparative risks for serious infections, cardiovascular events (e.g. myocardial infarction and stroke), and incident cancer associated with biologics and non-biologic therapies used for the treatment of adult and pediatric arthritis, psoriasis, IBD, and vasculitis. The second aim is to evaluate the comparative clinical effectiveness of various biologic and other medications using a variety of disease specific and generic patient reported outcome (PRO) measures.

VERITAS: Vasculitis: Effects of Remission maintenance Therapies - on relapse and Side effects on patient preferences
This study assesses how patients with vasculitis weigh the benefit of relapse risk reduction provided by maintenance therapy versus the potential risk of adverse events. The second aim is to assess whether issues surrounding long-term, low-dose prednisone for prevention of relapse is a research question that patients think is important.

Pathways to Diagnosis
This particular study stems from and builds upon our Journey study. The main aim of this protocol is to identify diagnostic pathways in large healthcare databases using predictive analytics and machine learning techniques to calculate the risk of having a specific autoimmune or systemic inflammatory syndrome. The second aim is to apply and test the predictive analytic model identified in our first aim to enable a learning healthcare system to calculate the risk of having a specific condition and notify the appropriate physician, and enact change in care.

Future Studies: V-PPRN Studies in Development

In addition to our current list of V-PPRN studies, we are in the process of reviewing and developing several more protocols. All V-PPRN studies are patient-centered and are of importance to patients and physicians. We continue to develop new ways to utilize our infrastructure to support novel research methods. Stay tuned for information about our other protocols in development including a study on the nasal microbiome of patients with ANCA-Associated Vasculitis (AAV) and another characterizing patient-reported quality of life among patients with cutaneous manifestations of vasculitis. Our research portfolio covers a wide range of research areas to help improve the lives of patients with vasculitis.

Please visit vpprn.org to learn more
The Vasculitis Clinical Research Consortium (VCRC) is the major clinical research infrastructure in North America dedicated to the study of vasculitis. The VCRC has grown to include 18 academic medical centers in the United States and Canada conducting investigator-initiated clinical and translational research. The VCRC also partners with 50 other centers worldwide for the conduct of clinical trials. The VCRC conducts observational cohort studies, biomarker development, studies of genetics and genomics, clinical outcomes research, studies using an online patient registry, pilot clinical projects, and multicentered, randomized clinical trials. Core components of the VCRC include the VCRC Clinical Data Repository, the VCRC Biospecimen Repository, the RDCRN VCRC Patient Contact Registry, the VCRC-NIH Data and Safety Monitoring Board.

Join The VCRC Contact Registry!

Research offers no guarantees, but research cannot move forward without your help. Every active role a patient takes may possibly play a part in discovering new groundbreaking research and finding new treatments.

Participating Institutions:

- Boston University School of Medicine Vasculitis Center
- Cedars-Sinai Medical Center United States
- The Cleveland Clinic
- Hospital for Special Surgery Vasculitis & Scleroderma Center
- Istanbul University
- The Mayo Clinic College of Medicine
- Mount Sinai Hospital
- Northwell Health
- Oregon Health & Science University
- St. Joseph's Healthcare, Hamilton
- University of California, Los Angeles Health
- University of California, San Francisco
- University of Kansas Medical Center
- University of Michigan
- University of Pennsylvania
- University of Pittsburgh
- University of Utah

Please visit the VCRC website to join the registry and to review the complete list of all current research studies available for patients to participate in. [https://www.rarediseasesnetwork.org/cms/vcrc/](https://www.rarediseasesnetwork.org/cms/vcrc/)

The VF Attends the 2017 American College of Rheumatology (ACR) Annual Meeting

Hundreds of rheumatologists, researchers, and medical professionals visited the VF’s booth during the ACR Annual Meeting in San Diego, November 3-7.

You can search for and read all the research abstracts/posters that were presented during the meeting November 3-9, 2017 in San Diego. Search the website using key words such as vasculitis or individual disease name such as Behcet’s or using terms such as ANCA, eosinophilic, or Cryoglobulinemia.

DCVAS Study Update Presented at ACR

Investigators provided updates on the VF-funded Diagnostic and Classification Vasculitis (DCVAS) Study during the ACR Annual Meeting in November. DCVAS is the largest study conducted in vasculitis to date with over 6,000 patients, and physicians and researchers from 133 sites in 33 countries participating in the research.

Speakers presented finalized updated classification criteria for GPA (Wegener’s), microscopic polyangiitis, and EGPA/Churg-Strauss Syndrome. The updated classification criteria will improve the quality of future clinical trials and clinical research because patients with specific diseases will be able to be reliably grouped for studies.

DCVAS researchers are still working on developing classification criteria for other vasculitis conditions and will subsequently develop diagnostic criteria using similar methods.

DCVAS is sponsored by the University of Oxford and is funded by the Vasculitis Foundation, the American College of Rheumatology, and the European League against Rheumatism. DCVAS is supported in the United Kingdom by the NIHR Clinical Research Network.
September and October 2017 Donors  •  Thank You for Your Gift of $50 or More!

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IN MEMORIAM

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

Donations are still being accepted to create a fund for your loved one. Contact Vasculitis Foundation at 877-VF-HELP-2 or info@vasculitisfoundation.org.


VF Store

When it feels like this...

Buy.  
Support.  
Celebrate!

The VF Store is a great way to do your holiday shopping while supporting the mission of the VF. We are offering a special sale on all of our warm weather clothing and gear. Proceeds from the sale of our products goes to support the education, research, and patient support services with the VF.

Visit http://vfwebstore.com

The VF has you covered!

The VF Store has released its first two DVDs featuring some of the most popular presentations from the 2017 VF Symposium. These presentations were professionally videotaped and edited to be a valuable educational resource for patients.

Topics include:  
• The Role of Genetics in Vasculitis  
• Pain Management  
• Integrative Medicine

More videos will be added to our collection in 2018.

The VF Victory Over Vasculitis Bear

It’s cute, cool, cuddly, and comforting. Just in time for the holiday season, the VF is selling a limited number of these popular bears through the VF Store.

THE VF STORE 2017 HOLIDAY SALE
The VF wishes everyone a safe and happy holiday season!

VF Calendar of Events • 2018

February 28, 2018
Rare Disease Day
The 2017 global theme is “Research”.

March 15 - 17, 2018
2018 International Conference on Large Vessel Vasculitis and Related Disorders
Mayo Clinic Rochester, Minnesota
For health care professionals:
Website: ce.mayo.edu
Email: cme@mayo.edu

April 28, 2018
5th Annual Vino for Vasculitis 2018
Junction Salon and Bar in downtown Raleigh, NC 27601
327 W Davie St #114, Raleigh, NC 27601
Organizer: Jess Foster
Email: jess@Vinoforvasculitis.com

May, 2018
Vasculitis Awareness Month

March 15-17, 2018
2018 International Conference on Large Vessel Vasculitis and Related Disorders
Mayo Clinic Rochester, Minnesota
Course Directors: Kenneth, J. Warrington, M.D., and Eric L. Matteson, M.D.

The 2018 International Conference on Large Vessel Vasculitis and Related Disorders is an intensive course to examine and review current knowledge about the biology and management of large vessel vasculitis.

The course draws together international experts in the fields of basic science, epidemiology, imaging and treatment of major forms of large vessel inflammatory diseases including giant cell arteritis, Takayasu arteritis, IgG4 related disease and others.

State of the art management and current research into large vessel vasculitis will be presented at this scientific meeting. Participants are encouraged to submit abstracts now.