VF V-RED Award Campaign Expands Into a Yearlong Campaign Promoting Awareness and Early Diagnosis

by Ed Becker, Director of Marketing and Communications

This year marks the fourth anniversary of the VF’s Recognizing Early Diagnosis Award (V-RED) and by every measure it has grown into one of the organization’s most important annual awareness programs. More than 120 medical professionals from around the world have been nominated by their patients for making a critical, early diagnosis of vasculitis.

Patients submit nominations to the VF where they are reviewed and evaluated by the VF Board. A single winning medical professional is chosen, along with several Honorable Mentions.

This year, Linda Brady, MD, a pediatrician, was selected as the winner and three other doctors received Honorable Mention.

Improving the rate of early diagnosis of vasculitis is a core objective for the VF and the V-RED Award is particularly effective because it helps to raise awareness not only among patients, but also throughout the medical community.

Raising Awareness Through Peer-Recognition

“These are powerful stories that showcase medical professionals in all areas of medicine who made a critical, early diagnosis of vasculitis and impacted the outcome for their patients,” says Karen Hirsch, president of the VF Board. Hirsch created the V-RED Award after her experience

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**ABROGATE Research Study Needs Patients To Enroll!**

Are you eligible to participate? Will you help us with research?

**ABROGATE Study Recruiting Patients: For the Treatment of Relapsing, Non-Severe, Granulomatosis with Polyangiitis (formerly Wegener’s)**

In this study, participants will be randomly assigned by chance (like flipping a coin) to either receive abatacept or a placebo (inactive solution that looks like the study medicine but it doesn’t contain abatacept) injected subcutaneously (by syringe) combined with standard doses of prednisone. If you are already receiving methotrexate, azathioprine (also called Imuran), mycophenolate (also called cellcept or myfortic), or leflunomide (also called arava) you would continue taking the same dose of this medication.

While on the study, if your symptoms come back or you have a non-serious disease relapse or if you have not improved after 6 months of being on the study, you will have the option of receiving open label abatacept, which means that you will receive abatacept and there is no randomization and no placebo involved. The decision to receive open-label abatacept is your choice. If you decide

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Executive Director Message

Dear Friends,

I am happy to introduce Beth Westbrook our new director of development. Beth joined the Vasculitis Foundation in June, and she has the critically important job of helping us raise funds for the organization. Although new to the vasculitis community, Beth brings tremendous knowledge and expertise from her previous work in the cancer field.

Fundraising activities come in many forms - from birthday celebrations to golf tournaments to walks, dinners, bowling rallies, wine tastings, company matching gifts, and simple donations. Our events are organized by individuals, families, friends, and co-workers. If you’d like to learn more about fundraising, please contact us. We’d be happy to talk to you about ways to fundraise.

All of the funds raised support our programs, which are designed to serve our patients and families, educate medical professionals, and bring awareness of vasculitis to the general public. Your support also funds our research studies and fellowships.

This summer we are updating all of our educational materials and building a new website, which will be more mobile friendly and easier to find the information you need/want. We also want the vasculitis community of patients, families, healthcare professionals, and researchers to be able to connect more quickly with each other.

We are also recruiting volunteers to be new area contacts for us. An area contact is someone who has agreed to be available by telephone and email to those who wish to talk with someone who is either a patient with vasculitis or relative/close friend of a patient with vasculitis. Please contact me if you are interested in learning more about the role.

Sincerely,
Joyce

Joyce A. Kullman
Executive Director

Mission Statement

Building upon the collective strength of the vasculitis community, the Foundation supports, inspires and empowers individuals with vasculitis and their families through a wide range of education, research, clinical, and awareness initiatives.

The Vasculitis Foundation is 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.
Introducing Beth Westbrook, Director of Development

The Vasculitis Foundation is pleased to introduce Beth Westbrook who brings a career in nonprofit development leadership to the organization. Beth’s experiences—both personally and professionally—make her uniquely qualified to help the VF to grow stronger in the coming years.

Dear Friends,

As the newest addition to the team at the Vasculitis Foundation, I am eager to roll up my sleeves and make a difference for the people we serve. My only concern when I started was my lack of knowledge about vasculitis. You see my journey began in another area—pediatric cancer. When my daughter, Katie, was diagnosed with bone cancer at the age of 12, I began to tirelessly work towards better outcomes for cancer patients. For the next 18 years, I advocated, fundraised, and educated people about why they should join in and help. I built a career in development working with nonprofits ranging in missions centered on cancer to disabilities. Now I want to use these skills to help people living with vasculitis and the people who support them.

Beth Westbrook

Most recently I worked on another team; a Major League baseball team. While I watched the young ballplayers develop their skills, my mind often wandered to the similarities between baseball and my work for nonprofit organizations. Every day, I go out and try to “hit a home run.” If I’m lucky, it will be a grand slam, walk off homerun! That doesn’t happen very often. However, being prepared, staying focused on what needs to be done, and knowing there are other players to help you score a run is essential to a winning team. On the wall near the entrance to the clubhouse, there is a quote by Roberto Clemente:

“Any time you have an opportunity to make a difference in this world and you don’t, then you are wasting your time on earth.”

You can help me build a more sustainable organization for the future. Share your stories, educate me on your journey living with vasculitis. Share your skills and experience to keep moving the VF mission forward. Share your resources—make a gift towards finding a long-term solution. Knocking on doors and asking for support doesn’t deter me (although at times I admit to being nervous). Your stories and your investment will inspire us to work effectively as a team to achieve earlier diagnoses, better treatments, and longer lives. Let’s start a conversation about how we can make a difference together.

Sincerely, Beth Westbrook bwestbrook@VasculitisFoundation.org

AARDA Announces New Autoimmunity Institute

The American Autoimmune Related Diseases Association (AARDA) is proud and honored to announce its collaborative partnership with Allegheny Health Network (AHN) and its new Autoimmunity Institute.

The AHN Autoimmunity Institute, with its hub at West Penn Hospital in Pittsburgh, Pennsylvania, is an unprecedented venture focused on integrated multispecialty care and multidisciplinary research for patients with all autoimmune diseases. More than a dozen specialties care for patients in a single 16,000 square foot suite. The patient care team is tightly integrated with clinical and translational research, education, training, and outreach for patients with any autoimmune diseases.


Become a Partner in Finding a Long-Term Solution

Join the Vasculitis Foundation in the effort to improve outcomes for people living with vasculitis. Here are some of the many ways you can help:

- **Give of your time, volunteer and make a tangible difference for those in need.**
- **Participate in an event.** Check out our website to see the most current list of what’s happening.
- **Consider donating towards our Annual Fund.** Each gift allows us to do more for the people we serve.

In the year ahead, we will highlight the efforts of our giving community and share ideas for you to get involved.

The Vasculitis Foundation values any donation of time, expertise and financial support. You can make a difference, and we would love to partner with you! THANK YOU!
Nashville Pediatrician Earns VF Award for Making Critical, Early Diagnosis

by Ed Becker

The 2018 V-RED Awardee is Linda Brady, MD, a pediatrician with Old Harding Pediatric Associates, Vanderbilt University Medical Center/Monroe Carrell Jr. Children’s Hospital, Nashville, Tennessee. Dr. Brady was nominated by Lisa Crabb the mother of Chip, who was diagnosed with Granulomatosis with polyangiitis (GPA/formerly Wegener’s) in September 2017.

Throughout the summer of 2017, Chip’s condition worsened from what at first appeared to be a persistent cold, to something much more complex and serious. He suffered intense fatigue, hearing loss, and breathing difficulty.

Tests showed a dramatically elevated sedimentation rate indicating inflammation, and dark spots on his lungs which at one point suggested a relatively rare condition Histoplasmosis, or “Black Bird Disease”. However, an ultrasound ruled out that illness and confirmed another rare disease—vasculitis.

Chip was treated with seven rounds of Rituxan®, and high doses of prednisone.

In April 2018, Crabb received the news that Chip was in remission. She believes the positive outcome was largely the result of Dr. Brady’s persistence and professionalism. “Dr. Brady knew she had to dig deeper when Chip didn’t respond to the courses of antibiotics, and other unexplainable symptoms which occurred,” said Crabb. “She consulted other specialists and ordered further testing to get answers. That tenacity is what eventually helped us get a diagnosis.”

Dr. Brady said it is critical to push for more answers when presented with a patient like Chip, and to involve a team of specialists to get those answers. “I strongly believe in using all my resources to make it a team approach. I am thankful to have access and working relationships with specialists (ear, nose and throat, pulmonary, rheumatology and nephrology) at Vanderbilt Children’s Hospital.”

Crabb thanks the VF for raising awareness with this special campaign.

“By awarding Dr. Brady the V-RED award, we are shining a spotlight on those who see the disease at its earliest stages - the primary care clinical community,” says Crabb. “It is here where we need to make doctors aware of what vasculitis symptoms look like and when to push forward with additional testing when their instincts tell them there is something seriously wrong. By educating and recognizing doctors like Dr. Brady with this much-deserved accolade, earlier diagnosis and better long-term outcomes can be obtained by all those affected.”

The Vasculitis Foundation is also pleased to recognize these physicians for Honorable Mentions:

Samir Parikh, MD
Ohio State Wexner Medical Center – Nephrology
Columbus, Ohio
Dr. Parikh was nominated by Sandy Nye, who was diagnosed with Microscopic polyangiitis in 2014 after being sick for more than five years with no definitive diagnosis. Dr. Parikh, a nephrologist, made the diagnosis in four weeks after performing a kidney biopsy and recognizing the symptoms of vasculitis.

Daniel Watson, MD
Park Nicollet St. Louis Park Clinic
St. Louis Park, Minnesota
Dr. Watson was nominated by Nicole Shankey in recognition of his diagnosis of Granulomatosis with polyangiitis (GPA/formerly Wegener’s) after an emergency room visit. Dr. Watson, an otolaryngologist, suspected the rare autoimmune disease after seeing Nicole during the ER visit. He recommended a course of high-dose steroids instead of an emergency tracheotomy.
VF V-RED Award Campaign, cont.

with her son’s diagnosis. “Sharing these V-RED stories with a wider media presence will help us to raise awareness—especially to other doctors, or specialists who may be the ones to first encounter a vasculitis patient.”

V-RED Campaign Grows In Scope and Outreach

A new web page on the VF website will feature not only the winning doctors, but the stories of each medical professional who was nominated. Moreover, the VF is expanding its outreach to additional clinical publications and medical media sources than in previous years.

The outreach is twofold—to recognize the nominated doctors and to elevate the importance of early diagnosis to a global audience.

Joyce Kullman, Executive Director of the VF, is encouraged by the increase in submissions for this year’s V-RED Award.

“These stories tell us that while early diagnosis continues to be a major challenge and priority, there are medical professionals who are significantly impacting the outcome for patients. We thank all of the patients who participated in the program, and we hope to increase the number of nominations next year,” says Kullman.

Visit the updated V-RED web page at https://bit.ly/2IatRjs

2018 V-RED Nominated Physicians Receive Certificates of Appreciation

In addition to the winner and Honorable Mentions, thirty-eight other medical professionals were nominated by patients, and were each given a special Certificate of Appreciation.

The VF will be featuring the photos and stories for each of these nominated physicians throughout the year on the VF website and social media.

New VF Web Page Makes Research Participation Even Easier

The Vasculitis Foundation encourages patients with vasculitis to participate in research whenever possible. Some studies are clinically based, others are being conducted by marketing research companies to help industry better understand disease activity.

The VF has created a new web page to consolidate information about these individual studies. You will find a short summary about a particular study, and a link to get more information.

Visit the page to learn more about these studies: https://bit.ly/2yv0Mzt
What Do You Think?

The Rare Diseases Clinical Research Network is looking for patients with
Granulomatosis with Polyangiitis (GPA/Wegener’s)
or
Skin/Cutaneous Vasculitis or Henoch Schönlein Purpura
(HSP or IgA Vasculitis)

U.S. or Canadian-based participants only.

The Rare Diseases Clinical Research Network (RDCRN) wants to hear more about your experience with your rare disease.

We are looking for patients to participate in interviews and/or focus groups online. You won’t need to leave your home to participate – just connect with us online!

Hearing your story helps the RDCRN understand how we can better help patients like you!

What’s Involved?

• Participate in a one-time 60-minute focus group and/or interview from the comfort of your own home
• Free to participate and no travel required
• You will need access to a computer, phone or mobile device with a good Internet connection
• You will receive a $10 Amazon gift card for participating. If you complete both an interview and focus group, you’ll receive two gift cards!

For more information, please e-mail:
PRISM@epi.usf.edu

Family members and caregivers of people with rare diseases are also welcome to participate.

The Rare Diseases Clinical Research Network is an initiative of the Office of Rare Diseases Research (ORDR) National Center for Advancing Translational Sciences (NCATS) funded through a collaboration between NCATS and the National Institutes of Health.
ABROGATE Study Recruiting Patients, cont.

not to receive this, you will stop all study medication treatment and be treated with the best medical approach as you and your Doctor decide upon.

Your total time on the study will range from 12 to 48 months (1-4 years). About 150 people will take part in this study across 30 medical centers in the US, Canada, Mexico, Europe and Australia.

At each study visit, you will receive the following:

- Medical history review
- Physical exam
- Blood/urine tests
- Study questionnaires

Target Enrollment:
To be eligible to participate, you must:

- have a diagnosis of GPA (also known as Wegener’s)
- have presence of active non-severe GPA within the past 28 days
- be 15 years of age or older
- be willing and able to follow treatment and follow-up procedures
- be willing to use an effective means of birth control during this study
- be willing and able to give written informed consent

To learn more about this study, including all the inclusion and exclusion criteria, and listing of all study sites, please visit: https://goo.gl/32yxP8

Participating Institutions in the ABROGATE Trial

- Cedars-Sinai Medical Center, Los Angeles
- University of California San Francisco, San Francisco
- University of South Florida, Tampa
- University of Kansas Medical Center, Kansas City
- Boston University School of Medicine, Boston
- University of Michigan, Ann Arbor
- Mayo Clinic College of Medicine, Rochester
- Hospital for Special Surgery, New York City
- Cleveland Clinic, Cleveland
- Oregon Health & Science University (OHSU), Portland
- University of Pennsylvania, Philadelphia
- University of Pittsburgh, Pittsburgh
- Vanderbilt University, Nashville
- University of Utah, Salt Lake City
- University of Alberta, Edmonton
- University of Calgary, Calgary
- St. Pauls Rheumatology Clinic, Vancouver
- St. Joseph’s Healthcare, Hamilton
- University of Toronto Mount Sinai Hospital, Toronto
- St. Vincent’s University Hospital, Dublin
- Aberdeen Royal Infirmary, Aberdeen
- Cambridge University Hospitals, Cambridge

Save the Dates! Mark Your Calendars!

2018-2019 VF Vasculitis Regional Conferences

The VF is pleased to announce that we will hold the following one-day regional conferences for patients and family members! These conferences feature medical experts discussing the most current treatments, updates on research, and managing the side effects of vasculitis. The conferences also provide an excellent opportunity to meet and network with other patients and family members and interact with experienced and knowledgeable physicians.

- **VF - KU Vasculitis Patient & Family Conference**
  Saturday, August 4, 2018
  Overland Park, Kansas

- **VF - UCLA Patient & Family Conference**
  Saturday, November 10, 2018
  Santa Monica, California

- **VF - University of Washington Patient & Family Vasculitis Conference**
  Saturday, January 12, 2019
  Seattle, Washington

- **VF - Mayo Clinic Patient & Family Vasculitis Conference**
  Saturday, March 9, 2019
  Scottsdale, Arizona

- **VF - Cleveland Clinic 1/2 Day Vasculitis Conference (TENTATIVE)**
  Tuesday, May 14, 2019
  Cleveland, Ohio

**Save these THREE days in July 2019**

Announcing the **2019 VF International Vasculitis Symposium!**

In partnership with the Mayo Clinic and University of Minnesota

July 19-21, 2019

Hyatt Regency, Mall of America
Bloomington, Minnesota

VF Fellowship Is Critical to Young Physician Advancing Career

by Kurt Ullman, RN

In medical school, the very complex diseases in rheumatology fascinated Rennie Rhee, MD, MS. In particular, vasculitis was a mystery she was interested in solving. Following her residency, she received a two-year fellowship from the Vasculitis Foundation.

“Treating vasculitis is very much like solving a puzzle since you get a little piece of information here and another there before putting it altogether to make a diagnosis and formulate a treatment plan,” says Dr. Rhee, who is an assistant professor of medicine at the University of Pennsylvania Perelman School of Medicine in Philadelphia. “There is no single test that gives you an answer and I found that very interesting personally and professionally.”

“The VF Fellowship allowed me to work with Dr. Peter Merkel, one of the world’s experts in the field,” she says. “At the Penn Vasculitis Program, I saw a large number of patients, and learned more about diagnosis and management of these diseases through working with Dr. Merkel and Dr. Antoine Sreih.”

Focus on Research

Her other focus during the fellowship was research. She was interested in investigating trends in outcomes over time in patients with ANCA-associated vasculitis (AAV) and kidney disease. She obtained access to a large database administered by the Glomerular Disease Collaboration Network at the University of North Carolina. Using records of patients entered between 1985 and 2005, she assessed changes in survival and kidney disease over that period of time.

“We found that compared to patients diagnosed in earlier time periods such as 1985, patients diagnosed more recently are actually living longer and are less likely to develop end-stage renal disease (ESRD),” says Dr. Rhee. “We looked at a fairly similar group of people with severe disease and found their outcomes are improving over time. It seems the best explanation for this benefit is earlier diagnosis.”

Additional Success

The VF fellowship has already led to additional success. She was recently awarded a prestigious National Institutes of Health K Award, which is a mentored early career development award. This award requires evidence that the grantee can complete research at high levels. Dr. Rhee said that the support from the Vasculitis Foundation was critical in that respect.

“I am appreciative of the VF and its donors for supporting people like me who are new and not well known in the field of vasculitis but have a real desire to engage and be part of this field of medicine,” Dr. Rhee says. “Without the fellowship, I don’t think I’d be able to do what I am doing today: seeing patients and doing research in vasculitis. The fellowship was critical to my ability to advance my career as a researcher and a clinician.”

Now Enrolling: A Randomized Multicenter Study for Isolated Skin Vasculitis (ARAMIS)

The purpose of the ARAMIS Study is to evaluate different treatment options for patients with skin vasculitis (also called cutaneous vasculitis). Patients with small- or medium-vessel vasculitis that only involves the skin (“isolated skin vasculitis”), including some forms of polyarteritis nodosa or IgA vasculitis (Henoch-Schönlein purpura) can join this study. There is not a common preferred or recommended treatment option for isolated skin vasculitis, and different doctors may advise using different drugs, based only on their personal experience. The most frequently used treatments for skin vasculitis are colchicine, dapsone and azathioprine. This study will compare how effective these three drugs are at treating isolated cutaneous vasculitis.

For Diseases

› Isolated cutaneous small-vessel (SVV)
› Isolated cutaneous medium-vessel vasculitis (MVV)
› Cutaneous polyarteritis nodosa (cPAN)
› IgA vasculitis (Henoch-Schönlein purpura, IgAV)

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Low Dose Steroid Maintenance Therapy May Lessen Vasculitis Flares

by Kurt Ulman, RN

Relapses of ANCA-associated vasculitis (AAV) have been linked to an increase in death, reduced kidney (renal) function and end-stage renal disease (ESRD). Long-term use of steroid medications is often used to help keep AAV under control.

However, there are concerns about adverse effects of the medicines, so patients and physicians have to walk a tight rope to lower the steroid dosage without triggering a relapse of the disease. An abstract presented at the 2017 Annual Meeting of the American College of Rheumatology looked at some of these issues.

Lack of Data When Stopping Steroids

“There is still a lack of data on when to stop steroid maintenance therapy when people have their disease well controlled,” said Amy Archer, MD, PhD, an assistant professor at Northwestern University and director of the NW Vasculitis Center. “If we stop the steroids too early, their vasculitis may flare and they need steroid doses that are much higher than maintenance to get it back under control.”

To learn more about long-term steroid usage, Jennifer Rodrigues, MD, MSc, a nephrologist and VCRC-VF clinical research fellow at McMaster University, Dr. Archer, and colleagues reviewed 24 studies published between 2008 and 2016. Of these 13 studies (54%) had stopped steroid treatment within one year They studied the records of 2,272 patients. All the patients received immunotherapy in addition to the prescribed steroids to achieve remission.

“Best Worst Medicine”

“We often call steroids our ‘best worst medicine’, says Dr. Archer. “Steroids work fast to decrease inflammation, but since they have so many side effects, particularly at high doses, most patients want to get off them if they can. This study tries to help clarify if there is a benefit to keeping patients with AAV on low levels of steroid medication.”

Relapse was more frequent with complete discontinuation of steroid medications at any one time when compared to long-term, low-dose maintenance therapy. This was confirmed by other statistical methods also showing long-term, low-dose steroid use was associated with lower relapse rates.

Overall follow-up time was linked to an increase in relapse rates. Other variables such as time to discontinuation of non-steroid immunotherapy, time to steroid discontinuation, renal function, and presence of relapse at baseline, did not show any significant association with relapse rates.

Benefit of Long-Term Treatment

“In studies where the doctors took people off of steroids, there were more relapses than seen in those studies where patients were left on at least a low dose of steroid,” says Dr. Archer. “Although this is not a prospective randomly controlled trial, it does provide additional clarity on the benefit of keeping patients with AAV on maintenance doses of steroids long term.”

Source:

New Vasculitis Program in Minneapolis

Patrick Nachman, MD, FASN, is the new director of the Division of Renal Diseases and Hypertension at the University of Minnesota in Minneapolis. Prior to that, he was at the University of North Carolina, where his research focus has been on ANCA vasculitis since 1992. Dr. Nachman is a longtime member of the VF Medical and Scientific Advisory Board and has helped with the research program, conferences, symposia, and North Carolina Chapter for many years.

Dr. Nachman is building a multidisciplinary vasculitis program (MVP) at the University with the collaboration of physicians from nephrology, rheumatology, pulmonary medicine, ENT, dermatology, and pediatric nephrology. The program goals are to provide integrated and coordinated multidisciplinary care to patients with systemic vasculitis, as well as give access to clinical trials in vasculitis. Although the logistics of the program are still in development, they are in fact already participating in clinical trials in ANCA vasculitis.

For appointments:

› 612.626.6100

› Patients should ask to be seen in the Nephrology GN/Vasculitis clinic, or specifically ask for Dr. Nachman, Dr. Surabhi Thakar, or Dr. Katti Woerner
Diagnosis Fuels Woman’s Passion to Help Others with Central Nervous System (CNS) Vasculitis

by Ed Becker

By her own definition, Jonelle Martin calls herself a survivor of CNS. That term has even greater power considering that when she was diagnosed there were rumors among some of her friends and neighbors that she would not live past 25 years old.

Today, Jonelle is 32, and she is not merely surviving, but thriving as she celebrates the recent news of being in full remission. Moreover, she is pursuing her passion as the founder and leader of an active group on Facebook for patients with CNS.

Her first symptom—numbness of her tongue—appeared in November 2008. Weeks later, Jonelle woke up to find the right side of her body was paralyzed. Jonelle was admitted to the neurology center at Saint John Regional Hospital, in Saint John, Brunswick, Canada where she was given a battery of tests that revealed significant inflammation and lesions. After her doctors consulted with the physicians at the Cleveland Clinic, they presented Jonelle with the diagnosis of CNS vasculitis.

“I will never forget that moment of pure despair,” Jonelle recalls. “Getting that diagnosis was by far the worst feeling I’ve ever felt and hopefully will ever feel again. Three doctors were explaining it to myself and my parents. They said it was the first case of CNS vasculitis any of them had ever encountered and what I read on the Internet about the disease led me to believe it was not only rare but often fatal.”

Treatment and recovery included infusions of cyclophosphamide, large doses of steroids, and many weeks incapacitated in a cloud of depression and anxiety. During this time, a rumor started in her small town that Jonelle’s prognosis was fatal. She decided to start a Facebook group specifically to dispel these dire rumors among her friends and neighbors.

Then something fortunate happened as the result of a simple grammatical error. When she set up the group, Jonelle mistakenly suggested it was for people with CNS. Quickly the online group began attracting hundreds of CNS patients from around the world. Today, Jonelle and her family serve as the administrators for the online community which has grown to over 400 members.

“CNS has many different symptoms beyond just the typical crushing headaches. We have patients in our group dealing with strokes and seizures. They’re all looking for more information, and support from others,” says Jonelle. “I remember what I went through with this illness, and hopefully this alleviates that hopelessness for others going through the same thing.

The Primary CNS / CEREBRAL Vasculitis Facebook Group can be found at https://bit.ly/2Nh4eR2

What does a VF fundraiser look like?

Almost anything you want it to!


These are just a few of the fun, creative, and successful fundraisers that helped to support the mission of the VF.

If you have an idea for a fundraiser you’d like to do, please contact the VF today, vf@VasculitisFoundation.org or 816.436.8211
VF Intern: Julia Metraux
by Ed Becker

Julia Metraux’s college plans were derailed in October 2016 after she developed an onset of symptoms that began as annoyances and then became dangerous. “I was eighteen years old and in my second month at McGill University,” Julia recalled. “My entire body was covered in hives, and I was unable to consume even liquid without vomiting. I had severe angioedema in my face and hands. Finally, the hospital had to use multiple EpiPens to control my breathing.”

Julia experienced an initial round of misdiagnoses which unfortunately is common for many patients with vasculitis. “The doctors just tested me for lupus. They either said they did not know what was wrong and stopped testing, or they accused me of searching for drugs, despite my urine and blood tests proving I didn’t use recreational drugs,” Julia explained.

After a year of fruitless testing, Julia actually received two diagnoses from doctors in two different countries in less than three months.

In November 2017, her rheumatologist at Boston Children’s Hospital concluded she had vasculitis based on her symptoms and an unusually high CRP report. Two months later while vacationing in Puerto Vallarta, Mexico, Julia experienced another flare which landed her in the hospital for 10 days. The doctor treating her diagnosed her with urticarial vasculitis based on a skin biopsy, high CRP, and elevated ESR.

Today she is managing her vasculitis with her team of doctors at Boston Children’s Hospital. Unfortunately, because her vasculitis wasn’t caught sooner, it left her with chronic pain that has slowed her recovery. Moreover, treating the vasculitis forced Julia to step away from her studies in gender studies at McGill University.

Despite the challenges, Julia is determined to get back on track with her academic pursuits. In August she will attend the New School in New York City to pursue degrees in Global Studies and Journalism.

This summer Julia is completing a VF internship to help hone her journalism skills. She is researching and writing short articles about all of the nominated medical professionals for the VF’s V-RED 2018 Award. The stories will be shared on the VF’s website and in future newsletters, and distributed to the physicians’ medical institutions and professional societies.

On June 3, an intrepid group of about 50 family and friends braved the elements for the 16th Annual W.NJ/E.PA Vasculitis Walk held in Media, Pennsylvania.

Center: Brook Hickle and her husband, Keith, sponsored their third annual VF fundraiser, a Spaghetti Western Dinner on May 19, at Neuwaukum Grange Hall in Auburn, Washington. The event raised over $15,000 with proceeds going to support the Vasculitis Foundation.
The VPPRN Rising Above Expectations
by Kalen Young, Network Manager, Vasculitis Patient-Powered Research Network

The Impact of Participation
Thank you for your support and participation with the Vasculitis Patient-Powered Research Network! 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. Every participant in the VPPRN helps to make our data become stronger and our community becomes healthier.

Collaborating To Find Answers
The VPPRN 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 overtime. Collecting patient data over time helps us better understand vasculitis and how to combat these diseases.

Your Impact
Each and every participant in the VPPRN makes an impact. The more people that enroll and complete all of the questionnaires, the more we learn about the vasculitides and the greater our impression becomes on both our understanding of the disease and the lives of patients.

We are building a foundation for ongoing learning and a long-term impact on the care and health of patients with vasculitis. The strength and growth of our continued learning is dependent upon the participation of patients with vasculitis and the dedication to providing data to our Network on an ongoing basis.

Our Studies
What is a VPPRN Study?
To uphold a standard of scientific excellence that aligns with the Network’s commitment to patient-centered research, a VPPRN study must possess ALL the following characteristics:

1. Asks a research question that is important to people affected by vasculitis (patient-centered).
2. VPPRN studies must be scientifically meaningful as well as relevant and important to people affected by vasculitis.
3. Includes significant patient engagement in all aspects of the research.
4. “Patient engagement” refers to patients having meaningful participation throughout the research process, from topic selection to design, and conduct, and reporting of research.
5. Utilizes VPPRN and/or PCORnet resources in a meaningful manner.
6. For a study to be considered a VPPRN study, it must use one or more VPPRN and/or PCORnet resources.

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

VPPRN Studies Soon to Launch
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) domains.

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: VPPRN Studies in Development
In addition to our current list of VPPRN studies, we are in the process of reviewing and developing several more protocols. All VPPRN studies are patient-centered and are of importance to patients and physicians. We continue to
The VPPRN Rising Above, *cont.*

develop new ways to utilize our infrastructure to support novel research methods. Our research portfolio covers a wide range of research areas to help improve the lives of patients with vasculitis.

**Dreaming Big**
With over 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 VPPRN, 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 VPPRN but you want to contribute to a bigger dream and brighter future for patients with vasculitis, join us today!

It is free, online, and you can participate at your level of comfort. Every person that enrolls makes a difference. Do something today that you will be proud of tomorrow. **Dream Big!**

**Webinars You’ll Want To Watch**

The VPPRN team has spent the past year coordinating a special collaborative research group, PCORnet Autoimmune and Systemic Inflammatory Syndromes Collaborative Research Group (ASIS CRG). With our partners we have created a series of webinars for patients to learn about issues important to them.

- **Glucocorticoids (steroids): A love/hate relationship**
  Michael George, MD, University of Pennsylvania, October 2017
- **Pain Management-Opportunities and Challenges**
  William Becker, MD, Yale School of Medicine, December 2017
- **Is it possible to predict and prevent autoimmune conditions?**
  Kevin Deane, MD, University of Colorado at Denver, January 2018
- **Cardiovascular Disease Risk in RA: Can a Clinical Trial Discover What Helps?**
  Dan Solomon, MD, Harvard/BWH, February 2018
- **Pregnancy and Family Planning Concerns of Women with Autoimmune Conditions**
  Megan Clowse, MD, Duke, March 2018
- **Patient Health Data and Record Linkage**
  Hye-Chung Kum, PhD, Associate Professor at Texas A&M University, April 2018
- **Gout: Fact Versus Fiction. Clearing Up Misconceptions About this Treatable Chronic Condition**
  Theodore Fields, MD, Hospital of Special Surgery (HSS), May 2018

Click here to access the webinars: [https://goo.gl/dTvsn7](https://goo.gl/dTvsn7)
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 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/)

**TAPIR Trial Recruiting Patients**

The Assessment of Prednisone in Remission (TAPIR) Trial has recently expanded its eligibility criteria to enroll patients that have recently taken or are currently taking Rituximab.

What we are studying:

The TAPIR trial is a clinical trial for patients with GPA in remission-individuals who had a reduced number of symptoms or no change in GPA symptoms.

Is it more beneficial for patients with GPA to maintain low-dose prednisone intake during remission versus eliminating prednisone intake altogether?

TAPIR aims to find the answer to this question and ultimately establish the most favorable treatment option for patients with GPA in remission.

You can participate in the TAPIR Trial if ...

1. You have been diagnosed with granulomatosis with polyangiitis (GPA, also known as Wegener’s granulomatosis)
2. You have needed to take 20 mg or more of prednisone each day at some point in the last 12 months
3. Your current prednisone dose is between 5-20 mg/day
4. You are at least 18 years of age
5. Your treating physician is based in the United States or you can travel to a VCRC Clinical Center

*Other conditions may apply

How to join the TAPIR trial:

1. You can participate from the privacy of your own home.
2. You do not have to be seen at a participating medical center to enroll in this study. You can join online and continue to see your own doctor. If you already receive your care from a participating VCRC clinical center, you can talk to your doctor about participating in TAPIR.

Visit [www.TAPIRTrial.org](http://www.TAPIRTrial.org)
May and June 2018 Donors

Thank you for your gift of $50 or More!

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Kansas City, Missouri
919.684.2965

Allen, Nancy B., M.D.
Duke University
Rheumatology/Immunology
Durham, North Carolina
919.684.2965

Benseler, Susanne, M.D., MSc, Ph.D.
Alberta Children’s Hospital
Rheumatology, Department of Paediatrics
Calgary, Alberta, Canada
403.955.2253

Bradley, Elizabeth A., M.D.
Mayo Clinic - Ophthalmology
Rochester, Minnesota
507.284.8538

Brant, Elizabeth J., M.D.
Nephrology and Hypertension
Dartmouth-Hitchcock Medical Center
Lebanon, New Hampshire
603.653.3830

Byram, Kevin, M.D.
Vanderbilt University
Rheumatology & Immunology
Nashville, Tennessee
615.322.4746

Cacoub, Patrice, M.D.
Istituto Nazionale Di Neurologia E Neurochirurgia
Rome, Italy
39.06.26.66.00

Carette, Simon, M.D., MSc., Ph.D.
Mount Sinai Hospital
Division of Rheumatology
Toronto, Ontario, Canada
416.603.6751

Chen, Sarah, M.D.
University of California - San Francisco
Division Of Rheumatology
San Francisco
415.514.1673

Cid, Maria C., M.D.
Hospital Clinic
Barcelona, Spain
34.93.227.5774

Dooley, Mary Anne, M.D.
WakeMed Rheumatology
Raleigh, North Carolina
919.235.6454

Falk, Ronald J., M.D.
University of North Carolina
Nephrology/Hypertension
Chapel Hill, North Carolina
919.966.4617

Fernandez, Fernando, M.D., Ph.D.
Mayo Clinic - Nephrology
Rochester, Minnesota
507.266.7083

Ferrandez-Suarez, Luis Felipe, M.D.
Instituto Nacional De Enfermedades Respiratorias
Tlapan, Mexico
52.55.5536.3702
52.55.5536.5777

Forbes, Lindsay, M.D., MSc.
Rheumatology
CEDARS-SINAI MEDICAL CENTER
Los Angeles, CA
310.854.3539

Garrity, James A., M.D.
Mayo Clinic - Ophthalmology
Rochester, Minnesota
507.284.8538

Geetha, Duvuru, M.D., MRCP.
The Johns Hopkins University
Vasculitis Center
Baltimore, Maryland
410.550.6825

Gokcen, James A., M.D.
University of Iowa
Pathology
Iowa City, Iowa
319.356.1966

Gota, Carmen E., M.D.
Department of Rheumatology
Cleveland Clinic - Center for Vasculitis Care and Research
Cleveland, Ohio
866.275.7496

Grayson, Peter, M.D., MSc.
National Institute of Arthritis and Musculoskeletal and Skin Diseases
Bethesda, Maryland
301.496.4560

Gross, Wolfgang L., M.D., Ph.D.
University of Lübeck
Dept. of Rheumatology
Bad Bramstedt, Lübeck, Germany
507.266.4439

Hashkes, Philip J., M.D., MSc.
Shaare Zedek Medical Center
Pediatric Rheumatology Unit
Jerusalem, Israel
972.2.6626624

Heeringa, Peter, Ph.D.
Department of Pathology
Mayo Clinic - Nephrology and Medical Biology
University Medical Center Groningen, The Netherlands
31.50.3610789

Hellman, David, M.D., MACP.
The Johns Hopkins University
Dept. of Medicine
Baltimore, Maryland
410.550.0516

Hoffman, Gary S., M.D., MS., M.A.C.R.
Professor Emeritus
Cleveland Clinic Lerner College of Medicine
Center for Vasculitis Care and Research
Cleveland, Ohio

Jayne, David, M.D.
Renal Unit
Addenbrooke's Hospital
Cambridge, United Kingdom
44.1223.586796

Kermani, Tanaz, M.D.
Division of Rheumatology
UCLA Medical Center
Santa Monica, California
310.582.6350

Khansin, Atul, M.D., MS.
Piedmont Peachtree City
Rheumatology
Peachtree City, Georgia
770.506.1400

Koenig, David, M.D.
University of Utah
Division of Rheumatology
Salt Lake City, Utah
801.581.4333

Koster, Matthew J., M.D.
Mayo Clinic
Rheumatology
507.266.4439

Langford, Carol A., M.D., MHS.
Cleveland Clinic - Center for Vasculitis Care and Research
Cleveland, Ohio
216.445.6056

Lebovics, Robert S., M.D., FACS.
Otolaryngology/Head & Neck Surgery
New York, New York
212.262.4444

Lee, Augustine S., M.D.
Mayo Clinic
Pulmonary and Critical Care
Jacksonville, Florida
904.953.2000

Levine, Stuart, M.D.
MedStar Harbor Hospital
Baltimore, Maryland
410.350.3483

Lorenz, Robert R., M.D.
Head & Neck Institute
Cleveland Clinic Main Campus
216.444.3006

Mahr, Alfred, M.D., Ph.D.
Department of Internal Medicine
Hospital Saint Louis
Paris, France
33.142499780

Maksimovicz-McKinnon, Kathleen, D.O.
Rheumatology
Henry Ford Medical Group
West Bloomfield, Michigan
313.916.2631

Matteson, Eric L., M.D.
Mayo Clinic (Retired)
Rheumatology
Rochester, Minnesota

Maz, Mehrdad, M.D.
Allergy, Clinical Immunology and Rheumatology
KU Medical Center
913.588.6009

McDonald, Thomas J., M.D., MS.
FA.C.S. (Retired)
Mayo Clinic
Otorhinolaryngology
Rochester, Minnesota

Merkel, Peter A., M.D., MPH.
Division of Rheumatology
University of Pennsylvania
215.614.4401

Molloy, Eamon, M.D., M.S., FRCPI.
Department of Rheumatology
St. Vincent’s University Hospital
Dublin, Ireland
353.1221.3142

Monach, Paul, M.D., Ph.D.
Boston University Vasculitis Center
Boston, Massachusetts
617.414.2501
Ghostbuster’s Daughter: Life with My Dad, Harold Ramis

When Harold Ramis passed away from vasculitis on February 24, 2014, the prolific Hollywood actor/writer/director left behind a legacy of classic film comedies such as Ground Hog Day, Stripes, and Ghostbusters.

His passing was also felt by his daughter, Violet Ramis Stiel, who details growing up with her famous father in a new book “Ghostbuster’s Daughter: Life with My Dad, Harold Ramis” from Random House.

Although his diagnosis and treatment of vasculitis comprises only a few pages in the final chapters, Violet captures how the experience of trying to manage a rare disease impacts not only the patient, but loved ones, too.

The book is available on Amazon.com at https://amzn.to/2L9841d
I Am Pleased To Support The Vasculitis Foundation Through My Membership Dues.

**DUES:**  
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* This gift is:  
  - ____ In memory of  
  - ____ In honor of  
  - ____ A Gift Membership for

Name: ____________________________________________

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Mail to: Vasculitis Foundation, P.O. Box 28660, Kansas City, MO 64188

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**ARAMIS, cont.**

**About this Study**

About 90 people with skin vasculitis will take part in this study. If you take part in this study, you will be asked to complete a minimum of 6 study visits at the study site. The number of visits will depend upon which stage you enroll into the study and how your skin vasculitis responds to the treatments. You may be in this study for up to 18 months.

In order to participate in a study, you must personally contact the study coordinator of any of the participating institutions by phone or by e-mail. Please use the information below to inquire about participation.

- University of Pennsylvania, Philadelphia  
  - Study Coordinator: Christopher Snider, MPH christopher.snider@uphs.upenn.edu  
  - Phone: 215.662.6597  
  - Source:  [www.rarediseasesnetwork.org/cms/vcrc/Research/Studies/5562](www.rarediseasesnetwork.org/cms/vcrc/Research/Studies/5562)

**The ARAMIS study site list includes:**

- University of Kansas Medical Center, Kansas City  
- Boston University School of Medicine, Boston  
- Mayo Clinic, Rochester  
- Hospital for Special Surgery, New York City  
- Northwell Health, Lake Success  
- Cleveland Clinic, Cleveland  
- Oregon Health & Science University, Portland  
- Penn State Hershey Medical Center, Hershey  
- University of Pennsylvania, Philadelphia  
- University of Utah, Salt Lake City  
  - Canada:  
  - St. Joseph’s Healthcare, Hamilton  
  - University of Toronto Mount Sinai Hospital, Toronto
**BE THE BEST-DRESSED PERSON AT THE BEACH (AND EVERYWHERE ELSE) THIS SUMMER!**

Look sharp, feel cool and support the VF while making a bold statement in your summertime VF gear!

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<th>Item</th>
<th>Description</th>
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<tbody>
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<td>VF logo on front, Dream Big! on back. Unisex.</td>
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<tr>
<td>VF Tote Bag</td>
<td>A durable carry-all to take anywhere!</td>
</tr>
<tr>
<td>Team Brandon T-Shirt</td>
<td>In grey or red.</td>
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These and many other cool summer items, now available at [www.VFWebStore.com](http://www.VFWebStore.com)!

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**Need a little Warm-Up?**

Deep discounts on cool weather gear are now available in the VF Web Store!

**Jackets, hoodies, fleece, caps, and more!**

Save big while supporting the VF!
VF Calendar of Events • 2018 - 2019

August 4, 2018
KU Regional Vasculitis Conference
▷ 9:30 a.m. - 2:30 p.m.
▷ BEST Conference Center, Room 125
    University of Kansas Edwards Campus,
    12600 Quivira Road, Overland Park, KS 66213

August 25, 2018
Nick Pascente Memorial Golf Tournament
▷ Prairie Isle Golf Course
    Crystal Lake, Illinois
▷ Organizer: Craig Alshouse, 815.980.9870
calshouse10@yahoo.com

September 10, 2018
Sacramento Chapter Meeting
▷ 6:00 p.m. - 7:00 p.m.
▷ Hofbrau Restaurant, 2500 Watt Ave., Sacramento, CA
▷ For more information contact:
    Hedy Govenar, HGovenar@govadv.com

October 12, 2018
VF Annual Membership Meeting
▷ Chicago, Illinois.
▷ vf@VasculitisFoundation.org

November 10, 2018
VF Patient Educational Conference
▷ UCLA - Santa Monica

January 12, 2019
VF - University of Washington Patient & Family Vasculitis Conference
▷ Seattle, Washington

March 9, 2019
VF - Mayo Clinic Patient & Family Vasculitis Conference
▷ Scottsdale, Arizona

May 14, 2019
VF - Cleveland Clinic 1/2 Day Vasculitis Conference (TENTATIVE)
▷ Cleveland, Ohio

July 19-21, 2019
VF International Vasculitis Symposium
▷ In partnership with the Mayo Clinic and University of Minnesota
    Hyatt Regency, Mall of America
    Bloomington, Minnesota