VF Congratulates 2019 V-RED Winners, Program Participation Soars in 6th Year

By Ed Becker
Director of Marketing & Communications

Two winners tied for first place and another received an honorable mention in the Vasculitis Foundation’s 2019 Recognizing Excellence in Diagnostics (V-RED) award program. With more nominations than ever before, the program, now in its 6th year, has grown into a powerful campaign that raises awareness about early diagnosis.

Mark Anderson, MD, an internist from Maitland, Florida, and Gwendolyn Shelton, MD, a pediatrician from Berlin, Vermont, shared the top honor. Honorable mention was awarded to Andrew Lee, MD, a neurologist in Kent Town, South Australia.

The V-RED program calls on patients worldwide to nominate a medical professional they want to recognize for making a critical, early diagnosis of vasculitis—thus enabling timely treatment, and potentially sparing permanent and ongoing health complications.

Karen Hirsch, past-president of the VF Board of Directors, is particularly encouraged by the program’s success. After her son, Michael, received an early diagnosis of vasculitis, Hirsch created the award to bring special recognition to medical professionals in a broad range of clinical specialties. She believes the award increases awareness among medical peers.

Continued on page 3

Early VF-Funded Study Paves Way for New ANCA Vasculitis Clinical Trial

By Sharon DeBusk

More than a decade ago, Donna O’Dell Bunch, PhD, was co-investigator in a VF-funded research study at the University of North Carolina (UNC) that examined changes in B cells (white blood cells that form antibodies) in patients with ANCA-associated vasculitis.

The findings from that 2007 study, and data gathered since, have led to an important new clinical trial on ANCA vasculitis that launched at UNC in May.

Continued on page 10

VF Newsletter Survey: We Need Your Feedback!

Are you an avid reader of the VF newsletter? Or even an occasional reader? If so, we want your opinion!

We are conducting a readership survey and hope you’ll participate! Your feedback will help us improve our newsletter and ensure that you are getting the information you need and want, in the format you prefer.

Please complete the online survey at https://www.surveymonkey.com/r/VFNL2019.
Responses are due July 31. We appreciate your participation!
Welcome to the July/August edition of the VF Newsletter! Whether you’re holding the print version or reading the newsletter on your computer or mobile device, we want your feedback!

For more than two decades, the VF has published a newsletter for the vasculitis community, and it remains an important membership benefit. In an effort to keep our newsletter fresh, relevant, and informative, we are conducting a readership survey. We want to know what you think! What types of articles do you like to read most? Please take a few moments to complete the survey, at https://www.surveymonkey.com/r/VFNL2019. We appreciate your feedback!

Thank you for stepping up to the plate during 2019 Vasculitis Awareness Month (VAM)! You responded to our annual call to action by sharing our social media messages, telling your stories online, ordering and distributing brochures, and supporting our Spring Appeal campaign.

In this issue, we congratulate the winners of the 2019 Recognizing Excellence in Diagnostics (V-RED) award. The V-RED program calls on patients worldwide to nominate a medical professional they want to recognize for making a critical, early diagnosis of vasculitis.

In research news, we feature a new clinical trial being conducted by co-investigator Donna O’Dell Bunch, PhD, along with a research team at University of North Carolina, on ANCA vasculitis. Of note, the findings of a VF-funded research project in 2007, and other data gathered since, formed the foundation of this clinical study.

We also profile Sebastian E. Sattui, recipient of the 2019 VCRC-VF Fellowship Award, a partnership of the Vasculitis Clinical Research Consortium (VCRC) and the Vasculitis Foundation. During his two-year fellowship, Dr. Sattui will conduct two different vasculitis studies at the Hospital for Special Surgery in New York City.

Finally, we hope to see you at the 2019 International Vasculitis Symposium in Bloomington-Minneapolis, Minnesota, July 19-21. Look for coverage of the symposium in the September/October issue!

Sincerely,

Joyce A. Kullman
Executive Director
2019 V-RED Award Winners, cont.

“We have seen many times over that a colleague of one of the previous winners goes on to make a diagnosis themselves,” said Hirsch. “When we honor a medical professional with this award, it helps to spread awareness throughout the whole medical community. It puts the disease on the radar of colleagues, patients, and even specialty medical associations.”

The program has seen a two-fold increase in patient-submitted V-RED nominations since it started in 2014. That year, the VF received 40 nominations; this year, a record-breaking 92. And that is only one of this year’s firsts. Two winners were chosen to share top honors. The VF also recognized a doctor in Australia—the first time an international physician was chosen.

The three winning medical professionals are personally presented with the award by the patient who nominated them. All of the other nominated physicians will be given a special certificate of appreciation from the VF.

For more information on the V-RED award program, please visit https://www.vasculitisfoundation.org/2018-v-red-award-winners-announced/.

First Place Winner: Mark Anderson, MD
Nancy Anderson’s experience with trying to get a diagnosis began in a way that is familiar to many vasculitis patients. However, it is a remarkable, ironic twist that makes her story stand apart.

Nancy’s early, nonspecific symptoms led to multiple visits with specialists who misdiagnosed the underlying condition. As her condition worsened, one doctor, in particular, was determined to get some answers—her husband, Mark Anderson, MD, who is board-certified in internal medicine and anesthesiology.

“When Nancy’s peripheral neuropathy (numbness and tingling) spread from her feet to her hands, I knew this was something very serious,” said Mark. “I also knew her doctors were missing the core issue when they suggested it was just arthritis or fatigue.”

Fortunately, he had some knowledge of vasculitis from treating patients with giant cell arteritis (GCA), so he knew what lab tests needed to be ordered for Nancy. When her ANCA test came back significantly elevated, they immediately contacted John Stone, MD, a vasculitis specialist at Massachusetts General Hospital, Boston, where Nancy was diagnosed with granulomatosis with polyangiitis (GPA/formerly Wegener’s) and treated with rituximab (Rituxan®).

“I feel so fortunate that my husband intervened when all of my other doctors were misdiagnosing, or not taking my condition seriously,” said Nancy. “His research and gut instinct ultimately prevented the vasculitis from becoming worse.”

First Place Winner: Gwendolyn Shelton, MD
If you are a patient, searching Google for disease symptoms can be a misleading and scary prospect. Your doctor might even give you a stern lecture about not using the internet to self-diagnose. However, in Meaghan Carpenter’s case, she’s thankful her doctor used Google to find clues that eventually led to her diagnosis of vasculitis.

In March 2008, during her freshman year in high school, Carpenter began exhibiting peripheral neuropathy in her legs, in addition to chronic asthma and allergy issues that didn’t appear to have any common thread. Eventually, Carpenter’s pain grew worse, and she was admitted to the pediatric ward at Presbyterian Hospital in Albuquerque, New Mexico. Doctors controlled her pain with morphine, but they were unable to “connect the dots” to pinpoint the diagnosis.

Fortunately, Gwendolyn (Lattimore) Shelton, MD, was a hospitalist on her medical team who felt Carpenter’s case needed more in-depth investigation. When none of the potential diagnoses in the hospital’s computer produced any leads, she searched Google for clues with more success. A website suggested Churg-Strauss syndrome, now called eosinophilic granulomatosis with polyangiitis (EGPA).

Dr. Shelton contacted one of her former residency supervisors (Wilmer Sibbitt, MD, who later became Carpenter’s first rheumatologist) for advice, and he agreed with her
conclusions. With her diagnosis, the doctors at Presbyterian Hospital were able to begin treatment early enough to prevent her vasculitis from progressing and causing more systemic damage.

“Dr. Shelton looked outside the box, took my case home with her, and saved me years of potential misdiagnosis,” said Carpenter. “Thanks to her investigation, my disease was identified and brought under control. I’ve been able to live an almost normal life. I’ll never forget what she did for me.”

Honorable Mention: Andrew Lee, MD

Carmen Haule Reaiche is enjoying life in remission. She has returned to teaching full time and is happily raising her 15-year-old daughter, Celina. However, she remembers when a series of strokes, at age 42, threatened to derail her life forever. Reaiche credits her comeback to Andrew Lee, MD, a neurologist in Kent Town, South Australia.

Her first stroke occurred in 2012. When she awoke, Reaiche was unable to speak or walk. She was examined by specialists at a local hospital, St. Andrew’s, Adelaide, who treated her for stroke. After a few days, she was released from the hospital. Unfortunately, several smaller strokes followed, and her doctors had no idea why they were happening with such frequency, or to someone who usually would not be at risk.

Reaiche was referred by a friend to Dr. Lee. Reaiche said Lee was as perplexed as the other doctors about the underlying reason, but there was one difference that set him apart from the other specialists. “He never accepted the idea that I would simply have to live in this condition,” said Reaiche. “Dr. Lee followed his gut feelings, and he ordered a series of tests that finally produced a diagnosis of cerebral vasculitis.”

Reaiche is now enjoying a life free from harsh medications and debilitating symptoms.

“Early diagnosis made a difference to my life in many ways,” said Reaiche. “It allowed me to grow stronger and to recover. I am back to work, and even though I am not at 100 percent, I am alive. I am also able to be here for my only daughter when she has needed me the most, as she lost her father to cancer. I am functioning the best I can.”

2019 International Vasculitis Symposium—July 19-21

Don’t Miss Out! Last Chance to Register for the Symposium is July 13!

Please join us for the 2019 International Vasculitis Symposium! Hundreds of patients and their families, vasculitis medical experts and researchers will converge in Bloomington-Minneapolis, Minnesota, for a weekend of education, entertainment, and fellowship. Don’t wait! Register today!

Registration
» $240/person
» Deadline: July 13, 2019
» Pre-registration required
» To register online visit: https://bit.ly/2UBwLVc

Symposium Headquarters
» Hyatt-Regency
  3200 E. 81st Street
  Bloomington, Minnesota
Dr. Sebastian E. Sattui Receives 2019 VCRC-VF Fellowship Award

By Sharon DeBusk

It was during a medical clerkship that Sebastian Sattui, MD, first recognized the complexity of vasculitis, and the profound impact the disease has on patients’ lives.

He had encountered a patient with EGPA (eosinophilic granulomatosis with polyangiitis) for the first time. “I will always remember the patient’s long list of symptoms, the medical mystery he had represented so far, and the certainty with which the attending rheumatologist made the diagnosis, just after listening to the patient and checking his chart,” recalled Dr. Sattui, a rheumatology fellow at the Hospital for Special Surgery in New York City.

That and other early experiences sparked an interest in vasculitis that has fueled Dr. Sattui’s medical career and the research he will conduct as the recipient of the 2019 VCRC-VF Fellowship Award.

The Vasculitis Clinical Research Consortium (VCRC)-Vasculitis Foundation (VF) Fellowship is a mentored training program of up to two years for physician-investigators who have a strong interest in vasculitis and wish to pursue specialized training in patient-oriented clinical investigation.

The VF contributes $50,000 in matching funds to the fellowship, made possible through donors and proceeds from the annual Chicagoland Vasculitis Golf Tournament. Organized by now-retired VF board member Jeffrey Fishbein, PsyD, and his extended family, the event has raised more than $500,000 since 2014, with proceeds going to the VCRC-VF Fellowship Program (and to the opening of the Vasculitis Clinical Research Program at Northwestern University, Illinois, three years ago).

“The VCRC-VF is an important fellowship program that has enabled young and talented physicians to train in the area of vasculitis,” said Dr. Fishbein. “The tournament has been a proud supporter of this program since we began this event five years ago.”

During the two-year fellowship, which begins in July 2019, Dr. Sattui will continue work on two research projects. The first project is analyzing the prevalence and impact of frailty in patients with polymyalgia rheumatica (PMR) and giant cell arteritis (GCA), which often strike people over the age of 50.

“Frailty is a process that can affect our ability to bounce back after an illness or other stressful events, such as a fall or an infection, as well as our ability to live independently,” said Dr. Sattui. “I think frailty is an unexplored outcome that needs to be further studied in PMR and GCA patients, since it can impact both quality of life and clinical outcomes.”

Dr. Sattui’s second project involves assessing a new biomarker, mitochondrial DNA, as a measure of disease activity in patients with ANCA vasculitis. (Mitochondrial DNA is a genetic material that when detected in the blood, can be used as a marker of inflammation.)

“We already have a small pilot study where we have shown some differences in the levels of this biomarker in patients with active disease and remission.” During the fellowship, Dr. Sattui will explore the potential clinical use of this biomarker, with the goal of potentially identifying changes in disease activity prior to symptoms and allowing prompt treatment.

Dr. Sattui expressed gratitude for the Fellowship, to his mentor Robert Spiera, MD, his sponsoring institution, the Hospital for Special Surgery (HSS), and the HSS Vasculitis, Scleroderma and Myositis Center, where the fellowship will take place.

“The Vasculitis Foundation is a unique and exemplary organization that not only empowers patients, but also gives them the opportunity to influence and change the landscape of medical care,” said Dr. Sattui. “The VCRC-VF fellowship is a great example of that, where the foundation is supporting a physician who shares the objectives of the VF.”

Dr. Spiera is excited about the prospect of Dr. Sattui focusing on vasculitis over the next two years as a VCRC-VF fellow.

“In addition to further developing clinical expertise in the care of these disorders, he has already initiated a number of studies hoping to better define frailty in patients with vasculitis and polymyalgia rheumatica,” said Dr. Spiera. “Frailty is an area that is increasingly recognized as important to patients’ well-being, but to date, not adequately studied in these diseases.”

**Sebastian E. Sattui, MD**
Rheumatology fellow, Hospital for Special Surgery, Weill-Cornell Medicine, NY, New York
**Medical degree:** Cayetano Heredia University in Lima, Peru (2012)
**Internship/residency:** University of Alabama at Birmingham (2014-2017)
**Board-certified rheumatologist:** Eligible (Taking boards in 2020)
**Current status:** In post-graduate year 5 (PGY-5); currently completing two years of ACGME-accredited rheumatology fellowship; VCRC-VF fellowship starting in July 2019 (PGY years 6 and 7)
Community Rallies to Support Vasculitis Awareness Month 2019

The Vasculitis Foundation thanks everyone who stepped up to the plate to make Vasculitis Awareness Month (VAM) 2019 a resounding success this year.

Joyce Kullman, executive director of the VF, said the campaign, which ran the month of May, was a success for several reasons.

“We always challenge and encourage our community to help us spread the word about the impact of vasculitis to friends, family, and coworkers. Once again, they responded to our call to action by sharing out hundreds of our social media messages, ordering and distributing brochures, sharing their own stories online, and especially through supporting our Spring Appeal campaign,” said Kullman.

As part of VAM 2019, the VF offered a $15K Matching Gift Campaign so every donation was matched dollar-for-dollar up to $15,000. Beth Westbrook, VF director of development, said the $15K Matching Gift Campaign goal was met, and the contributions from VAM rolled into the Spring Appeal fundraising campaign.

“As it always does, the vasculitis community came together again to raise both awareness of the disease, and to support the VF’s mission of funding research, and developing more resources such as our website, brochures, and regional conferences,” said Westbrook.

Here are just a few of the ways that individuals raised awareness during VAM 2019:

Beth Howe, leader of the Behcet’s Disease Facebook Group, raised awareness through a radio broadcast on 95.9 The River, in Aurora, Illinois.

Kate Tierney shared her story about being diagnosed with EGPA in 2000, through a daily posting on Facebook during the month of May.

Sorab Tayal, from Punjab, India, shared his VAM 2019 selfie across the world on social media.

Employees of ChemoCentryx gathered to celebrate Vasculitis Awareness Month 2019. The Mt. View, Calif.-based biopharmaceutical company supports the vasculitis community in searching for novel therapies to address the unmet needs of patients with ANCA-associated vasculitis.
Wrangling Support for the VF with Spaghetti Western Dinner

This spring, Keith and Brook Hickle once again hosted a Western-themed VF fundraiser in a small grange hall just down the road from their ranch in Auburn, Washington. On May 18, they welcomed about 175 guests to their 4th Annual Rocking Bar H Spaghetti Western Dinner, which raised nearly $22,000 the night of the event.

Keith and Brook Hickle

Brook Hickle said their fundraiser is a way to support the VF because the organization paved the way for Keith to be seen by Ulrich Specks, MD, at the Mayo Clinic in Rochester, Minnesota.

“Dr. Specks put Keith on a new treatment plan that included rituximab (Rituxan®), which was approved by the Food and Drug Administration as a treatment for GPA/Wegener’s the same month as his diagnosis,” said Hickle. “Keith has continued to remain in good health under the ongoing care of Dr. Specks. By holding this event, we can provide financial support to the VF, as well as helping to raise awareness about this rare family of diseases.”

Trivia Night Fundraiser Brings in Donations, New Members to VF

This spring, Tony and Kelly Calabria held their 3rd annual VF Fundraiser at their home in Raleigh, North Carolina. This year’s event was themed: “Around the World Trivia Night,” where more than 60 guests dressed in traditional attire, from eight selected countries, participated in a live trivia competition. Their event, held May 10, raised approximately $2,000 as the guests became members of the Vasculitis Foundation.

Tony and Kelly Calabria

Tony Calabria said their event is a true celebration of life because he knows how a disease like vasculitis can quickly and dramatically affect one’s health.

He was diagnosed in 2017 with ANCA vasculitis and was subsequently treated at University of North Carolina-Chapel Hill. The experience prompted him to raise awareness about the disease and inform people about the Vasculitis Foundation.

Tony Calabria

“The fundraiser is for a serious reason, but we want to mix in some fun, too. It’s a great way for family and friends to get together and celebrate the positive outcome,” said Calabria.
Planned Gift Can Be Legacy for the Vasculitis Community

By Beth Westbrook
VF Director of Development

Early in my development career, I met Sam. He was an older gentleman who contacted the nonprofit organization where I worked at the time. Sam was a bachelor who had worked hard in a government job his entire career, and he had a generous proposal. He wanted to donate his home after he passed away.

We went to lunch to get to know each other, and at the end of our lunch, we made a date for me to visit his home. What I found was a modest two-bedroom brick house full of Sam’s history. He loved his home. Sam and I stayed in touch over the next couple of years and when he passed away, the nonprofit received the home, as outlined in his will. His home in Washington, DC, netted more than $400,000 for the organization. Sam’s legacy was a planned gift.

In my role as director of development for the VF, I am often asked, “What is a planned gift?” One example is what Sam gave—a gift left in a will or trust. It doesn’t have to be your home; you decide what you wish to leave.

Here is how planned giving is described by DonorSearch: “Planned Giving is the process of donating planned gifts. A planned gift is a contribution that is arranged in the present and allocated at a future date. Commonly donated through a will or trust, planned gifts are most often granted once the donor passes away.”

The VF continues to fund promising research, share the news about new treatments and expand our education and awareness efforts, with an eye toward earlier diagnosis. A planned gift is one of many choices a donor can make to help the VF fulfill its mission. When you decide on a planned gift, it is a legacy for the future. It is a promise to the patient community you will be there to help them after you are gone.

In the upcoming months, I will share other ways to make a planned gift. To learn more about this topic, and additional ways to give, please contact the VF. Together we will work toward positive change for the vasculitis community.

Thank you for joining our journey.

Beth

Last Chance to Register for the 2019 CME Conference on Vasculitis!

Register by July 17, 2019

For Medical Professionals

July 20, 2019
Hyatt Regency Bloomington - Minneapolis
3200 E. 81st Street
Bloomington, Minneapolis 55425

Register by July 17, 2019
For more information and to register: https://mayo.in/2F7fvl6

Jointly sponsored by the Vasculitis Foundation and the Mayo Clinic.
Living with Kawasaki Disease Brings Out Strength, Hope and Resilience

By Ed Becker

For Nicol Jackson, one particular incident stands out as a stark reminder of how rarely some doctors ever see a patient with vasculitis. Her 5-year-old son, Josh, who was being treated for Kawasaki disease, experienced severe chest pains. Nicol and her husband, Rob, rushed him to the emergency room at a hospital in London, Ontario, Canada, to be seen by their cardiologist.

“When we arrived at London Health Sciences Centre, we were swarmed by more than 20 nurses, doctors, and interns. All of them wanted to see ‘the child with Kawasaki disease.’ That made us realize we were dealing with a very rare condition,” recalled Nicol Jackson.

Josh’s first symptoms appeared as high fever, swollen, sore joints, bloodshot eyes, and peeling lips. Initially, Josh was treated for an ear infection, but it soon became apparent that something much more serious was happening. It was during Josh’s 5th birthday party they realized his condition was worsening, so he was taken back to their doctor, who on closer evaluation suspected Kawasaki disease. The visit was followed by an exam with a pediatrician who then confirmed the diagnosis.

Josh began treatment with intravenous immunoglobulin (IVIG), but he experienced a life-threatening allergic reaction. “As I watched the doctor and nurse try to revive my 5-year-old son’s limp body, I decided I would learn as much as I could about Kawasaki disease, and to make sure everyone I knew, and those I didn’t know, were educated about this disease,” said Jackson.

Months of treatment with prednisone and immunosuppressants left Josh susceptible to chronic infections, or bouts of pneumonia, making his ability to live a normal life virtually impossible. Over the last 14 years, he has lived with chronic pain and rashes common with Kawasaki disease. Since the disease affects the large arteries in the heart, a full cardio check-up is necessary every six months. However, Jackson said that Josh is resilient, and has a stoic mindset about his condition.

“When I look at Josh, I see his pain, but I also see a strong young man who has made good out of an illness,” said Jackson. “Kawasaki disease does not define Josh. But it sure has made one thing true—he is our hero.”

For more information about Kawasaki disease, please visit the VF’s Kawasaki disease page at: https://bit.ly/2QLDriL

Nicol Jackson is the founder and creator of a Facebook group called the Kawasaki Disease Support Group, which she moderates with her daughter, Maddy. The group has attracted more than 6,700 members. To request membership into the group, visit: https://bit.ly/2M7mros.
New ANCA Vasculitis Trial, cont.

We spoke with Dr. Bunch, assistant professor, Division of Nephrology and Hypertension, UNC School of Medicine, about both studies and how they will help patients with ANCA vasculitis.

**VF: Can you please describe your VF-funded study on B cells in 2007 and the key outcomes?**

**DB:** The VF grant was titled “ANCA Vasculitis: Autoimmune B Cell Dysregulation and its Clinical Impact.” Dr. Patrick Nachman, who was at UNC at that time (now at University of Minnesota), was the principal investigator, and I was co-investigator.

We hypothesized that patients with ANCA (anti-neutrophil cytoplasmic antibody) vasculitis have B-cell abnormalities that are associated with more severe disease and/or a higher frequency of relapse. We found that a special type of B cell called “CD5+” was decreased during active disease and returned to normal levels during remission. That finding fueled additional studies and has now led to the current clinical trial.

**VF: What are the goals of the new clinical trial?**

**DB:** Patients with ANCA vasculitis (GPA, MPA and EGPA) are routinely treated with immunosuppressants—medications that decrease their immune system function. The treatment lasts several months with an initial “induction” phase aimed at stopping the inflammation and a “maintenance” phase aimed at decreasing risk of relapse. The risk of relapse varies considerably between patients, and we believe that some patients have a relatively low risk of relapse and may not need continued maintenance immunosuppression.

The purpose of this research study is to learn if a special blood test can help us identify which patients could be closely monitored without additional immunosuppressive maintenance treatment during remission. By collecting health information and laboratory samples, our goal is to learn more about this disease and find better ways to tailor treatment of ANCA vasculitis to an individual’s needs.

**VF: How will the study be conducted?**

**DB:** Patients will be enrolled in this study after they have completed the initial phase of treatment for ANCA vasculitis and they are in remission. We will monitor patients’ blood for return of B cells, and treat according to whether the CD5+ B-cell levels are low or near normal, using the same medications they would receive if they were not participating in this trial. We believe that the number of these B cells can give us an indication of the risk of having a relapse of ANCA vasculitis in the future.

**VF: How is this study different from others on this subject?**

**DB:** This study is not testing new medications. Treatment will use the same medications that are routinely used for maintenance treatment in ANCA vasculitis. We’re testing whether some patients whose CD5+ B cells return to normal levels can be followed closely without receiving additional maintenance treatment.

**VF: How will this study help people with vasculitis?**

**DB:** We believe that by monitoring the CD5+ B-cell levels to guide decisions about immunosuppressive medication, we can better tailor treatment to each patient’s individual needs, avoid unnecessary treatment and potentially avoid relapse.

**VF: Do you have any concluding remarks?**

**DB:** I want to express my appreciation to the Vasculitis Foundation for funding our B-cell study over a decade ago. Those initial studies formed the foundation for our subsequent work that has led to this “proof of concept” trial.

I also want to thank all the VF members and the patients who contribute research blood samples—without their participation, there would be no research and no progress.

For more information on this trial, please visit: https://clinicaltrials.gov/ct2/show/NCT03906227?cond=ANCA+vasculitis&rank=4

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**Clinical study title:** “Tailoring Maintenance Therapy to Cluster of Differentiation 5 Positive (CD5+) Regulatory B Cell Recovery in ANCA Vasculitis”

**Funding:** National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK)

**Principal investigator:** Vimal Derebail, MD, University of North Carolina (UNC), Chapel Hill

**Co-investigators at UNC:** Donna O’Dell Bunch, PhD; Ronald Falk, MD; John Schmitz, PhD; Shannon Mahoney Murphy, MD; Koyal Jain, MD; Manish Saha, MD

**Study coordinators:** Anne Froment and Sandy Grubbs, MSN, RN

**Statistician:** Susan Hogan, PhD

**Sponsors/collaborators:** UNC, Chapel Hill, NIDDK

**Study location:** University of North Carolina, Chapel Hill

**Study timeframe:** May 2019-December 2022
NORD Launches New Program Aimed at Providing Caregivers with Relief

The National Organization for Rare Disorders (NORD), the leading independent nonprofit organization representing the 25 to 30 million Americans living with rare diseases, has launched the Rare Caregiver Respite Program, a first-of-its-kind program aimed at providing caregivers of rare disease patients a much-needed respite.

Initial funding for the program was donated by Retrophin, a biopharmaceutical company specializing in identifying, developing and delivering life-changing therapies to people living with rare disease, in honor of its former CEO Steve Aselage’s retirement from the company.

Caring for a loved one with a rare disease demands significant time, attention, patience and dedication. NORD’s Rare Caregiver Respite Program is designed to give back to caregivers—the parent, spouse, family member, or significant other—of a child or adult living with a rare disorder, and provides financial assistance to enable the caregiver a well-deserved break.

“At NORD, we are proud to have provided a variety of services and assistance to patients over the years,” said Jill Pollander, director of patient services for NORD. “The new Rare Caregiver Respite Program allows us to acknowledge the hard work that families and significant others do so tirelessly every day by enabling them some time away while ensuring their loved one is well cared for.”

Through the program, NORD will provide financial assistance to eligible caregivers covering up to $500 annually so that a respite caregiver may be secured to care for a loved one. Potential applicants can reach out to NORD to ascertain if they meet eligibility requirements. The grant may be dispersed throughout a calendar year or be used in a single award. Examples of what the NORD Rare Caregiver Respite Care Program financial assistance may cover include:

Registered Nurse (RN) care
Licensed Practical Nurse (LPN) care
Certified Nursing Assistant (CNA) / Nursing Assistant
Home Health Aide (HHA)

“Caregivers in the rare disease community spend a significant amount of time, effort, and resources helping their loved ones—and they rarely get to take a break,” said Eric Dube, PhD, chief executive officer of Retrophin.

For more information or to apply, please visit rarediseases.org.

New Video Playlist Features Vasculitis Presentations from Patient Conference

The Vasculitis Foundation recently debuted eight new videos on its VF YouTube Education Channel. These presentations were featured at the Phoenix Vasculitis Patient Conference in March.

The collection of videos are housed in this playlist: https://bit.ly/2EFOEfN

» Large Vessel Vasculitis
  Kenneth J. Warrington, MD

» Lung Involvement in Vasculitis
  Rodrigo Cartin-Ceba, MD

» Advances in Treatment of ANCA-Associated Vasculitis
  Ulrich Specks, MD

» Upper Airway Involvement in Vasculitis
  David G. Lott, MD

» Vasculitis Patient-Powered Research Network (VPPRN)
  Kalen Young, MA

» Patient Experience Story
  Suzanne DePaolis

» Kidney Involvement in Vasculitis
  Alicia Rodriguez-Pla, MD, PhD

» New Biologicals for Asthma Management
  Matthew A. Rank, MD

2019 Vasculitis Foundation Annual Membership Meeting

Sunday, July 21, 2019
7:30 – 8:30 a.m.
Hyatt-Regency
3200 E. 81st Street
Bloomington, Minnesota
Advisory List

Abou-Nabih, I., MD, PhD, FACP (Retired)
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Mount Sinai Hospital
Toronto, Ontario, Canada
416.586.4800 Ext. 8549

Carr, Jema, MD
Mayo Clinic
Pulmonary Medicine/Critical Care Medicine
Phoenix, Arizona
800.446.2279

Chonko, Arnold M., MD, FACP
Kansas University Medical Center, The University of Kansas Medical Center
Rheumatology and Hypertension
Kansas City, Kansas
913.588.6048

Chung, Sharon, MD, MAS
University of California San Francisco (USF) Health
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**IN MEMORIAM**

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

Christine Augustine  
Lois Coleman  
Ricky Coleman  
Christine Cox-Marinelli  
Constance Freimark  
Frank Hertz  
Dale Ihry  
Bruce Macdonald  
Donald Maroney  
Irene O’Flynn  
Ilya Peckerman  
Darlene Reich  
Julie Riger  
Lisa Gruben Seigler  
Harrison Whetzel
The Vasculitis Clinical Research Consortium (VCRC) is the major clinical research infrastructure in North America dedicated to the study of vasculitis. The VCRC has grown to include 18 academic medical centers in the United States and Canada conducting investigator-initiated clinical and translational research. The VCRC also partners with 50 other centers worldwide for the conduct of clinical trials.

The VCRC conducts observational cohort studies, biomarker development, studies of genetics and genomics, clinical outcomes research, studies using an online patient registry, pilot clinical projects, and multicentered, randomized clinical trials. Core components of the VCRC include the VCRC Clinical Data Repository, the VCRC Biospecimen Repository, the RDCRN VCRC Patient Contact Registry, the VCRC-NIH Data and Safety Monitoring Board.

Join the VCRC Contact Registry!

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

**Participating Institutions:**

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

Please visit the VCRC website to join the registry and to review the complete list of all current research studies available for patients to participate in. [www.rarediseasesnetwork.org/cms/vcrc/](http://www.rarediseasesnetwork.org/cms/vcrc/)
Sunday, July 21, 2019
Vasculitis Foundation Annual Membership Meeting
› Hyatt-Regency
   3200 E. 81st St.
   Bloomington, Minnesota  55425
› 7:30 a.m. - 8:30 a.m.

Saturday, August 24, 2019
The 3rd Annual Nick Pascente Memorial Golf Outing
› Prairie Isle Golf Club,
   2216 W State Road, Crystal Lake, IL 60014, USA
› Noon - 7 p.m.
› This year features 18 holes and a two-man scramble. Cost is $85 per person, which covers 18 holes, a golf cart and dinner. If you are just coming for the dinner, cost is $15.
› Contact: Craig Alshouse
calshouse1@yahoo.com
(815) 245-9848

September 21, 2019
14th Annual Celebrating A Life: Keesha Vessell Vasculitis Walk
› Newnan City Veteran's Park,
   38 Jackson St., Newnan, GA 30263
› Registration starts at 8 a.m., welcome at 8:30 a.m., and walk starts at 8:45 a.m.
› For more information: Diann Alford, diannrip12@aol.com