VF Research Program Funds Three New Studies in 2018

By Jason Springer, MD, MS
Chairman, Research Committee Vasculitis Foundation
VF Board of Directors

The VF is funding three new research studies in 2018. (Please see page 4 to learn more about the three VF-Funded studies)

Every year we get proposals for very high-quality research from investigators who have a wealth of experience. These three studies were chosen from a selection of 20 applications submitted by investigators world-wide.

Study Selection Promotes VF Commitment to Research
A panel of consultants made up of international vasculitis specialists reviews each research application. The consultants give each application a score, which is used by the Research Committee to make recommendations to the Board of Directors of the Vasculitis Foundation to determine which research will be funded. The VF Consultants, Research Committee and the Board of Directors all volunteer their time to make this process happen successfully. We want to thank all those who volunteered their time for this year’s review.

To date, the Vasculitis Foundation has funded more than $2.5 million dollars for 49 individual research studies including the three funded this year. It is amazing to see how much vasculitis research has grown. We would like to thank all the researchers for their dedication to understanding these devastating diseases.

Your Donations Fuel VF-Funded Vasculitis Research
In 2017 we saw exciting developments in vasculitis which are a direct result of generous funding to VF research. In 2009, the Vasculitis Foundation funded $99,738.00 for two years to the Diagnostic and Classification Criteria in Vasculitis (DCVAS) study. This is the largest study done in vasculitis including centers throughout the world. As a result of their work, the DCVAS group presented a new set of classification criteria for ANCA-associated vasculitis in November 2017 at the American College of Rheumatology Annual Meeting. These criteria will be critical for use in future research studies.

Also in 2017, the Vasculitis Foundation provided funding to A Randomized Multicenter Study for Isolated Skin Vasculitis (ARAMIS). This is the first randomized clinical trial to compare treatment options for skin limited vasculitis. The study is now recruiting at multiple vasculitis centers across North America.

Additionally, during 2017, the Vasculitis Patient-Powered Network (V-PPRN) provided the structure to support multiple studies including JOURNEY, V-PREG, VascWork and AAV-PRO.

We want to thank everyone who has enrolled, and participated, in the V-PPRN. We encourage everyone else to join at https://bit.ly/2Un3rV.

This is an exciting era in vasculitis research. Many advancements in vasculitis research have been a result of funding provided by the Vasculitis Foundation. We are grateful for our many generous donors who have made this a reality.
Dear Friends,

I recently attended the International Experience Exchange for Patient Organizations 2018 Conference in Athens, Greece. It was an amazing experience - connecting with leaders from advocacy organizations from around the world who share similar missions - raising awareness, fighting for earlier diagnosis and better treatments in the quest to improve quality of life for our loved ones.

Some of the takeaways:

- Researchers acknowledged the importance of committing to having patients participate in research - from the development of the idea to study design through trial and compilation and dissemination of data. Including the “patient’s voice” has been a buzz word for the past ten years. We have to do better at making sure it happens AND actually listening to them.

- The use of technology continues to change everything in medicine except the importance of personal human touch. Even as we embrace e-learning on our phones and tablets, connecting with others via social media instead of in-person, communicating with our physicians through their online patient portals, we have to remember that some patients don’t have access to these same resources and to not leave them behind.

- Patients, health care providers, insurance providers, government agencies, and industry all have to work together.

- Support groups have to evolve if they want to remain relevant to their community. We have to embrace technology and connect with our members wherever they are. We must be proactive in developing apps and tools that will help our patients become better patients and our health care professionals become better too!

We will celebrate Vasculitis Awareness Month during the month of May. Please plan to participate. This year’s theme is built around our Dream Big Campaign and focuses on the importance of early diagnosis, helping push for and develop better treatments, and finding a cure and better quality of life for people with vasculitis.

Sincerely,

Joyce A. Kullman
Executive Director
New VF Board Members Bring Their Talents and Vision to Fulfill VF Mission

by Ed Becker

Don Nagle and Suzanne DePaolis recently became the two newest VF Board Members. Although affected by vasculitis in different ways, they share the same desire to positively impact the vasculitis community.

Fifteen years ago, at the age of 19, Nagle’s daughter, Sarah, was diagnosed with vasculitis. Today, she continues to manage her illness and live a relatively normal life with her family. Nagle credits the VF with being an invaluable source of information and support.

“The VF exposed us to vasculitis experts, and to other patients,” says Nagle. “They gave us hope to manage her illness. I joined the Board because I believe in how the VF improves patient lives.”

Nagle is Chief Financial Officer and Senior Vice President for the Asia Society. “I’m excited to bring my knowledge of non-profits, as well as my financial experience to help the VF fulfill its mission.”

Suzanne DePaolis’ passion for education led her through a career in teaching, but a diagnosis of EGPA abruptly changed that life path. She found herself in a position to channel her teaching to directly help other patients understand and manage their illness.

During the 2017 Symposium, DePaolis was publicly recognized for her outstanding work at helping educate patients and raise awareness about vasculitis. When the VF Board invited her to join, she readily accepted.

“I bring a unique point of view which is the patient perspective,” said DePaolis. “I understand what patients need, and I also understand what we may need in the future. Sharing these patient needs to the Board is very important. I’m both honored and excited to be in that role.”

Learn more about Don and Suzanne in these VF video interviews.


Skin Involvement in Vasculitis and the ARAMIS Study Focus of February VF Webinar

Learn about skin involvement in vasculitis with the VF’s February Webinar presented by Robert G. Micheletti, MD, who is Assistant Professor of Dermatology at the Hospital of the University of Pennsylvania.

Dr. Micheletti covers a range of critical issues including:

- Skin vasculitis symptoms
- How skin vasculitis is treated
- The ARAMIS Study: Randomized Multi-Center Study for Isolated Skin Vasculitis
- Cutaneous Small Vessel Vasculitis

View this webinar at: [https://youtu.be/zAjBHSsH9kc](https://youtu.be/zAjBHSsH9kc)

Announcing New VF Medical Consultant Dr. Brent A. Senior

We welcome otolaryngologist Dr. Brent A. Senior as a new VF Medical Consultant. Dr. Senior is the Nat and Sheila Harris Professor of Otolaryngology and Neurosurgery at the University of North Carolina at Chapel Hill where he also serves as Vice Chair of Clinical Affairs and Chief of Rhinology, Allergy, and Endoscopic Skull Base Surgery. Dr. Senior treats patients and works closely with the vasculitis program at UNC. At national and international professional meetings he seeks to increase awareness of vasculitis among his peers and is known by his patients for his compassionate care and great skill.

In 2005, he co-edited the very successful text “The Frontal Sinus,” now in its second edition. His passion for education has been honored with his receipt of “Teacher of the Year” awards and the “Cottle Award” from the American Rhinologic Society, the highest award for education from that society. His clinical expertise has been honored with numerous annual “Top Doctor” awards, while his humanitarian efforts garnered him a “Humanitarian of the Year” Award from the American Academy of Otolaryngology in 2005.
VF News

VF Announces $162,000 To Fund Three New Research Studies in 2018

**Endothelial Cell Inflammasomes in ANCA-Associated Vasculitis**

*Investigator:* Dan Jane-Wit, MD, PhD  
*Co-investigator:* Caodi Fang, MS  
*Institution:* Yale University  
*Award:* One-year, $50,000

Inflammasomes are shown to play a role in a number of other diseases associated with inflammation including gout, Muckle-Wells Syndrome, Familial Cold Autoinflammatory Syndrome and many others. The research focuses on the role of inflammasomes in the development of atherosclerosis in ANCA-associated vasculitis. The implications from this research could include a better understanding of why patients with ANCA-associated vasculitis develop atherosclerosis. The findings could then be used to develop strategies to prevent atherosclerosis and cardiovascular diseases.

**Metabolic dysregulation of pro-inflammatory responses in DADA2 vasculitis**

*Investigator:* Sonia Sharma, PhD  
*Co-investigators:* Rekha Dhanwani, PhD; Mohit Jain, MD, PhD  
*Institution:* La Jolla Institute for Allergy and Immunology  
*Award:* One-year, $50,000

Adenosine deaminase 2 deficiency (DADA2) is an inherited disorder which can cause vasculitis of medium-sized blood vessels. The disease is caused by mutations in the CECR1 gene. DADA2 was first discovered in 2014. DADA2 can present similarly to polyarteritis nodosa. It is not clear how DADA2 leads to vasculitis and there are currently limited treatment options. Dr. Sharma and colleagues have found that a deficiency of adenosine deaminase 2 can cause the accumulation of purines. The over accumulation of purines can lead to an over-exaggerated inflammatory response. The research aims to determine the ways in which an accumulation of purines affects the immune system. This is the first research to explore the metabolic basis for the disease. The implications of this research could include the development of new treatment strategies for DADA2.

**Long-Term Patient Follow-up of ANCA-Associated Vasculitis**

*Research team:* David Jayne, FMedSci, Laura Moi, M.D., Ingeborg Bajema, M.D., Thomas Hauser, M.D., Alfred Mahr, M.D., MPH, Ph.D., Kerstin Westman, M.D., Peter Hoglund, M.D., Mikkel Fauschou, M.D. and Raashid Luqmani DM FRCP, FRCP(E)  
*Institution:* University of Cambridge, United Kingdom  
*Award:* One-year, $62,000

There is limited data regarding long-term outcomes in forms of ANCA-associated vasculitis and factors that prevent adverse outcomes. These researchers are developing a large database using the information collected as part of ANCA trials from 1995 to 2010. The team is examining factors such as survival, long-term kidney function, co-morbidities, relapse status, vasculitis-related damage, drug exposure, mortality, cancer rates, cardiovascular events, drug safety, relapse rate and other kidney-related outcomes.

Dr. Moi, the fellow supported by the grant, will manage the project.
VF Announces Kansas City Regional Conference

› August 4, 2018
› 10:00 a.m. - 2:00 p.m.
› KU - VF Patient & Family Conference
› BEST Conference Center, Room 125
University of Kansas Edwards Campus
12600 Quivira Road
Overland Park, Kansas 66213

NOTE: Registration has not yet opened, but you will be informed when it's ready in the next newsletter, and on VF social media.

2018 Regional Kansas City Patient Vasculitis Symposium
Tentative Agenda

9:30 - 10:00 Light Snacks
10:00 - 10:15 Opening comments
10:15 - 10:45 Vasculitis 101: Jason Springer, MD, MS
10:45 - 11:15 The Immune System: Selina Gierer, DO (Immunologist)
11:15 - 11:45 Sino Nasal Manifestations of Vasculitis: David Beahm, MD (ENT)
11:45 - 12:45 Lunch and Program
12:45 - 1:15 Bone Health: Rajib Bhattacharya, MD (Endocrinologist)
1:15 - 1:45 In the Pipeline: Jason Springer, MD MS
1:45 - 2:00 Closing comments

Breakout sessions
11:15 - 11:45 Large Vessel Vasculitis: Giant cell arteritis, Takayasu's arteritis, Polymyalgia Rheumatica

VF Bob Continues to Raise Awareness

Now in its third month, the VF Bob Awareness Campaign continues to grow as people throughout the world shoot selfies holding the poster. These selfies are appearing on Facebook, Instagram, and throughout other social media.

Here’s how to get involved:

1. Visit the VF Bob webpage at: www.vasculitisfoundation.org/vfbob/
2. Download & print the official VF Bob poster
3. Snap a selfie holding the poster (or if you’re camera shy just take a photo of the poster in your hand)
4. Share it on your favorite social media platform with the hashtag #VFBOB

www.vasculitisfoundation.org/vf/bob/

VF News
Vino for Vasculitis Fundraiser

**Vino for Vasculitis**

- **April 28, 2018**
- **The Junction Salon & Bar**
  327 West Davie Street, #114
  Raleigh, North Carolina
- **7:00 p.m. - 11:30 p.m.**
- **Tickets are $25 each for entry and a glass of wine.**

Join us for a night of glam and goodness to raise hope and awareness for rare vasculitis diseases.

April 28th will be our fifth annual Vino for Vasculitis silent auction event benefiting the Vasculitis Foundation! All the proceeds from this event go to the VF, a non-profit organization dedicated to patients with vasculitis, their families, friends and the healthcare professionals who care for them.

You can make this a successful event with your donation to the event's silent auction, please contact Jess at jess@vinoforvasculitis.com to see what she needs and to learn more about Vino for Vasculitis.

Vino for Vasculitis was created by a group of Danielle’s friends dedicated to honoring her memory and raising awareness about these rare diseases that took her life. To learn more about Danielle and our 501 (C)(3) charity, visit our website vinoforvasculitis.com or our Facebook page facebook.com/vinoforvasculitis.


A Little Magic Behind Success of VF Fundraiser

**Make Believe Charity Show**

- **April 8, 2018**
- **Taha Twisted Tiki in The Grove**
  4199 Manchester Ave, St. Louis, Missouri 63110
- **4:15 p.m. - 5:15 p.m.**
- **Contact: amandalindseymagic@gmail.com**

Donations accepted at the door or provide proof of online donation

Amanda Lindsey knows how to make things disappear in front of your eyes, so it wasn’t a surprise that she knew what to do for her VF fundraiser. As a professional magician, Amanda decided a magic show would help to raise awareness and support for her friend, Christine Augustine.

"Chris has done so much for me in my life and has done so much for others in her life that she inspires me," says Lindsey. "Therefore, I want to support my friend and help people become aware that vasculitis is out there affecting wonderful people like Christine."

This will be the third Make Believe Charity Show and Lindsey believes it will continue to be a successful fundraiser. Last year they only expected 20 guests, but the event quickly became standing room only and raised more than $400. “Although the reason we’re doing this fundraiser is serious, our goal is to make it an enjoyable, and fun experience,” says Lindsey. “It’s an interactive show where we encourage guests to participate in our performance.”
North Carolina VF Chapter Meeting

Bringing Mindfulness to Vasculitis

- April 7, 2018
- 9:30 a.m. - 2:00 p.m.
- UNC Wellness Center
  at Meadowmont in Chapel Hill
  100 Sprunt St, Chapel Hill, NC
- Registration is $15.00 per person
- Guest speaker: William Frey

William Frey works as an Organization & Professional Development consultant at UNC, teaching classes for University employees, offering workplace coaching, conducting internal consulting, and coordinating leader development. He has served as an instructor of Mindfulness-Based Stress Reduction for the UNC School of Medicine for over 17 years and co-authored research papers on mindfulness.

For registration questions:
John Wall at jwall26@gmail.com or
Donna Wall at tkdonna@gmail.com, 919-761-8826

Learn more at: http://bit.ly/2DJmxsV

VF Kansas City Chapter Meeting

- April 14, 2018
- 1:00 p.m. - 3:00 p.m.
- BEST Conference Center, Room 125
  University of Kansas Edwards Campus
  12600 Quivira Road,
  Overland Park, KS 66213

The speaker will be Katie Strahan, Program Coordinator at Turning Point, talking about the programs available at their center for hope & healing. Turning Point, a program of the University of Kansas Hospital, offers innovative, educational and comprehensive support programs at no charge, for patients and families touched by serious or chronic illness.

For more information contact:
Denny and Ruth Hale, dhale3@kc.rr.com or 913.764.7557

VF Events

What’s a VF Fundraiser?

Each year dozens of people hold special VF Fundraisers. Golf outings, a magic show, wine tastings, walks, basketball games, or motorcycle runs are just some of the ways people combine fun with fundraising.

If you would like to learn more about holding a VF Fundraiser please contact the VF Office at 1-816-436-8211, or email, www.vasculitisfoundation.org/contact-us-2/

Save the Date

Vasculitis Awareness Month is May 1–31

Almost anything you want it to be!
Protein Not Linked to Heart Damage

by Kurt Ullman

Kawasaki disease (KD) affects children between six months and six years of age. One of 5 patients develops aneurysms, or damaged and scarred blood vessel walls, in the heart. A VF-funded study looked at the molecule Follistatin-like-1 (FSTL-1) that has been shown to play a major role in producing scar formation and damage in other inflammatory and non-inflammatory diseases.

“What happens [in KD] is that there is some trigger of inflammation causing the immune system to attack blood vessels in the heart,” said lead investigator Mark Gorelik, MD, assistant professor at the Baylor College of Medicine in Houston, TX. “These vessels are damaged and bulge out, which can cause clot formation or rupture, leading to early heart attack or failure. This is a problem whose current treatment is only partially effective.”

Molecule Reason for Scarring?

The molecule is elevated in patients with active KD. Other investigators have been looking at FSTL-1 in heart and lung diseases characterized by scarring. It appears that when this protein is “knocked out”, or removed from the organism under study, there is less damage. The question was whether this was also true in children with KD.

Intriguingly No Vessel Damage

The researchers found that in the mouse model, FSTL-1 is elevated during KD as it is in humans. When they took out the protein by blocking its production, they hoped to show a reduction in the development of aneurysms. Unfortunately, but perhaps intriguingly, they found no significant differences in vessel damage.

“In one sense this outcome was disappointing,” said Dr. Gorelik. “However, it suggests that there are multiple pathways for developing scar formation; by eliminating this pathway as a candidate, we can perhaps uncover other mechanisms of scar formation in vasculitis that were previously unknown. At the moment, we are in the process of demonstrating that we still see the previously known downstream signal changes that have been previously described when we remove FSTL-1 from activity, but that we still see none of the typical improvement in scar formation.”

Science Made Up of Small Steps

He notes science is always made up of small steps and contributions to the data. In this case, we can direct researchers to look at other pathways of scar formation in KD.

To Dr. Gorelik, trying to find out why a person’s body decides to attack itself and looking for ways to fix it is very satisfying work. Focusing on KD as the number one cause of acquired heart disease in kids, is especially so. The resources available from the Vasculitis Foundation are very helpful in that endeavor.

“When you are a doctor seeing these patients in the clinic there is currently no way to fix the problem,” said Dr. Gorelik. “It inspires you to go the laboratory and look for ways to lessen the damage and suffering. Even if an idea doesn’t work, it still gives us knowledge about the disease process that we did not have before.”

“It inspires you to go the laboratory and look for ways to lessen the damage and suffering. Even if an idea doesn’t work, it still gives us knowledge about the disease process that we did not have before.”
ADVOCATE Trial Recruiting Patients

Phase III ADVOCATE trial of avacopan for ANCA vasculitis nears 75% of patient enrollment target as European Medicine Agency continues review process of Conditional Marketing Authorization application.

ChemoCentryx’s Phase III ADVOCATE pivotal trial of avacopan for ANCA vasculitis has 200 sites activated and 220 patients enrolled to date. The trial will evaluate the safety and efficacy of avacopan following 52 weeks of treatment and will include approximately 300 patients. In addition to testing the effect of avacopan on improving active vasculitis, the ADVOCATE trial will also test avacopan’s efficacy in preventing the recurrence of vasculitis, one of the major limitations of the current standard of care for patients with ANCA vasculitis.

LEARN MORE ABOUT THE ADVOCATE TRIAL:
http://www.advocateclinicaltrial.com

Watch the webinar at: http://bit.ly/2pwXggh

What is Precision Medicine?

According to the Precision Medicine Initiative, precision medicine is "an emerging approach for disease treatment and prevention that takes into account individual variability in genes, environment, and lifestyle for each person." This approach will allow doctors and researchers to predict more accurately which treatment and prevention strategies for a particular disease will work in which groups of people. It is in contrast to a one-size-fits-all approach, in which disease treatment and prevention strategies are developed for the average person, with less consideration for the differences between individuals.

What is the difference between precision medicine and personalized medicine? What about pharmacogenomics?

There is a lot of overlap between the terms “precision medicine” and “personalized medicine.” According to the National Research Council, “personalized medicine” is an older term with a meaning similar to “precision medicine.” However, there was concern that the word “personalized” could be misinterpreted to imply that treatments and preventions are being developed uniquely for each individual; in precision medicine, the focus is on identifying which approaches will be effective for which patients based on genetic, environmental, and lifestyle factors. The Council therefore preferred the term "precision medicine" to “personalized medicine.” However, some people still use the two terms interchangeably.

Learn more about the science behind the ADVOCATE trial in this webinar led by Dr. Peter Merkel.

Webinar topics include:
• The science behind ADVOCATE
• Neutrophils and their role
• What is avacopan
• Rationale for use of avacopan
• ADVOCATE and clinical trials
• ADVOCATE Trial – Study design specifics
• ADVOCATE Trial – Study schedule
• Inclusion criteria – How do you get into the trial
• Summary / Question and Answer Session

Source: NIH U.S. National Library of Medicine

Resource:
https://ghr.nlm.nih.gov/primer/precisionmedicine/definition
Gabby: Sharing Patient Experience with Young Adults throughout the World

by Ben Wilson

As part of the recently celebrated National Rare Disease Day, I Skyped with Gabriella (Gabby) O’Donnell for this issue’s patient feature. Gabby is a 16-year-old from the Netherlands who was diagnosed with GPA/Wegener’s over two years ago. She recently started a blog to talk about her experiences dealing with vasculitis, which you can read here: http://bit.ly/2FQh1up

Hearing her story, I was amazed at Gabby’s bravery and courage since her diagnosis. Gabby spent Christmas Day 2015 being shuttled from hospital to hospital in the Netherlands after initially contracting flu symptoms that would not go away. While her age is relatively unique among most GPA patients, her struggles follow the same path of many others with the diagnosis. Rounds of Rituxan, high doses of prednisone, and occasional relapses have been the norm for Gabby, who now attends a high school that specializes in teaching chronically-ill students.

While Gabby continues to deal with classic GPA symptoms daily, complications from the disease forced her to undergo several painful procedures, including plasmapheresis. She also had operations to remove scarring in her airways, which can make it difficult at times for her to talk.

“It’s been hard to control the disease,” Gabby said. “I started the blog because I just felt like writing stuff down would be therapeutic for me, and it has been.” For most teenagers with vasculitis, talking about their symptoms with friends can be difficult and frustrating, especially given that it’s hard for other adolescents to comprehend the true nature of the disease.

Gabby is not the only young vasculitis patient to have these types of feelings. However, few are willing to put all those thoughts in a public forum for others to read. For that, we should all commend Gabby for spreading the word about life with GPA and through those words, educating others.

Tribute to Glenn Kullman, a Devoted Volunteer

Glenn Kullman, longtime VF volunteer, passed away in January after a brief battle with cancer. He was diagnosed with Wegener’s (now GPA), in October 1994. When Dr. Ann Warner, a rheumatologist, diagnosed him, she said, "You have a rare disease called Wegener’s granulomatosis. You’ve probably never heard of it." But, Glenn, and his wife, Arlene, were familiar with the disease because their friend, Marilyn Sampson, had founded the Wegener’s Granulomatosis Support Group, (now the Vasculitis Foundation), and they often helped her with projects.

Glenn served on the board of directors, committees, and maintained the organization’s computers, printers, and phones for years. He and Arlene were active members of the Kansas City VF Chapter and often represented the WGSG at medical conferences. If you have ever received a flyer for a meeting, fundraising event or dues renewal notice, it is likely that they helped with the mailing. Their dining room table has served as a VF satellite office for years.

Glenn was also a member of the Wegener’s ListServe, the first online support group for patients. He saved over 8,000 posts with the intention of writing a computer program to determine the number of times patients wrote that they hated prednisone.

He was most proud of his work on the 1997 first-ever survey of Wegener’s patients. Over 1,000 patients answered 40 questions about their diagnosis, treatment, side effects, careers, hobbies, childhood illnesses, and much more. Glenn compiled the data and the results were published in the February 2002 Journal of Rheumatology article “Wegener’s Granulomatosis: Survey of 701 Patients in North America. Changes in Outcome in the 1990s.” The article was authored by Dr. Nabih Abdou and other VF Medical Consultants. Glenn was listed as an author and considered it the highlight of his volunteer work with the organization.
Stephanie Sakson: A Vasculitis Patient’s Journey Through Diagnosis and Treatment to a Normal Life

by John Fries

One day in October 2009, Brittany Sakson came home from high school sick with the H1N1 influenza, commonly known as swine flu. In the days that followed, Brittany’s mother Stephanie, caught the flu as well. Although her symptoms weren’t as severe, they continued for several months. After numerous doctor visits, tests and trips to the emergency room, there was no clear conclusion about what was making her feel so sick.

Stephanie finally got a diagnosis the day she went with her mother to an appointment with her mother’s longtime rheumatologist, Mark Cruciani, MD. He asked Stephanie how she was doing. “I told him that I’d been experiencing prolonged weakness, a fever, and chest and upper back pain. He didn’t examine me, but did immediately—and correctly—diagnose the problem as vasculitis.”

Stephanie made a follow-up appointment with Dr. Cruciani, who explained to her the range of vasculitic diseases. Initially, believing that she might have Wegener’s, he prescribed 40 mg. of prednisone a day and referred her to a vasculitis center for further treatment.

In May 2010, however, a few weeks before her appointment at the vasculitis center, she became seriously ill with a variety of symptoms and was taken to the emergency room. The doctors there didn’t concur with the vasculitis diagnosis. Instead, they placed her on numerous medications—including Labetalol for high blood pressure and increased heart rate, and Cymbalta for neuritis—and instructed her to wean off the prednisone.

Months later, she experienced a number of unexpected health-related issues including scalp lesions, swollen lymph nodes and shingles near her eyes. She told her ophthalmologist, Arthur Jordan Jr., DO, about her emergency room experience and he urged her to get a second opinion.

In November 2011, she saw New York City rheumatologist Stephen Paget, MD. “During my first visit he immediately recognized my illness as polyarteritis nodosa (PAN)—the rarest form of vasculitis,” said Stephanie.

Stephanie has since learned to live with PAN. “I was in remission for more than two years,” she said. “Although I had a subsequent flare-up. And I am currently in the process of weaning off Imuran.”

Stephanie now feels mostly healthy, and lives a relatively normal life. She often visits Brittany, now a college graduate who lives and works in New York City. Stephanie was also one of the founders of the Vasculitis Patient Powered Research Network (V-PPRN) and is now the moderator of the PAN Support Network.

“Early, accurate vasculitis diagnosis is crucial,” she said. “The VF directs an incredible amount of resources into research and physician education, which benefits patients. And the support they provide is invaluable.”

She also credits her husband, Joe, for his support, and her doctors for their roles in her diagnosis and treatment. “I truly believe that Dr. Cruciani may have saved my life,” she said. “My three heroes are him, Dr. Jordan, and Dr. Paget.”

“I told him that I’d been experiencing prolonged weakness, a fever, and chest and upper back pain. He didn’t examine me, but did immediately—and correctly—diagnose the problem as vasculitis.”
**Fundación Vasculitis Chile: Raising Awareness and Impacting the Health Care System in Chile**

My name is Ximena Romo Quintana. I was born in Concepción, which is 500 kilometers south of Santiago, the capital of Chile, and where I have lived since 1988. I studied at the University of Concepción, Chile and am a Spanish-English translator.

I’ll never forget what doctors told me when they diagnosed me with vasculitis, “It is not in our minds and that is what we have to change”.

Vasculitis is so rare, that doctors didn’t think of it as a possible diagnosis. In fact, most of the doctors will never see a patient with vasculitis during their careers.

So, I decided to make vasculitis famous.

One night, in the summer of 2010, while I was in my wheelchair looking for people with my disease in on the internet, I got in contact with my first friend with GPA wegener’s. I knew about the Vasculitis Foundation and I was added to the support group.

I started working to raise awareness about my illness—Wegener’s—which at that time had changed its name to Granulomatosis with polyangiitis. In 2015, the Fundación Vasculitis Chile was legalized. Today we’re 1,155 members strong in our Facebook support group with members from many Spanish-speaking countries. Over 600 people are from Chile.

Fortunately, vasculitis is more known now, and so is the Fundación Vasculitis Chile. We have already created three chapters in other cities in Chile. The first one, of course, was created in my hometown, Concepción.

When I was first diagnosed, the disease was not known by the Ministry of Health, and therefore it was not included in our health system. Now they are going to develop Clinical Guidelines for vasculitis, something that was unthinkable when I started raising awareness here thanks to the Chilean Rheumatology Society, SOCHIRE, which took the initiative, since the Ministry of Heath didn’t take much interest in the disease.

Clinical guidelines will help us to have a code for vasculitis in the National System for medical benefits and to apply vasculitis to the different health care programs for the medication and medical care we require.

Our current campaign is called “Venciendo la Vasculitis con Diagnóstico Precoz,” Defeating Vasculitis with Early Diagnosis. It’s aimed to give primary health care doctors information to help them recognize the symptoms of the disease, so they could have a suspected diagnosis of vasculitis.

We have the hope the new Health Authorities, who will take office in March, will be more involved in the needs of rare diseases such as vasculitis and all the people can have access to the proper medical care.
Vasculitis Patient-Powered Research Network (V-PPRN)

www.vpprn.org

The goal of the Vasculitis Patient-Powered Research Network’s (V-PPRN) research program is to conduct high quality studies that will improve the care and the health of patients with vasculitis by exploring research questions that matter most to patients and advance medical knowledge about vasculitis.

The Challenge
All the different types of vasculitis are rare diseases - this makes it especially hard to do research because it is difficult to find enough patients for research studies, patients are spread out geographically, and it is hard to get health information from physicians to researchers.

The Solution
Vasculitis is rare but vasculitis research doesn’t have to be! The V-PPRN will enroll more patients than ever studied in the past, from all parts of the country, and collect data on-line to break down barriers and involve patients in the research process so health information is easily shared with researchers.

Who Can Join the V-PPRN?
You can join the V-PPRN if:

• You are a patient with vasculitis
• You are the parent of a child with vasculitis
• You are the caregiver of an adult patient with vasculitis
• You have regular access to the Internet
• A strong English proficiency. The V-PPRN forms are currently provided in English and require a strong English proficiency.

Join the Network

• As a patient, you will be a partner with investigators and clinicians in research and care.
• You contribute your disease experience by providing patient-reported data as well as electronic health data.
• Together, we are making vasculitis research happen now!
• Better studies, better treatments, because of you!

Join the www.vpprn.org today!

VF Dream Big Educational Webinar Series 2018

Topic: Pregnancy and Family Planning Concerns of Women with Vasculitis
Guest Speaker: Megan Clowse, MD, MPH, Duke University Hospital
Date: Tuesday, April 24, 2018
Time: 6:00 p.m. Eastern
Register: https://attendee.gotowebinar.com/register/3951903565114074627

Dr. Megan Clowse is the principal investigator of the Vasculitis Pregnancy Registry Study (V-PREG), a V-PPRN Study. The purpose of V-PREG 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.

Many women with vasculitis wonder whether they should stop or continue their medications during pregnancy or breastfeeding – is it riskier to stop them or continue them? During the webinar, Dr. Clowse will talk about the safety, risks, and benefits of medications during these two periods. At the end of the webinar, attendees should have a better idea about how to weigh the risks to the patient, and a baby, from vasculitis and medications.

Dr. Clowse also leads the Reproductive Concerns Research Interest Group of the PCORnet Autoimmune and Systemic Inflammatory Syndromes Collaborative Research Group (ASIS CRG).

Learn more at https://www.vpprn.org/VPREG
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/)

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**TAPIR Trial Now Open to Patients Taking Rituximab**

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)
January and February 2018 Donors

Thank You for Your Gift of $50 or More!

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**Two Ways to Get the Latest News Online about Vasculitis / Autoimmune Research**

   - This page pulls in news stories and press releases and provides links to the stories.

2) Like the VF News and Info Facebook Page: [https://www.facebook.com/VasculitisFoundation/](https://www.facebook.com/VasculitisFoundation/)
   - More than 6,500 people follow this Facebook page that provides a pipeline of news about the VF, vasculitis clinical studies, autoimmune research, and issues of interest to patients with vasculitis. Simply click on the LIKE button to receive the news feed.

Learn more about vasculitis and autoimmunity on Facebook!
### Membership

**Vasculitis Foundation Membership Campaign – JOIN!**

_Fill out form completely, detach and send to VF office._

**I Am Pleased To Support The Vasculitis Foundation Through My Membership Dues.**

**DUES:**
- ____ $35 U.S. for all members
- ____ $500 U.S. Lifetime Membership

_In addition, I would like to make a tax-deductible gift* of:_
- ____ $45
- ____ $60
- ____ $75
- ____ $100
- ____ $150
- ____ Other $ ______

Enclosed is my check or _Please Bill My Credit Card (circle one)._ Visa/MasterCard/Discover/American Express

Card #: ____________________________

Name as listed on Card: ____________________________

Signature: ____________________________

Exp. Date: ____________ Total: $ ____________

Email: ____________________________

___ I would like to make a monthly pledge of $ _______ billed to my credit card.

___ Check if you would like to designate the VF as a beneficiary in your will.

* This gift is: ___ In memory of ___ In honor of ___ A Gift Membership for

Name: ____________________________________________________________________________

Address: ____________________________________________________________________________

City: ____________________________ State: ____________ Zip: ____________

Country (if outside the U.S.): ____________________________

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

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**Have you considered receiving your bi-monthly newsletter in a new way--- delivered to your email Inbox instead of your postal mailbox?**

More of our members are asking to opt out of the hardcopy version because they prefer the convenience of getting the newsletter in a PDF format.

You get the entire newsletter in a single PDF. **But wait, there's more:**

- **The digital newsletter contains hyperlinks.** That means you can instantly link to the resources mentioned within an article.

- **Every article is bookmarked so you can immediately click and go to that article or section in that issue.** You can’t do that with your hardcopy newsletter.

Yes, we will continue to offer the newsletter in hardcopy that is delivered to your postal mailbox.

But, if you're ready to think outside of our mailbox let us know!

**Contact the VF Office to change how you receive the VF newsletter at:** [vf@VasculitisFoundation.org](mailto:vf@VasculitisFoundation.org)
Connecting with Urticarial Vasculitis Patients

Hi friends,

I have been trying to make contact with members with Urticarial Vasculitis for a few months. Dr. Kermani recommended contacting the VF to connect with other Urticarial Vasculitis patients to share and learn about this form of vasculitis.

I don’t do social media, but I can correspond via email. My address is: artsycath@gmail.com

Thank you, Cathy
April 7, 2018
North Carolina VF Chapter Meeting
9:30 a.m. – 2:00 p.m.
UNC Wellness Center at Meadowmont in Chapel Hill
100 Sprunt St, Chapel Hill, NC
Speaker/Topic: Will Frey of Pathfinders Coaching:
Stress Management
For registration questions:
John Wall at jwall26@gmail.com or
Donna Wall at tkdonna@gmail.com, 919-761-8826

April 8, 2018
Make Believe Charity Show to Benefit VF
4:15 p.m.– 5:15 p.m.
Taha Twisted Tiki in The Grove
4199 Manchester Ave, St. Louis, Missouri 63110
Donations accepted at the door or provide proof
of online donation
Contact: amandalindseymagic@gmail.com

April 14, 2018
VF Kansas City Support Group
1:00 p.m. - 3:00 p.m.
BEST Conference Center, Room 125
University of Kansas Edwards Campus
12600 Quivira Road, Overland Park, KS 66213
Guest: Katie Strahan, Program Coordinator at Turning Point

April 28, 2018
5th Annual Vino for Vasculitis
7:00 p.m – 11:30 p.m
Junction Salon and Bar in downtown Raleigh, North Carolina
Order tickets at: https://vino2018.brownpapertickets.com
For more information email Jess Foster at: jess@Vinoforvasculitis.com

May, 2018
Vasculitis Awareness Month

May 14, 2018
Sacramento Chapter Meeting
6:00 p.m – 7:00 p.m.
Hofbrau Restaurant, 2500 Watt Avenue, Sacramento, CA
Organizer: Hedy Govenar, HGovenar@govadv.com

May 19, 2018
Rocking Bar H Spaghetti Dinner
37811 176 Avenue  SE, Auburn, WA 98082
Organizer: Brook Hinkle 253.405.7183 brook.hinkle@gmail.com

August 4, 2018
KU - VF Patient & Family Conference
10:00 a.m. - 2:00 p.m.
Best Conference Center, Room 125
University of Kansas Edwards Campus
12600 Quivira Road, Overland Park, KS 66213