GlaxoSmithKline (GSK) achieves approval for Nucala (mepolizumab) for the treatment of eosinophilic granulomatosis with polyangiitis (EGPA) for adults in the US

On December 13, 2017, GSK announced that the U.S. Food and Drug Administration (FDA) approved Nucala (mepolizumab) as the first targeted treatment for eosinophilic granulomatosis with polyangiitis (EGPA), previously known as Churg-Strauss syndrome (CSS).

The approval for EGPA is based on results from the pivotal, 52-week, Phase III MIRRA1 study, conducted as a collaboration between GSK and the National Institute of Allergy and Infectious Diseases, part of the U.S. National Institutes of Health.

Joyce Kullman, executive director of the Vasculitis Foundation (VF), said, “Nucala is the first FDA-approved drug for treatment of EGPA/Churg-Strauss Syndrome vasculitis, and the VF is delighted for our patients and their families. EGPA/CSS is a chronic illness and patients often face repeated relapses, which can cause serious health problems. We are hopeful that Nucala will enable many more of our patients to achieve longer remission with a greater quality of life.

“The true champions are the dedicated patients who participated in the study trials and the many scientists committed to improving treatments for our patients. We are grateful for all their efforts to improve the lives of other patients with EGPA, and future patients with the diagnosis. Until we discover a cure, we must work to develop more effective treatments to help all of our patients living with vasculitis.”

Nucala was the second drug approved by the FDA for the treatment of vasculitis in 2017. In May 2017, Atermra received approval to treat giant cell arteritis. This brings to a total, three drugs approved by the FDA since 2010 for vasculitis.


NEW VF Bob Campaign - Inspiring Our Community & Honoring Bob Sahs

In April 2017, the vasculitis community lost a dear friend and champion of our cause, Bob Sahs. For nearly 20 years, Bob was a passionate advocate of vasculitis awareness, using his warm and friendly demeanor to connect with everyone he met, so that they could learn more about vasculitis. Bob came to the organization in support of his wife, Elaine, who was diagnosed with Wegener’s/GPA in 1999.

Bob was such an advocate for raising awareness that he typically carried a six-foot banner on his world travels to China, Africa, and other exotic locations. To honor his spirit of awareness and outreach, the foundation has launched a new campaign, VF Bob, to encourage the vasculitis community to spread the word about vasculitis, by showcasing how we continue to dream big and live with passion.

Instructions:
1. Pull VF Bob out of the newsletter. (Page 13)
2. Hold while taking a photo of yourself living big - walking, traveling, exploring, enjoying a special moment
3. Post your photo on Instagram, Twitter or Facebook using the hashtags #VFBob #VFDreamBig

To learn more about VF Bob visit www.VasculitisFoundation.org/VFBob
Dear Friends,

Like many of you, the Vasculitis Foundation is looking ahead to the new year with a list of goals, expectations, and benchmarks to achieve. Thanks to all of you, the bar is high to match our successes from 2017. Our Dream Big campaign launched last year exceeded our expectations. It’s because of your generous contributions that we can continue our commitment to funding research, and providing patient support and educational opportunities in the coming year.

Our annual V-RED Campaign is now accepting nominations for health care professionals who made an early diagnosis and changed a patient’s life. See page 3 for more information.

Later this year we will host regional conferences around the US to connect with patients and families closer to their homes. These one-day meetings will focus on new treatments, recent research updates, and how to live successfully with vasculitis. The conferences will give attendees the opportunity to connect with others and to share their experiences.

We’re also updating our educational materials for our print and electronic formats and upgraded website. We will also host more educational webinars; if you have a topic and/or speaker you’d like to suggest, please let us know.

Volunteers are at the heart of the VF and last year we lost Lloyd Krivanek, the longtime leader of the Las Vegas Chapter. Lloyd was diagnosed with Wegener’s in 2001, and, with his wife, Lois, hosted meetings for patients and their families for many years at their home. Lloyd was committed to helping other patients with Wegener’s learn about the disease and finding physicians experienced in treating it.

Let’s continue to dream big and work together towards another successful year.

Sincerely,

Joyce A. Kullman
Executive Director
2017 Campaigns Raise $200,000; Donations Earmarked for Programs to Impact Patient Lives in 2018
By Kalen Young

You Gave on Giving Tuesday!

You did it! Your generosity raised over $26,000 on Giving Tuesday! On November 29, 2017 our community was vibrant with a collective desire to change lives by supporting the VF’s many programs, from research to education, that improve patients lives. Your enthusiasm and collective giving was generously matched by an anonymous donor, doubling all donations and making 2017 our most successful Giving Tuesday yet. Your contributions not only support the VF’s programs, you inspired something bigger, the VF 2018 Dream Big! Campaign.

Building Your Big Dreams with Donations

Electric with the momentum of your collective giving, the VF launched our VF Dream Big! Campaign. The campaign is built around the idea that by working together, we can help patients with vasculitis get diagnosed sooner, have better treatments to choose from, gain the support they need to best manage their disease, and, live longer, healthier lives as we work towards a cure.

We are thrilled to announce that the campaign has raised almost $200,000 as the newsletter went to print. This is the largest amount ever raised for a VF annual campaign.

“We thank everyone who contributed not only financially, but also by raising awareness about the need to tackle these challenges facing the vasculitis community,” Joyce Kullman, executive director of the VF.

YOUR IMPACT: Your contributions and support have created incredible momentum for 2018 and the VF isn’t slowing down!

Thank you for your support!

V-RED 2018
Nominations Now Being Accepted

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

The Vasculitis Foundation also recognizes that there are many health care professionals who have MADE the diagnosis of vasculitis, and we want to honor them for their efforts to care for our patients. Each year the Vasculitis Foundation solicits patients in the vasculitis community to nominate a health care professional who made an early call on their diagnosis.

We invite you to nominate your special health care provider for the 2018 V-RED Award. Fill out the nomination form at: http://bit.ly/2mgqWg1

The deadline for nominations is March 6, 2018. Everyone who submits a nomination will receive a 2018 Vasculitis Awareness t-shirt!
North Carolina Student Raises Vasculitis Awareness at School Fundraising Project

On December 3-4, 11-year-old, Evan Calabria, a sixth grader at Wakefield Middle School in Raleigh, North Carolina, participated in an exciting school project. Evan was one of 33 students in the class to compete in a charity/fundraiser program to help show the importance of non-profits, and to help build the students' presentation skills.

Evan chose to showcase the Vasculitis Foundation for a personal reason. His father, Tony Calabria, was diagnosed in 2017 with vasculitis. Fortunately, Tony responded well to the treatment and today is successfully managing his disease. They thank the VF for helping to provide education and support and presented their case to the panelists who selected the best presentations from all the participants.

In addition to creating the presentation, Evan spent two days at a local Barnes and Noble wrapping gifts for shoppers and talking about vasculitis, and the Vasculitis Foundation. Although he wasn't chosen as a finalist in the competition, Evan achieved a solid win for his advocacy work.

"We are so proud of Evan, and his whole family for helping to raise awareness about this disease," said Joyce Kullman, Executive Director of the VF. "We appreciate his time and talents to do something that is vitally important. The VF thanks Evan for his successful campaign."

A Celebration of Two Birthdays Becomes VF Fundraiser

What started out as a small birthday party in November turned into a fundraiser for the Vasculitis Foundation. Clyde Frymark invited his family and friends to a night of mead and pizzas at Larsen's Mead works in Mechanicsburg, Pennsylvania to celebrate the "6th" Birthday of his GPA/Wegener’s diagnosis (instead of the real count of his turning 64 years young).

The group enjoyed tasting flights of extraordinary mead and eating great pizza. The VF provided brochures about GPA and vasculitis as party favors to share with the guests, who in turn, opened their hearts and wallets to help support the VF.

"Many thanks to all of our friends and family. It was a fun time and I look forward to my 7th birthday." Clyde said after the event.

VF Thanks Fundraisers for Successful Year; Encourage More Events in 2018

In 2017 we had 30+ fundraising events in support of the VF! Events ranged from birthday parties, to bowling, basketball, and golf tournaments, runs, walks, beer-tasting and wine-tasting evenings, a magic show, shrimp boil, spaghetti dinner, concerts, and numerous online social media campaigns. All of the events raised funds for the VF's patients and programs and raised awareness in their local communities. Thank you to all of our event organizers! Thank you for your support and hard work!

Are you interested in hosting an event in 2018? The VF staff is ready to help you plan a successful fundraiser by supplying you with some basic tools and information that you can adapt to any type of fundraiser. We want your fundraising experience to be gratifying and fun.

If you are interested in learning more about hosting an event, please contact the VF office: vf@vasculitisfoundation.org or 816.436.8211.
Violin for Vasculitis: Allison Lint Performance
Friday, March 16, 2018
The Modbo Gallery
Colorado Springs, Colorado

Join Allison at the Modbo Gallery on March 16th for an intimate evening of chamber music to benefit rare disease awareness! Attendees are encouraged to browse works by local artists for a multi-sensory experience. Featuring music by Bach, Ysaye, Schumann, and more, with a Q&A to follow. This concert is free and open to the public. Contact Allison for information on an event in your state: violin4v@gmail.com

Allison’s Facebook Live Video Chats Continue to Attract Audiences

Every Monday and Thursday evening, you will find Allison hosting a live video chat on Facebook. Monday’s Facebook Live session is geared primarily to patients with vasculitis or rare diseases. Allison talks about the challenges of managing a life with vasculitis, and does Q&A with the participants.

Thursday's video is directed toward a wider audience who may not even know about vasculitis. She performs music, does Q&A, and raises awareness about the disease.

To learn more about these video chats (or to watch past sessions in the archive) visit: https://www.facebook.com/v4vinc

Seeking Items: Vino for Vasculitis Silent Auction

Our first fundraiser in 2018 is the Fifth Annual Vino for Vasculitis, a night of glam and goodness held annually in Raleigh, North Carolina. The evening honors the memory of Danielle D’Haene, who passed away from GPA/Wegener’s at the age of 27. Danielle loved family, friends, wine, and celebrating.

Vino for Vasculitis was created by a group of Danielle’s friends dedicated to honoring her memory and raising awareness about the rare disease which took her life. The event has been 100% supported by the local community, enabling the organizers to raise as much money as possible for the VF.

Jess Foster, one of the event’s organizers, shared, “We could not feel more grateful and inspired by the outreach and support we have received the last four years in Danielle’s memory. This year we want to grow the event and are seeking additional support. If you would be interested in supporting our silent auction, we would love to get your support!”

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
The Junction Salon & Bar
327 West Davie Street, #114
Raleigh, North Carolina
7:00 p.m. - 10:00 p.m.
http://www.vinoforvasculitis.com/about-our-event.html
or https://www.facebook.com/events/112499619467856/
The European Medicines Agency (EMA) has accepted for review the registration dossier in support of a conditional marketing authorization for avacopan in the treatment of patients with ANCA-associated vasculitis. The EMA’s Committee for Medicinal Products for Human Use (CHMP) will now start to assess the CMA application.

Avacopan (previously called CCX168) is an investigational medicinal product that is being tested in patients with ANCA-associated vasculitis. Avacopan is manufactured as pills that are taken by mouth.

In ANCA-associated vasculitis, the immune system is activated in a way that can cause inflammation and damage to blood vessels and organs including the kidney. Avacopan was developed to reduce activation of a part of the immune system that is known to be active in ANCA-associated vasculitis. Specifically, avacopan binds and blocks activation of a protein called the complement 5a receptor (C5aR). By blocking C5aR, avacopan reduces the inflammatory effects of C5aR.

Avacopan is currently in late-stage clinical development for the treatment of orphan and rare renal diseases, including ANCA vasculitis. In a randomized, double-blind, placebo-controlled Phase II study in ANCA vasculitis patients, known as the CLEAR trial, avacopan demonstrated that blocking C5aR at the terminal effector pathway of the complement cascade provides therapeutic efficacy and a favorable risk/benefit profile with a rapid onset of action.

ADVOCATE Trial Recruiting Patients

Avacopan is currently being studied in the Phase III ADVOCATE Trial for the treatment of ANCA vasculitis and is on track to complete enrollment by mid-2018.

For people who suffer from vasculitis who may want to participate in the ADVOCATE trial, more information can be found on the ADVOCATE website at http://www.advocateclinicaltrial.com.

International Conference on Large Vessel Vasculitis and Related Disorders 2018

The 2018 International Conference on Large Vessel Vasculitis and Related Disorders will be held at the Mayo Clinic in Rochester, Minnesota, on March 15 -17, 2018. The course draws together international experts in the fields of basic science, epidemiology, imaging and treatment of major forms of large vessel inflammatory diseases including giant cell arteritis, Takayasu arteritis, IgG4 related disease and others. State of the art management and current research into large vessel vasculitis will be presented at this scientific meeting.

Participants will include rheumatologists, general internists, vascular surgeons, laboratory researchers, medical students and residents, radiologists, and other healthcare providers who care for persons with vasculitis. The conference is not open to the public.

Recently the VF talked with Eric L. Matteson, M.D., rheumatologist at the Mayo Clinic, about this upcoming conference to learn why the topic of large vessel is important to medical professionals.

**VF:** What are some of the key initiatives of this upcoming conference?

**Dr. Matteson:** In the past three years since the last conference, there have been major advances in the understanding of the biology of large vessel vasculitis and advances in technologies used to detect and manage these diseases. At the conference, we will discuss the many areas of uncertainty regarding how to diagnose and follow these diseases and how to apply new therapeuti strategies.

**VF:** Although there will be many topics covered which ones do you think are particularly important or relevant?

**Dr. Matteson:** One of the sessions will be dedicated to examining the best radiology techniques for evaluation of large vessel vasculitis. These include novel uses of ultrasound, PET scanning, as well as MRI and computed tomography used to assess disease extent, activity, and damage. Another session will examine current and new therapies on the horizon for treatment of large vessel vasculitis and how these therapies can change the course of the disease and reduce the burden of steroid therapy. Finally, the surgical management of large vessel vasculitis will be an important topic of the conference.

For more information, visit: http://mayo.1n/2CWDaSW
Many physicians tend to look at relapses of complex diseases such as systemic vasculitis as mirroring the symptoms seen at the original diagnosis. However, this isn’t always the case. Understanding the frequency and types of a patient’s new symptoms of vasculitis over the course of the disease is an important part of both clinical practice and the development of clinical and diagnostic guidelines.

Peter Grayson, MD, and others set out to quantify the new signs and symptoms presenting after the initial diagnosis in six kinds of vasculitis. They studied patients enrolled in the Vasculitis Clinical Research Consortium (VCRC) longitudinal study cohorts from 2006 to 2012.

Using the VCRC records, standardized data collected on 95 disease manifestations in the following six vascular diseases: granulomatosis with polyangiitis (Wegener’s Disease or GPA), microscopic polyangiitis (MPA), eosinophilic granulomatosis with polyangiitis (Churg-Strauss, EGPA), polyarteritis nodosa (PAN), giant cell arteritis (GCA) and Takayasu’s arteritis (TAK). They published results in the January 2015 edition of the Journal of Rheumatology.

“When caring for a patient with chronic, relapsing disease, physicians often rely on the past medical history to guide ongoing clinical assessment with the assumption that features of a relapse will likely resemble patterns of prior disease,” said Dr. Grayson. “In this study we were able to show that patterns of relapse in vasculitis can be similar or completely different to the original presentation of the disease.”

Among the 838 patients included, 490 (59%) experienced at least one new disease manifestation after their diagnosis. On average, patients with one of the studied forms of vasculitis experience 1.3 new symptoms. A subset of each from 7% to 28% (depending on the disease) experienced 3 or more new manifestations.

Twenty-seven (27) percent of the patients presented with new severe manifestations (defined as life- or organ-threatening in nature). There was no relationship between the time of onset of these new manifestations and how long it had been since diagnosis.

“These findings show that the majority of patients with vasculitis will develop at least one new disease symptom after diagnosis,” said Dr. Grayson. “There will also be a number of new, severe manifestations.”

The next question the researchers asked was how well did their results compare with what had been reported in previous studies. Overall, the frequency of disease involvement at diagnosis and going forward was consistent with past findings. However, Dr. Grayson noted that for some of the diseases, good data was not available.

“This is important to the patient because it shows that ongoing assessment of patients with established vasculitis should be broad in scope,” he continued. “The data also emphasizes that there is significant room for improvement in finding newer treatments that are effective to prevent future disease relapse.”
**Rare Disease® Day 2018 is February 28**

Rare Disease Day is the international awareness-raising campaign for rare diseases. Since Rare Disease Day started in 2008, thousands of events have taken place throughout the world, reaching millions of people. Rare Disease Day 2018 is an opportunity for participants to be part of a global call on policy makers, researchers, companies and healthcare professionals to increasingly and more effectively involve patients in rare disease research.

For more information: [https://www.rarediseaseday.org](https://www.rarediseaseday.org)

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**NIH Rare Disease Day: Thursday, March 1**

8:30 a.m. – 4:00 p.m. ET

Masur Auditorium, Building 10

National Institutes of Health

Bethesda, Maryland

Sponsored by NCATS and the NIH Clinical Center the event will feature presentations, posters, exhibits, an art show and CC tours. Admission is free and open to the public. In association with Global Genes®, participants are encouraged to wear their favorite pair of jeans. Be sure to follow the event on social media using #RDDNIH.

If you can’t attend the event in person, you can watch the presentations through a free, NIH webcast. Tune in at: [http://bit.ly/2DiMb8S](http://bit.ly/2DiMb8S)

Highlights of Rare Disease Day at NIH:

(View the full agenda at: [https://events-support.com/Documents/RDD_NIH_2018_Agenda.pdf](https://events-support.com/Documents/RDD_NIH_2018_Agenda.pdf))

**Engaging the Next Generation of the Rare Diseases Community**

This panel focuses on the perspective of youth and young adults with rare diseases. The panelists will share personal experiences and discuss how their generation can support research, access to care, or advocate for change using the power of social media, digital communications, and modern technology.

**Collaborating for Successful Research**

Patient groups play an essential role in advancing rare disease research. Patient organization representatives will discuss how collaborations improve understanding of these disorders and help advance development of new therapies.

**Gene Therapy**

Gene therapy for rare diseases is moving forward rapidly. Panelists will share their perspectives on gene therapy scientific advances and research gaps, and on how to advance gene therapies for more rare diseases.
**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)

**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.

If you are eligible for the study, you will be randomized to take one of the three study drugs: colchicine, dapsone, or azathioprine. You will take this drug for at least 3 months. After that time, if your skin vasculitis is responding (improving) to the drug, you will continue to take this drug for another 6 months (Stage 2), until the end of the study.

**For each visit, you will be asked to:**

Provide information about your medical history and history of medications used for both your vasculitis and any other medical conditions you may have

- Have a physical exam performed
- Get blood tests done as part of normal routine monitoring / standard of care
- Give a urine sample (some visits)
- Have a chest x-ray (only at the first visit)
- Complete questionnaires about how your vasculitis impacts your life
- Take photographs of your skin lesions
- Complete a study diary to track the doses of the study drug(s) you are taking

**Target Enrollment**

**To be eligible to participate, you must:**

- Have isolated skin vasculitis which is vasculitis not associated with any significant problems besides in the skin. To participate, you will need to have a diagnosis of either:
  - Isolated cutaneous small- or medium-vessel vasculitis
  - Cutaneous polyarteritis nodosa (PAN)
  - IgA vasculitis (IgA, formerly Henoch-Schönlein purpura), without active kidney involvement
- Having mild joint or muscle pains, leg swelling (edema), fatigue, mild weight loss, low-grade fevers, and mild anemia will be allowed.
- Have a confirmed diagnosis of vasculitis by skin biopsy before enrolling in this study (earlier, at diagnosis, and/or just prior to enrollment) that confirms the diagnosis of vasculitis
- Have active skin vasculitis lasting for at least 1 month continuously and/or have had 2 or more flares over the six months before enrolling.
- Have active/ongoing skin vasculitis lesions at the time of enrollment (old scars alone will not be considered active vasculitis)
- Be at least 18 years old

You may still be able to participate in the study if you meet the above requirements even if you have a previous bad side effect to one of the study drugs or were treated in the past with one of the study medications.

**You are not eligible participate if:**

- Your vasculitis has significant involvement of other organs besides the skin
- You have been diagnosed with a form of systemic vasculitis such as granulomatosis with polyangiitis (Wegener’s, GPA), eosinophilic granulomatosis with polyangiitis (Churg-Strauss), microscopic polyangiitis (MPA), cryoglobulinemic vasculitis, central nervous system vasculitis, or hypocomplementemic urticarial vasculitis, or
- Other diseases that can cause skin vasculitides such as systemic lupus erythematosus, Sjögren’s syndrome, some cancers, some infections, or some medications.

*Continued on page 19...*
Young Adults

Lauren’s Story Highlights Challenges for Young Adults with Vasculitis

By Ben Wilson

Under the recent "Big Dream" campaign, the Vasculitis Foundation asked me what my dream was for the Vasculitis Community. Part of my response included the idea that it would be great to see all doctors understand and treat vasculitis with the same respect and attentiveness as they do for other serious and life-threatening diseases. This month’s feature highlights a great example of a proactive team of doctors’ approach to identify and care for a young adult with vasculitis.

I had the pleasure of meeting Lauren Becchetti, who received a diagnosis of Takayasu arteritis (TAK) in November 2014. Lauren's initial path to diagnosis mirrors many vasculitis patients, when she began experiencing a rash of scattered symptoms throughout 2013 and 2014. After experiencing extreme fatigue, ocular migraines, and throat pain, among other symptoms, her local doctor made the crucial diagnosis. Having treated patients with TAK, Roger Diegel, MD a rheumatologist based in Kalispell, Montana, was aware of the initial symptoms. “At first, you don’t realize how lucky or important it is to have an early diagnosis,” Lauren says. “It was a huge blessing in disguise.”

Like many in the vasculitis community, Lauren’s journey towards remission is not straight-forward. After getting settled on a regimen of prednisone and Imuran, Lauren decided to move back to her home state of Minnesota in February 2016 to take a job at the Center for Diagnostic Imaging. While the physical move was relatively simple, the difficult part was the challenge of finding a new healthcare team, especially considering the challenges that come with having a rare disease.

An introduction to a pair of doctors with ties to Mayo Clinic was a lucky one for Lauren. The two doctors, Peter Kent, MD and Kenneth Warrington, MD, routinely communicated back and forth to verify she was getting the right care. Ultimately, Lauren’s experienced team of doctors came through in a big way this summer, when she underwent a difficult bypass surgery that lasted nearly 12 hours. While recovery from the surgery was tough and required her to be off work for over a month, Lauren is now doing well. She says her biggest hope is that improved technology will make diagnosis and treatments much easier going forward. “It's extremely important to make doctors aware, and get them the education they need on these diseases.” That is certainly a hope and a dream the vasculitis community can all get behind.

Do you know of a young adult with vasculitis whose story should be shared? Email Ed Becker at: ebecker@vasculitisfoundation.org with the name of the person and Ben may feature an interview with them in a future column.

Takayasu arteritis is a condition that causes inflammation of the main blood vessel that carries blood from the heart to the rest of the body (aorta) and its associated branched blood vessels. Because of the inflammation, the blood vessel walls become thick and make it difficult for blood to flow. Over time, impaired blood flow causes damage to the heart and various other organs of the body. Although the cause remains unknown, Takayasu arteritis appears to be an autoimmune condition, in which cells that fight infection and disease wrongly target the body’s own healthy tissues.

Source: https://rarediseases.info.nih.gov/diseases/7730/takayasu-arteritis
Two Ways to Get the Latest News Online about Vasculitis / Autoimmune Research

1) Visit the VF’s Newsfeed at: http://www.vasculitisfoundation.org/news-about-vf/
   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/
   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! Here is a list of just some of the Facebook Groups that provide education and discussion for patients.

**Victory Over Vasculitis_VF Team Brandon**
http://bit.ly/2DU2Yjn

**Giant Cell Arteritis / Temporal Arteritis / GCA**

**Cryoglobulinemia-Alliance for Cryoglobulinemia**
http://bit.ly/2mVUUqQ

**Vasculitis 2018-Current news & Information**
http://bit.ly/2mRa1ko

**Behcet’s Disease : You Are Not Alone!**
http://bit.ly/2DmXlZN

**Henoch Schonlein Purpura HSP / vasculitis**
http://bit.ly/2mQk9Kk

**Churg Strauss Syndrome Association**

**Autoimmunity Awareness**
http://bit.ly/2nbbKBm
**Australian Vasculitis Perspective**

*By Mark Street*

My story regarding vasculitis is probably not dissimilar to many others with the disease. In late 2015, I acquired a rhinovirus infection. This then led into a bacterial sinusitis. Despite various antibiotic regimes, my sinuses did not improve. In fact the symptoms worsened.

Along with the sinus pain, I had daily nose bleeds, loss of hearing, tinnitus, weight loss (approximately 23 kilograms or 50.70 pounds), blurred vision, night sweats, and finally hemoptysis (coughing up blood). All along, my primary doctors were unable to definitively diagnose my condition. I finally managed to convince one of my general practitioners to let me see an ear, nose and throat (ENT) surgeon. He immediately suspected a systemic condition and sent me off for a chest scan. The scan showed lesions consistent with a number of conditions, including vasculitis.

In January 2016, my health continued to decline and I was finally admitted into hospital to undergo a battery of tests. A CT guided lung biopsy revealed I had GPA Wegeners. I was started immediately on cyclophosphamide along with Rituximab.

Despite the treatment, I relapsed in October and received Rituximab once again to push the disease back into remission. I will receive retreatment as soon as my B cells return.

For me, the mental aspect has been the most challenging. Initially, I was satisfied that I had a diagnosis and treatment plan and was confident that I would be able to quickly return to my love and job of flying; creating music; pursuing my physical activities such as cycling, and my goal of achieving a black belt in Taekwondo. After several months post diagnosis however, I began to realize that I may never fly again; that my ability to write music may cease, due to the inability to hear; and that I would have to give up cycling and Taekwondo due to too much pain. What else could I do with my life? To be honest, I was not in a good mindset.

After some counseling, I decided to attempt to turn the negative aspects of my disease into positives. I began by creating a website [www.vasculitisoz.com](http://www.vasculitisoz.com) to heighten awareness and be a source of information on all things vasculitis as well as inform doctors and patients on the research currently being undertaken in vasculitis, particularly in Australia.

I continued developing friendships and networking with other patients and doctors and was contacted by Professor Richard Kitching, from Monash University. After some initial conversations, Prof. Kitching invited me to be a part of a new group called ANZVASC (Australian New Zealand Vasculitis). It is a collection of Australian and New Zealand specialists, as well as me representing the patient cohort. The overall intent of the group is to promote collaboration and excellence in both research into vasculitis and the clinical care of affected individuals. Essentially bringing health professionals together with patients.

There are a number of scoped goals including establishing a patient clinical quality register; bio banking; clinical trials; holding/hosting national and international conferences for health professionals, researchers, and patients; information dissemination through the main website (yet to be finalized) as well as through the vasculitisoz website.
NEW VF Bob Campaign - Inspiring Our Community & Honoring Bob Sahs

In April 2017, the vasculitis community lost a dear friend and champion of our cause, Bob Sahs.

For nearly 20 years, Bob was a passionate advocate of vasculitis awareness, using his warm and friendly demeanor to connect with everyone he met, so that they could learn more about vasculitis. Bob came to the organization in support of his wife, Elaine, who was diagnosed with Wegener’s/GPA in 1999.

Bob was such an advocate for raising awareness that he typically carried a six-foot banner on his world travels to China, Africa, and other exotic locations. To honor his spirit of awareness and outreach, the foundation has launched a new campaign, VF Bob, to encourage the vasculitis community to spread the word about our vasculitis, by showcasing how we continue to dream big and live with passion.

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2. Hold while taking a photo of yourself living big - walking, traveling, exploring, enjoying a special moment
3. Post your photo on Instagram, Twitter or Facebook using the hashtags #VFBob #VFDreamBig

To learn more about VF Bob visit www.VasculitisFoundation.org/VFBob
The VF Frequently Asked Questions Reference Guide

How do I contact the VF Office?
Email: vf@vasculitisfoundation.org
Phone: 1.816.436.8211

Where can I learn more about my particular type of vasculitis?
Visit the VF Website.
Click on Vasculitis in the gray navigation bar. A drop-down menu listing all the types of vasculitis will appear.

Where can I find a listing of vasculitis specialists and centers throughout the world?
Visit VF Website.
Click on Find a Physician in the gray navigation bar.
Click on the red dot and an information box will appear on the upper right.

What is VF E-News and how do I subscribe to it?
VF E-News is a free monthly electronic newsletter produced by the VF. It features news about upcoming VF events, exclusive interviews and news stories, and patient profiles.
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The VF Dream Big Educational Webinar Series 2018

Topic: Dermatology/Skin Involvement in Vasculitis and the ARAMIS Study

Guest Speaker: Robert G. Micheletti, Assistant Professor of Dermatology at the Hospital of the University of Pennsylvania

Date: Thursday, February 22, 2018
Time: 1:00 p.m. EST

Register: https://attendee.gotowebinar.com/register/7972066620060363521

Dr. Robert Micheletti is an Assistant Professor of Dermatology at the Hospital of the University of Pennsylvania. He is a dermatologist-internist and his clinical and research focus is on complex medical dermatology conditions, including vasculitis and inpatient consultative dermatology. He is also the co-principal investigator for two Vasculitis Clinical Research Consortium (VCRC) pilot projects, including ARAMIS, a randomized multicenter research study.

Dr. Micheletti will discuss the impact of vasculitis on patients and treatment options. He will also discuss ARAMIS, which is evaluating different treatment options for patients with skin vasculitis. Patients with small- or medium-vessel vasculitis that only involves the skin, including some forms of polyarteritis nodosa (PAN) or IgA vasculitis (Henoch-Schönlein purpura) can join ARAMIS. The study will compare how effective colchicine, dapsone and azathioprine are at treating isolated cutaneous vasculitis.

Now Available: Popular Presentations from the 2017 International Symposium

We have compiled six of the most popular presentations from the 2017 Vasculitis Symposium on this exclusive, two-disc, DVD set. These are the entire presentations presented in HD-video, and carefully edited so that you can easily read and follow along with the slides as the instructor shares the information.

You will learn about some of the most critical issues facing patients with vasculitis delivered by the world’s leading experts.

Disk One:
- The Role of Genetics in Vasculitis: Sharon Chung, MD, MAS
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- Integrative Medicine: Arti Lakhani, MD

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- Research as Self-Care: Peter Merkel, MD, MPH

The two-disc set is an exclusive resource available only through the VF Store. The DVD set costs $15, plus shipping and handling.

Order the DVDs at the VF Store: http://vfwebstore.com
Research That Matters Through Collaborative Research Groups

Who should decide what questions need answering? Clinicians? Patients? Caregivers? Researchers? If we want to conduct research that is meaningful, the answer is: all of the above. That is why the Vasculitis Patient-Powered Research Network has launched a Collaborative Research Group the Autoimmune and Systemic Inflammatory Syndromes Collaborative Research Group (ASIS CRG). PCORnet launched 10 other Collaborative Research Groups in addition to ASIS.

PCORnet is comprised of 13 Clinical Data Research Networks, 20 People-Powered Research Networks; the VPPRN is one of the 20 patient-powered research networks.

The ASIS CRG is composed of patients, clinicians, investigators, and other stakeholders who will work together to:

1. Identify and prioritize research questions of high importance
2. Develop approaches for using electronic data to address unmet research needs in prevention, diagnosis, treatment, and outcomes of autoimmune and inflammatory conditions
3. Promote and facilitate patient participation in clinical research;
4. Reduce disparities in access to treatment and participation in research for these diseases.

ASIS CRG Patient-Powered Research Networks and Clinical Data Research

The ASIS CRG is currently focusing on three main research interest areas across all the PPRNs and CDRNs involved. Each area of research interest has an established group within the ASIS CRG dedicated to proposing and conducting research in these areas.

1. Predictive Analytics or Pathway to Diagnosis: Lead Dr. Antoine Sreih (V-PPRN, University of Pennsylvania)
2. Comparative Effectiveness of Biologic (Immunosuppressive) Agents: Lead Dr. Jeffrey Curtis (AR-PoWER, University of Alabama, Birmingham)
3. Reproductive Concerns: Lead Dr. Megan Clowse (Mid-South CDRN, Duke)

The VPPRN will provide updates on the research efforts of the ASIS CRG and will disseminate study findings as they become available.
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!

(ARAMIS) continued from page 9

• You have had bad side effects to two or three of the study drugs (azathioprine, colchicine, or dapsone), or have been treated prior to enrollment with two or three of the study drugs but failed to respond to them, or had to stop two or three of them because of side effects.
• You have evidence of significant liver disease.
• You have evidence of significant low kidney function.
• You have evidence of significant or symptomatic anemia.
• You have another condition that has moderate or high likelihood or requiring treatment with prednisone during the study.
• You have active cancer or history of malignancy within the previous 5 years. Note: If you have been in remission of a cancer for greater than 5 years, or have/had non-metastatic prostate cancer, treated basal or squamous cell carcinoma of the skin, or treated cervical cancer, you may still be able to be enrolled.
• You have an active uncontrolled or serious infection that may stop you from taking or may impact the use of the study medications.
• You are unable to consent (agree to be part of this study)
• You are pregnant or nursing

Note: There are other things that may stop you from being in the study.

How to participate

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: https://www.rarediseasesnetwork.org/cms/vcrc/Research/Studies/5562
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
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- 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/

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:
There are 2 ways you can join the TAPIR trial:
You can participate from the privacy of your own home.
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
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Check out the Hottest items in the VF Store!

- Micro Fleece Beanie (black) $22.00 $15.00
- Women’s Galaxy Jacket (indigo) $69.00 $48.00
- Nuvola Cotton Heathered Hood (gray) $65.00 $45.00
- Men’s Long Sleeve T-Shirt (charcoal) $35.00 $26.00

http://vfwwebstore.com
VF Calendar of Events • 2018

2018

February 25, 2018
Violin for Vasculitis Concert
First Baptist Church
124 Kings Hwy. East
Haddonfield, NJ
Allison Lint and Julia Chinn
violin4v@gmail.com

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

March 12, 2018
Sacramento Area VF Chapter Meeting
6:00 p.m.
Hofbrau Restaurant, 2500 Watt Avenue, Sacramento, CA
Contact: Hedy Govenar, HGovenar@govadv.com

March 15 - 17, 2018
2018 International Conference on Large Vessel Vasculitis and Related Disorders
Mayo Clinic
Rochester, Minnesota
For health care professionals:
Website: ce.mayo.edu
Email: cme@mayo.edu
March 16, 2018

April 7, 2018
Violin for Vasculitis - Free Recital
The Modbo Gallery
17 C E Bijou Street
Colorado Springs, CO 80903
Contact: Allison Lint, violin4v@gmail.com

April 7, 2018
North Carolina VF Chapter Meeting
100 Sprunt St, Chapel Hill, NC
Speaker/Topic: Will Frey of Pathfinders Coaching: Stress Management
Jill Powell, jill_powell@med.unc.edu

April 28, 2018
5th Annual Vino for Vasculitis 2018
Junction Salon and Bar in downtown Raleigh, NC 27601
327 W Davie St #114, Raleigh, NC 27601
Organizer: Jess Foster
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May, 2018
Vasculitis Awareness Month

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