VF 2018 Annual Appeal Launches “Join Our Journey” Campaign

by Ed Becker, Director of Marketing and Communications

Last year when the Vasculitis Foundation asked the vasculitis community to “dream big” the response was powerful, positive, and personal. Patients and caregivers from around the world shared their dreams about what they wanted to see that would bring hope, and real impact on their lives.

The campaign resonated so deeply with the vasculitis community, the VF decided to make it an ambitious road map for the future. Over the next three years the VF will focus on the three key areas of earlier diagnosis, better treatment, and quality of life.

Focus On Three Key Areas
“Through our surveys, conferences, and conversations with patients we realized these three areas have the most direct impact on patients and their families,” says Joyce Kullman, Executive Director of the VF. “The collective dream is all about improving the overall quality of life for patients with vasculitis. Earlier diagnosis is critical to lessening the potential impact of the disease. Secondly, developing new and less invasive treatments and better medications, which could reduce the toll that current medications have on the body. Finally, while a cure is most desired, until that happens we want to improve the quality of life. These are the three parts of the big dream.”

Our Journey Forward
Beth Westbrook, Director of Development, views these concepts as an integral part of the VF and each one will be showcased during the Annual Appeal Campaign over the next three years. “The Campaign focuses on programs and services important to the vasculitis community,” Westbrook says. “We have established these three goals as milestones on what is essentially a patient’s journey.” Last year the generosity during the annual appeal was unprecedented. “We are grateful not only for the financial support, but also the contributions of time, talents and dedication of our volunteers.”

Programs such as the Recognizing Early Diagnosis (V-RED), development of educational materials for medical professionals, and funding new studies such as Pathways to Diagnosis are all tangible examples of the VF’s early diagnosis initiative.

Pathway to Diagnosis (P2D), an Innovative Study with the Goal of Reducing Delays in Diagnosis

P2D Objective
Using big data to accurately predict a diagnosis using predictive analytics and machine learning methods.

The Reality: Delays in diagnosis for patients with vasculitis
Despite remarkable medical advances, diagnostic delays for patients with vasculitis remain extremely common and are a major cause of increased morbidity and mortality.

This project directly responds to, and aligns with, the top research priorities of patients with vasculitis; specifically, to conduct research that will reduce the delay in diagnosis for new patients and improve clinical outcomes.

(continued on Page 6)
Dear Friends,

We recently participated in the PALS United for Lung Health Advocacy Roundtable to meet other advocacy groups and learn how we can better collaborate with them to improve the lives of our patients struggling with lung disease.

One of the key objectives of the meeting was to set some common goals and action steps to raise the profile of lung disease and advance patient-centered solutions relating to access to care, services, and innovations in lung health. The VF is working with the other attendees to develop messaging for two upcoming events:

- On September 18, Tonya Winders, President and Chief Executive Officer of the Asthma and Allergy Network, will be speaking at the United Nations on lung health.
- On September 25, the VF will join other organizations to support World Lung Day, to rally advocacy for respiratory health and air quality globally. The global impact of the five main respiratory diseases (COPD, asthma, respiratory infections, tuberculosis (TB) and lung cancer) is massive. Combined they represent an immense burden of suffering, as well as a leading cause of death and disability. They include both acute and chronic, infectious and non-communicable diseases.

We recognize that many patients with vasculitis do not suffer from lung disease, however we believe that this model of collaboration will guide us as we extend our outreach in the rare disease, autoimmune, rheumatology, nephrology, dermatology, and neurology communities.

The VF is also a member of the Kidney Health Initiative (KHI) and we look forward to sharing more information about our work with the coalition in the future.

Sincerely,
Joyce

Joyce A. Kullman
Executive Director

To learn more, please visit the calendar of events on the website or email the office at vf@VasculitisFoundation.org or call 816.436.8211.
Ohio State University Opens Multidisciplinary Vasculitis Clinic

by John Fries

The Ohio State University Wexner Medical Center, a large academic medical center on the campus of The Ohio State University in Columbus, Ohio, has established an on-site Multidisciplinary Vasculitis Clinic to provide enhanced care for patients with vasculitis.

The Clinic, which opened in December 2017 and is now treating more than 60 patients, is located at 1800 Zollinger Road.

Because vasculitis often affects multiple organ systems, many patients require care and treatment provided by a collaborative team representing multiple specialties, including rheumatology, nephrology and pulmonology. The Multidisciplinary Vasculitis Clinic brings these specialists together in the same location, allowing patients to interact with multiple providers during the same visit. The Clinic offers patients a streamlined experience as well as opportunities to participate in research studies, while fostering communication among care providers.

“This collaborative environment truly allows us to work together to formulate a cohesive plan for patients with these complex chronic diseases,” said Lynn Fussner, MD, Assistant Professor of Clinical Medicine in the Division of Pulmonary, Critical Care, and Sleep Medicine and pulmonologist at the Clinic. “Patients are very engaged in the process and seem to appreciate the team approach.

We are committed to providing vasculitis patients with the highest level of care possible.”

“As a patient with vasculitis I can tell you this clinic is so important to those of us who need their expertise and technology,” said Sandy Nye, who lives in Mansfield, Ohio.

Sandy has been treated by Dr. Fussner for a year, and she believes the new clinic will be a resource for patients in that area. "Managing vasculitis requires a knowledgeable staff of medical professionals who know about the latest research in treating the disease. I know that Dr. Fussner and the other doctors at this clinic will provide that expertise and guidance to their patients," said Nye.

In addition to Dr. Fussner, physicians at the Clinic are rheumatologist Alexa Meara, MD, MS, and nephrologist Salem Almani, MD, MS. Physicians at the Clinic also collaborate closely with colleagues in Dermatology and Otolaryngology.

Formerly known as The Ohio State Medical Center, The Ohio State University Wexner Medical Center has been named among the best hospitals in the U.S. by U.S. News and World Report for 25 consecutive years, and is recognized as a national leader in nephrology and pulmonology, among other specialty areas.

More details are available at wexnermedical.osu.edu/vasculitis

New Jersey Physician Awarded V-RED Recognition for Early Diagnosis of Takayasu’s Arteritis

Maureen Howard knew something was physically off-kilter when she began experiencing extreme fatigue, weight loss, difficulty breathing, rashes, and other symptoms. After visiting numerous specialists, Maureen went to Dr. Keith Goldstein at Huterdon Medical Center in Flemington, New Jersey.

What Dr. Goldstein discovered when examining Maureen was alarming. “He found me to be lacking a right radial pulse and left arm blood pressure, carotid and subclavian bruits, and abnormal blood work,” Maureen shared. “He discussed at length the characteristics of large vessel vasculitis and its treatment options.”

Dr. Goldstein referred Howard to John Hopkins Vasculitis Center, where she enrolled in their Translational Takayasu’s Arteritis Study and began treatment for vasculitis. Today, Maureen says she is on Humeria and Cellcept with the status of “inactive disease” confirmed by a PET scan.

Maureen nominated Dr. Goldstein for the VF’s V-RED Award because he was crucial in getting her a diagnosis, and helping her begin treatment.

(continued on Page 12)
Highlights from the Kansas University Vasculitis Conference

by Suzanne DePaolis
VF Board of Directors

On August 4, I had the pleasure of attending and speaking at the Kansas University – VF Vasculitis Educational Conference. I am an education junkie, so I love attending these conferences. I always end up learning a few new things that can better help me better manage my EGPA/CSS vasculitis during each and every meeting.

We are extremely lucky that we have the Vasculitis Foundation working so hard to bring these regional one-day conferences to many regional vasculitis centers. Here are some of the highlights from the meeting:

› Tanaz A. Kermani, MD, MS from UCLA gave an excellent overview of the medications used in treating vasculitis and the side effects of those medications. She talked about some of the new medications that could potentially reduce the need for steroid therapy.

› I had the pleasure of speaking to the audience about “Finding a New You” after a vasculitis diagnosis. Drawing from my own experience I explained that after a diagnosis you have to accept and adjust to a new normal.

› Jason Springer, MD, MS gave the closing comments and everyone left feeling positive about the future of vasculitis research.

You can read my full blog posting at https://bit.ly/2vJ2lpA

More than 60 participants attended the August 4, 2018, VF Vasculitis Educational Conference.

Vasculitis Foundation Regional Patient Conference

› Saturday, November 10, 2018
› Time: 9:00 a.m. - 3:30 p.m.
› UCLA Center for Health Sciences, 10833 LeConte Avenue, Los Angeles, CA 90095

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<th>Time</th>
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<tr>
<td>9:00 a.m.</td>
<td>Registration, Light Continental Breakfast</td>
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<td>Welcome and Introduction</td>
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<td>Tanaz A. Kermani, MD, MS</td>
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<td>Division of Rheumatology, UCLA</td>
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<td>10:00 a.m.</td>
<td>Vasculitis Risk</td>
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<td>Lindsay Forbes, MD, MSc</td>
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<td>Earlier Diagnosis of Vasculitis</td>
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<td>Antoine G. Sreih, MD</td>
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<td>Penn Vasculitis Center Univ. of Penn.</td>
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<td>Morning Break</td>
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<td>Vasculitis Patient-Powered Research Network</td>
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<td>Joyce Kullman, Executive Director, VF</td>
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<td>Kalen Young, MA</td>
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<td>Network Manager</td>
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<td>11:45 a.m.</td>
<td>Lunch</td>
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<td>Suzanne DePaolis, Board of Directors, VF</td>
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<td>12:40 p.m.</td>
<td>Nerve Involvement in Vasculitis</td>
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<td>Perry Shieh, MD, PhD</td>
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<td>Director, Neuromuscular Division, UCLA</td>
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<td>Dealing with Nerve Involvement from Vasculitis</td>
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<td>Francy Shu, MD</td>
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<td>Division of Neuromuscular Medicine, UCLA</td>
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<td>Q&amp;A Regarding Nerve Involvement in Vasculitis</td>
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<td>Dr. Shieh and Dr. Shu</td>
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<td>Stephen Sideroff, PhD</td>
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<td>Department of Psychiatry &amp; Biobehavioral Sciences</td>
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<td>Director of the Raoul Wallenberg Institute of Ethics</td>
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<td>Vasculitis, Looking Ahead</td>
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<td>Joyce Kullman, Executive Director, VF</td>
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Victory Over Vasculitis Update: Brandon Hudgins Battles Back

by John Fries

On a hot, muggy evening in July, Brandon Hudgins competed in the Liberty Mile in Pittsburgh, Pennsylvania, and finished third, ahead of one longtime rival, but behind two others. “My times weren’t very fast due to the sweltering conditions,” Brandon recalled, “but the effort was there. I fought off many demons and negative thoughts during that last mile, that were begging me to give into the pain and horrible conditions. It was a huge step in the right direction, mentally, as I begin to prep for shorter races the rest of the summer.”

He added, “As the Liberty Mile approached, I found myself getting extremely anxious. I couldn’t quite put my finger on it for the weeks leading into the race, but basically, the fear of racing the best in the country again slowly started to wear me down. Luckily, by race day I found myself in the zone when the gun went off. The 4:10 I ran was seven seconds faster than I was capable of in May, so I knew my body was finally responding to the training and work I had done since March.”

Unfortunately, in late July, blood work revealed that Brandon is still battling some lingering anemia. “A wonderful side effect that can occur following Rituxan treatment,” he said sardonically. “This explained a lot about how I was feeling during training sessions and races.

“With a 10-15% reduction in oxygen-carrying capacity, there is no way that I can return to the level of fitness and racing capabilities that I desire. I had to decide whether to scrap my remaining races or show up in less-than-ideal fitness that didn’t reflect my workload. After long talks with my coach, girlfriend, and parents, we all decided I need to get back out there and keep fighting.”

Brandon noted that he’d battled far tougher odds in life.

“While I talk about my running goals, they are the goals of the entire vasculitis community and fellow #victoryovervasculitis campaign members: live the life you wish and not let our vasculitis stop us from chasing our dreams. I know that with each passing month I’ll be stronger. Our campaign is not done reaching and inspiring people. The more places I visit, the more people I get the chance to share our story with, and the bigger mountains we climb, the easier it’s going to be for the next generation of patients with vasculitis.”

Brandon said there are still a few races left this year and his goal is to focus on both the mental and physical challenges and finish each race satisfied with his time and effort.

“While my times won’t be up to my normal standard,” he said, “I’ve still got lessons to learn and experience to gain.” He added, “Whatever your journey, path, or mission in life is, listen to it. It will bring great wisdom.”

Brandon Hudgins flashes the Victory Over Vasculitis sign after running the Liberty Mile Race. Photo: Ed Becker

“Whatever your journey, path, or mission in life is,
listen to it. It will bring great wisdom.”

-Brandon Hudgins
Pathway to Diagnosis, cont.

Why are there still delays in diagnosis?
The delays in diagnosis are frequently attributed to:

- The rarity of the disease
- Providers’ lack of awareness of the disease
- Inadequate medical knowledge
- Practice referral patterns

With recent increases in clinical and administrative demands on clinicians, there is often insufficient time to understand, gather or even piece together patients’ complex and often fragmented medical histories.

Each patient then becomes a data challenge with a vast amount of complicated information that is not always easily accessible for care providers.

Potential Solution: Harnessing the power of “big data”
What can be done when patients become a data challenge with immense amounts of complicated information that isn’t easily accessible for the care providers trying to piece together the bigger picture and find a correct diagnosis?

In today’s technology driven world, large consumer companies like Amazon can suggest to you merchandise you are likely to buy based on an algorithm. This algorithm is designed to collect large amounts of data about you (e.g. what you like to buy, where you live, how old you are, etc.) and accurately predicts what items you are likely to buy. In the healthcare industry, large amounts of data from lab results to medications are collected about each person, similar to how data is collected about one’s buying habits. The same basic principle of using an algorithm, or model, to predict what one might purchase can also be used to sift through, and make sense of an individual’s health data.

Testing a machine learning model to achieve a diagnosis
Machine learning capabilities and predictive analytics offer a potential solution for assisting busy providers in sorting through an individual patient’s “big data” to establish accurate diagnoses and reduce diagnostic delays.

“We’ve seen tremendous advancements in treatment options available to patients, but they can’t be offered until an accurate diagnosis is obtained. We are excited that P2D will accelerate diagnosis and allow our patients to start their journey to wellness much sooner.”

George Casey, Co-Principal Investigator VPPRN, VF Board Member

VF Board of Directors Seeks Candidates

The VF Board of Directors governs on behalf of the members of the Vasculitis Foundation and ensures appropriate organizational performance which includes fulfilling the mission of the organization, determining its future direction, and managing the organization’s fiscal health.

The Board is seeking candidates who will bring a high level of motivation and personal interest in the work of the VF, and a desire to help people with vasculitis get diagnosed sooner, receive the best care available, and gain the support they need to best manage their disease. Candidates will bring a strong knowledge in areas such as strategic planning and assessment, program development, fundraising, and finance. We seek patients, family members, and health care professionals, representing different types of vasculitis, professional experience, residence, age, race, and ethnicity.

The board meets quarterly; two meetings are held in person and two meetings via conference call and holds additional meetings as needed and are also asked to serve on committees. Board members serve three-year terms.

An election of board members will be held at the 2018 VF Annual Membership Meeting on October 18, in Chicago.

For more information, please contact Joyce Kullman, VF Executive Director: jakullman@vasculitisfoundation.org
Kidney Biopsies Help Predict End-Stage Disease in Older AAV Patients

July 23, 2018
by Iqra Mumal

A kidney biopsy is valuable in establishing a diagnosis and prognosis for end-stage renal disease in older patients with ANCA-associated vasculitis who have kidney involvement, although they are not useful for predicting overall survival, a study shows.

"Prognosis and Histological Classification in Elderly Patients with ANCA-Glomerulonephritis: A Registry-Based Cohort Study" was published in May in BioMed Research International.

Although ANCA-associated vasculitis (AAV) can occur at any age, the risk of fatal AAV seems particularly high among elderly patients. Nearly half of patients older than 80 die within a year of diagnosis.

Patients with AAV frequently have kidney involvement, which manifests as focal necrotizing glomerulonephritis (ANCA-GN) — an acute inflammation of the kidney. ANCA-GN is associated with a poorer outcome and increased risk for end-stage renal disease (ESRD), which occurs when the kidneys no longer work as they should, leaving patients dependent on dialysis or a kidney transplant.

Kidney biopsies are often conducted to establish and confirm a diagnosis of ANCA-GN. Biopsies are used to study the structure and composition of cells and tissues. They also help determine prognosis by classifying patients into four subcategories — focal, crescentic, mixed, and sclerotic.

Age has been known to affect the validity and clinical value of histological classification in patients with ANCA-GN. There is also a risk associated with doing a kidney biopsy in older patients. That, and the fact that a kidney biopsy is not necessary to diagnose ANCA-GN can lead physicians to question a biopsy’s merits.

So researchers, using information from the Norwegian Kidney Biopsy Registry and the Norwegian Renal Registry, analyzed the prognostic value of the classification in patients age 70 and up at the time of diagnosis. Among 81 patients examined, 20 progressed to ESRD and 34 died.

After one year, 97% of patients in the focal subcategory were alive and without ESRD. That dropped to 76% in the crescentic group, 70% in the mixed group, and 49% in the sclerotic group.

At five years, the same 97% of patients were alive and without ESRD. For those in the crescentic, mixed, and sclerotic groups, the numbers were 63%, 57%, and 49% respectively.

Both the one-year and five-year ESRD-free survival were statistically different among groups, indicating that histological classification in older patients is useful for predicting ESRD.

However, overall survival did not vary among groups, suggesting that histological classification is not useful for predicting survival.

Researchers also identified other factors that influence whether a patient will be alive and without ESRD at year one. These include the glomerular filtration rate (an indication of kidney function), amount of protein in the blood, presence of proteins in urine, and percentage of normal glomeruli — the filtering units of the kidney. These factors are known as prognostic markers.

"Histological classification predicts risk of ESRD including in elderly patients (≥70 years) with ANCA-GN, and this finding supports the diagnostic value of kidney biopsy for establishing both the diagnosis and prognosis," researchers wrote. "Therefore, when feasible, a biopsy should be performed to confirm diagnosis, including in elderly patients."


Second Annual Victory Over Vasculitis 3V3 Basketball Tournament

Fourteen teams participated in the Second Annual Victory Over Vasculitis 3V3 Basketball Tournament on July 21, in Medford, MA. Cleary Club, a group of alumni from Bentley University, won their second straight championship at the VF fundraiser. The event raised $9,200.

Patrick Lane, diagnosed with vasculitis in 2015, is the force behind the basketball competition. Combining his love of basketball with a passion for advocacy, Lane brought together friends and family to not only raise funds, but also awareness of vasculitis.
Vaccine Benefits

Once your immune system is trained to resist a disease, you are said to be immune to it. Before vaccines, the only way to become immune to a disease was to actually get it and, with luck, survive it. This is called naturally acquired immunity. With naturally acquired immunity, you suffer the symptoms of the disease and also risk the complications, which can be quite serious or even deadly. In addition, during certain stages of the illness, you may be contagious and pass the disease to family members, friends, or others who come into contact with you.

The Impact of Vaccines in the United States

Vaccines, which provide artificially acquired immunity, are an easier and less risky way to become immune. Vaccines can prevent a disease from occurring in the first place, rather than attempt to cure it after the fact.

Benefits for You and Others

It is also much cheaper to prevent a disease than to treat it. In a 2005 study on the economic impact of routine childhood immunization in the United States, researchers estimated that for every dollar spent, the vaccination program saved more than $5 in direct costs and approximately $11 in additional costs to society.

Vaccines protect not only yourself but also others around you. If your vaccine-primed immune system stops an illness before it starts, you will be contagious for a much shorter period of time, or perhaps not at all. Similarly, when other people are vaccinated, they are less likely to give the disease to you. Vaccines protect not only individuals but entire communities. That is why vaccines are vital to the public health goal of preventing diseases.

If a critical number of people within a community are vaccinated against a particular illness, the entire group becomes less likely to get the disease. This protection is called community, or herd, immunity. On the other hand, if too many people in a community do not get vaccinations, diseases can reappear. In 1989, low vaccination rates allowed a measles outbreak to occur in the United States. The outbreak resulted in more than 55,000 cases of measles and 136 measles-associated deaths.

Source: National Institute of Allergy and Infectious Diseases
https://www.niaid.nih.gov/research/vaccine-benefits

What You Need to Know About Vaccines

Watch the October 2017 Vaccines and Vasculitis Webinar presented by Eric Ruderman, MD, Associate Chief, Clinical Affairs, Division of Rheumatology Northwestern University Feinberg School of Medicine.

Dr. Ruderman provided a detailed background on how immunization works, what happens when a person is vaccinated, the effectiveness of vaccines, and the many different types of vaccines. He discussed live vaccines, including those for shingles and flu. After his presentation, Dr. Ruderman answered questions from the audience.

It is very important that patients with vasculitis and their family members talk with their physicians about what vaccines they should receive.
https://www.youtube.com/watch?v=yGOhViqT2pQ&feature=youtu.be
FDA Clears 2 PerkinElmer’s Assays to Help Diagnose ANCA Vasculitis

August 2, 2018
by Jose Marques Lopes, PhD

The U.S Food and Drug Administration (FDA) cleared two assays to be used in the diagnosis of ANCA-associated vasculitis (AAV), according to PerkinElmer.

Specifically, the FDA cleared the EUROPLUS Granulocyte Mosaic and the EUROIMMUN ANCA IFA — also referred to as EUROIMMUN IFA Granulocyte assays — to be used with the company’s EUROPattern microscope, which also received FDA clearance. Germany-based EUROIMMUN is owned by PerkinElmer.

The assays, commonly known as ANCA Mosaic, are tests that use fluorescence to determine ANCA antibodies of the immunoglobulin class IgG, the most abundant antibody form in humans.

The EUROPLUS Granulocyte Mosaic assay enables specific detection of anti-proteinase 3 (PR3), anti-myeloperoxidase (MPO), and anti-glomerular basement membrane (GBM) antibodies, which may all be found in AAV patients.

As approximately one-third of patients with anti-GBM disease — an autoimmune condition causing inflammation of small blood vessels in the kidneys and lungs — are positive for ANCA antibodies, current recommendations include parallel testing for both ANCA and anti-GBM in the presence of kidney problems.

Singh underscored the “complete and reliable ANCA screening result” achieved with the assays without needing to perform several analyses per sample. “This can minimize the risk of error and greatly benefit patients who are suffering from these disorders,” Singh added.

Specifically, EUROIMMUN’s BIOCHIP technology enables the simultaneous detection of antibodies against various organs or infectious agents with minimal use of samples.

In addition to detecting anti-PR3, anti-MPO, and anti-GBM antibodies, which help in diagnosing ANCA vasculitis and GBM disease, the test also measures for antinuclear antibodies, which are often found in patients with lupus, Sjogren’s syndrome, scleroderma, and other autoimmune diseases.

In turn, the fully automated EUROPattern system was designed for computer-aided microscopy and, according to PerkinElmer, enables faster processing, as well as automated classification and evaluation of results.

By targeting the underlying inflammatory disease process while permitting otherwise normal functioning of other components of the immune system, avacopan may provide a basis for a totally new way of improving ANCA vasculitis outcomes.

The Phase III ADVOCATE trial is designed to show the effect of avacopan on improving active vasculitis, as well as testing durable clinical benefit, which is still an unmet need in this patient population. The ADVOCATE trial will evaluate the safety and efficacy of avacopan following 52 weeks of treatment. Top-line data from the ADVOCATE trial is expected in the fourth quarter of 2019.

ChemoCentryx is very grateful to the patients and the dedicated clinicians who took part and are continuing to take part in this study.

Largest, Randomized Controlled Trial of a New Pharmacologic Agent to Treat ANCA Vasculitis Completes Patient Enrollment

ChemoCentryx Pivotal Phase III ADVOCATE Evaluates Safety and Efficacy of Avacopan in the Treatment of ANCA-Associated Vasculitis

Patient enrollment is now complete in the Phase III ADVOCATE clinical trial of avacopan in the treatment of patients with ANCA-associated vasculitis. The trial exceeded its 300 patient goal with 316 patients enrolled and more than 200 activated clinical sites in 20 countries worldwide.

Avacopan is an orally-administered drug candidate that inhibits the complement C5a receptor, or C5aR.

By targeting the underlying inflammatory disease process while permitting otherwise normal functioning of other components of the immune system, avacopan may provide a basis for a totally new way of improving ANCA vasculitis outcomes.

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ChemoCentryx is very grateful to the patients and the dedicated clinicians who took part and are continuing to take part in this study.
A Parent’s Guide to Section 504 in Public Schools

by Mary Durheim, GreatSchools.org

Read the entire article at: https://bit.ly/2GYcHWa

Section 504 — just what exactly is it? You’ve probably heard about it, but every school district addresses Section 504 in a different manner. Some districts have even been heard to say, “We don’t do that in this district.” But in fact, compliance to Section 504, which is a federal statute, is not optional.

What is Section 504?
Section 504 is a part of the Rehabilitation Act of 1973 that prohibits discrimination based upon disability. Section 504 is an anti-discrimination, civil rights statute that requires the needs of students with disabilities to be met as adequately as the needs of the non-disabled are met.

What is an “impairment” as used under the Section 504 definition?
An impairment as used in Section 504 may include any disability, long-term illness, or various disorder that “substantially” reduces or lessens a student’s ability to access learning in the educational setting because of a learning-behavior- or health-related condition. Many students have conditions or disorders that are not readily apparent to others. They may include conditions such as specific learning disabilities, diabetes, epilepsy and allergies. Hidden disabilities such as low vision, poor hearing, heart disease or chronic illness may not be obvious, but if they substantially limit that child’s ability to receive an appropriate education as defined by Section 504, they may be considered to have an “impairment” under Section 504 standards.

What types of accommodations will my child receive if determined eligible under Section 504?
Each child’s needs are determined individually. Determination of what is appropriate for each child is based on the nature of the disabling condition and what that child needs in order to have an equal opportunity to compete when compared to the non-disabled.

Accommodations that may be used, but are not limited to, include:
- Extended time on tests or assignments
- Rearranging class schedules
- Taping lectures
- Peer assistance with note-taking

Learn how a Section 504 plan is helping to make attending school safer, easier, and more productive for young adults with vasculitis.

“My daughter, Leah, was diagnosed with GPA at 10 years old. As a parent I advocate for her with the school. I set up a 504 plan around the issue of exposure to germs which is critical when you are being treated for vasculitis.

Each classroom has sanitation wipes that Leah can use to sanitize her desk and chair. She is allowed to leave and wash her hands afterwards, too. Also, she can wash her hands in between classes if necessary. If there is a class where there are shared supplies, Leah has her own supplies that only she uses.”

Helaine Goldman Meyer, and Leah

“My daughter, Sara, will start sophomore year of high school this week. She has GPA vasculitis.

We have met with the school nurse and the 504 coordinators. A 504 plan will provide specific accommodations for her throughout the school year. Ours will give her extra time to turn in assignments as she frequently misses school for appointments and hospitalizations, a pass to leave class if she needs to go to the nurse’s office, permission to carry water and snacks, permission to use the elevator at school. Sara’s main issues are fatigue and bronchial stenosis which causes shortness of breath. This 504 plan will follow her through college.”

Teri Gignac Raspanti
Balancing School and Vasculitis: Perspectives from Students and Parents

by Ed Becker

Being a young adult with vasculitis is challenging enough, but trying to navigate through school while managing the illness demands extraordinary skills. We asked a cross-section of young adult patients (and some parents) how they found the balance between health and academics.

“One of the hardest things for me as a mom was encouraging our son to take over managing his illness. Matt was diagnosed with GPA in 2015 as a sophomore in high school, so I organized all of his care. I realized I needed to turn things over to him, like ordering and setting up his meds, helping him start communicating directly with his doctors, and keeping track of when his labs are due. It’s still a work in progress for me to let go, but next week he will be heading back for his sophomore year of college and is doing very well.”

-Lori Larson

“I will be going to university in September. I was diagnosed with IgA/Henoch-Schönlein purpura (HSP) 11 years ago. I’ve found that during my school exams my HSP tends to get worse and it has been difficult for me to manage that and also study and do reviews. Stress and vasculitis do not mix! I was lucky that my school understood my situation. The best thing you can do to stop the flare ups from being so bad is to try and keep your routine normal. Don’t make any massive changes like staying up really late to study because that will only make it worse (speaking from experience!).”

-Alys Bailey-Wood

Author Chronicles Search for Answers in “Prognosis for Misdiagnosis”

by Ed Becker

The reason why Eileen Radziunas wrote a book about her struggle with Behcet’s is almost as powerful as her story itself. Initially she simply wanted to keep notes about her condition because she didn’t know if she would survive the disease.

“I started out with no intention of writing a book,” said Radziunas. “I was so ill – actually convinced I was dying – and I wanted to provide the medical profession with every detail I could remember in the hope of giving enough information to be accurately diagnosed – and more importantly, appropriately treated. However, because of the multiple specialists I consulted, nationwide, the notes became sentences – and the sentences became chapters – and the chapters became a book.”

In “Prognosis for Misdiagnosis” Eileen shares how an onset of oral/vaginal ulcers, inflamed joints, and a host of other symptoms became chronic, increasing excruciating pain. Her book also documents the string of frustrating doctor visits that proved not only a waste of time, but made her increasingly frustrated and angry by dismissive, unhelpful doctors.

Her search to get a diagnosis for the “mystery illness” is recounted through several chapters of the book— but in reality it spanned a couple of decades until she finally got the answers from a caring, competent doctor.

“He was refreshingly confident in his own medical expertise, in a humble but decisive way – in that he did not refer to, or depend on medical records from other specialists. Consequently, his opinion – and accurate diagnosis – was determined without bias,” said Radziunas.

Her Behcet’s was treated with large doses of prednisone and Cytoxan which ultimately helped her to begin living a somewhat normal life again.

“Once the disease was identified and managed by a skilled rheumatologist I was able to live a far more normal and enjoyable life – the type I remembered, and missed, from before the disease became so active,” said Radziunas.

“Prognosis for Misdiagnosis” can be ordered on Amazon at https://amzn.to/2Mh0cv4
Young Patient Inspired by Other Achievers with Vasculitis: Completes Kids’ Triathlon

This edition’s patient profile features Katrina Bargender, a high school senior from Racine, Wisconsin and a Takayasu’s arteritis (TAK) patient.

by Ben Wilson

Diagnosed with TAK in March 2016 and faced with enormous obstacles on her road to recovery, Katrina attended the 2017 International Vasculitis Symposium in Chicago, which was the turning point in her vasculitis battle.

Meeting VF pioneers like Brandon Hudgins and Kate Tierney, among many other young adults, served as great inspiration for Katrina, and she has stayed in touch with them ever since. “It was such a blessing to find other people who understood what I was going through,” she said. “I was able to relate so much to Brandon and Kate, and I’m definitely able to find a positive side to things now, no matter what.”

Since last summer, Katrina’s health has gradually improved. After several trips to the National Institutes of Health in Maryland for consultation, her TAK is now in its “quiet” phase. And while weekly methotrexate infusions are still required, she is now able to be much more active than in the past, an ability that came in handy this summer.

Last December, Katrina’s physical therapist told her about a nearby triathlon for kids with disabilities that would be held the following summer and Katrina set a goal to compete. After working hard to build up her stamina, she dedicated two months leading up to the race to train, which included learning how to swim. The August triathlon included a 200-meter swim, 2-mile bike, and 1-mile walk. It was no sweat for Katrina, who finished in 1 hour, 20 minutes. “I haven’t felt that much pain in a long time, but it was all worth it,” Katrina remembers.

In a nod to Brandon, an elite distance runner, she sprinted across the finishline as family and friends cheered her on.

Young Adult Spotlight

V-RED Recognition, cont.

“Even though she is limited to homebound instruction from tutors at Racine Case High School, Katrina hasn’t used her difficult circumstances or the fact she must teach most of the course work to herself, as an excuse, and is on track to graduate at the end of the year as a result. Her goal is to become a doctor, an occupation that piqued her interest while learning about the treatments for her own disease. “I would research everything and ask the doctors all sorts of detailed questions,” Katrina says. “And they would all say, 'I wish my students asked the kind of questions you do.' When I heard that, I knew this field was something I wanted to go into.”

Katrina’s story is a powerful example that having great perseverance and optimism, even in the most difficult of times, can help anyone get over the many mental and physical hurdles that come with fighting vasculitis. Many of us within the community are incredibly proud of Katrina and her continued inspiration by virtue of her hard work and never-give-up attitude.

"It is extremely important to reward physicians who are instrumental in identifying and successfully treating vasculitis and to share who they are and how they were successful in the process with others," Maureen said.

She continues to see Dr. Goldstein to help manage her symptoms and is grateful for his level of care.

"I am so lucky to have found such a caring, brilliant, knowledgeable physician who answers my texts, tells me no concern of mine is silly, empowers me to be active in the treatment of my disease and is not intimidated by other members of my healthcare team,” Maureen said. “I know I wouldn’t be here today to submit this application if it weren’t for Dr. Goldstein."
Triathlete with GPA declares Victory Over Vasculitis

by John Fries

On Sunday, July 22, Abby Cobey woke up in Lake Placid, New York, a village in the Adirondack Mountains known for its picturesque natural environs—trees, trails and lakes—and for being the site of the 1932 and 1980 Winter Olympic Games. It was an important day for Abby, a psychologist from Alexandria, Virginia who has dedicated her career to helping clients manage a variety of personal issues. This, however, was a day that Abby would test her own mettle.

In a short time, Abby would join many other people from across the U.S. who were in town to take part in the Ironman Lake Placid, the nation’s longest-running Ironman event. Like them, Abby had spent considerable time training for the event. Unlike many of them, Abby had spent the past few years dealing with granulomatosis with polyangiitis (GPA), an autoimmune disorder that primarily affects the sinuses and respiratory system.

Abby completed the 2.4-mile swim, 112-mile bike ride across wet, hilly terrain and 26.2 miles of running and walking in 15 hours and 38 minutes, later declaring “Victory over Vasculitis!” on her Facebook page.

Just three years before, in 2015, Abby had planned to compete in her first-ever ironman distance race as part of a fun, friendly competition with her older brother, Fred. Two months before that event she was diagnosed with GPA.

“Listen to your body, stay focused and keep your eye on the prize.”

- Abby Cobey

“The illness changed my life significantly,” she recalled. “I went from focusing on my training to training while under my doctors’ care. I was pushing my limits—I wanted to be able to continue pushing my limits and prepare for the race. In 2015, I did an iron distance triathlon in Wilmington, North Carolina called the PPD Beach2Battleship Triathlon and chose to delay immunosuppressive treatment until after the race.”

Determined not to let anything get her down as 2015 rolled into 2016, Abby—by now taking high doses of prednisone and being monitored on an ongoing basis—tried to keep training in the new year.

“After I started treatment, I tried to train for another one in 2016, but never felt ready because of the impact of the prednisone,” she says. “In 2017, I was able to do a half ironman but it was really hard because of the prednisone taper. I did compete against my brother that year and still beat him by 10 minutes once I was finally off the prednisone. Then, I contacted Brandon Hudgins and asked him to help me train for the Big Sur Marathon in California in 2018.

After working with him for a bit, I decided to go whole hog for an ironman which was my victory over vasculitis in Lake Placid.”

This year, she’s pleased to note, her GPA went into remission. “My other coaches for the Ironman Lake Placid didn’t even know about my GPA.”

Abby is now about to undergo plastic surgery to correct the damage the disease caused to her nose. Still as competitive as ever, she looks forward to the next event, although she doesn’t yet know what it will be. And she will have a period of recuperation following surgery.

She believes in the power of motivation and advises others with vasculitis to “Listen to your body, stay focused and keep your eye on the prize.”
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 Recruiting Patients**

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

**What we are studying:**

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

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

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

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

*Other conditions may apply*

**How to join the TAPIR trial:**

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

Visit [www.TAPIRTrial.org](http://www.TAPIRTrial.org)
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Thank you for your gift of $50 or More!

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<td></td>
<td>University of Missouri Rheumatology/Immunology Kansas City, Missouri</td>
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<td>Allen, Nancy B., M.D.</td>
<td></td>
<td>Duke University Rheumatology/Immunology Durham, North Carolina</td>
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<td></td>
<td>Alberta Children’s Hospital Rheumatology, Department of Pediatrics Calgary, Alberta, Canada</td>
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<td></td>
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<td></td>
<td>Division of Rheumatology University Health Network/ Mount Sinai Hospital, Toronto, Ontario, Canada</td>
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<td></td>
<td>Division of Pulmonary and Critical Care Medicine, Mayo Clinic, Scottsdale, Arizona</td>
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<td>Chonko, Arnold M., M.D., FACP.</td>
<td></td>
<td>University Of Kansas Nephrology/Hypertension Kansas City, Kansas</td>
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<td>Chung, Sharon, M.D., MAS</td>
<td></td>
<td>University of California - San Francisco Division Of Rheumatology San Francisco 415.514.1673</td>
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<td>Ciampi, Maria C., M.D.</td>
<td></td>
<td>University of Barcelona Hospital Clinic Barcelona, Spain</td>
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<td></td>
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<td></td>
<td>University of Chicago Rheumatology/Vasculitis Chicago, Illinois</td>
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<td>Duvvuru, Geetha, Duvvuru, M.D., MRCGP</td>
<td></td>
<td>The Johns Hopkins University Vasculitis Center Baltimore, Maryland 410.550.6825</td>
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<td>Garrity, James A., M.D.</td>
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<td>Mayo Clinic - Ophthalmology Rochester, Minnesota</td>
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<td>Geetha, Duvvuru, M.D., MRCGP</td>
<td></td>
<td>The Johns Hopkins University Vasculitis Center Baltimore, Maryland 410.550.6825</td>
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<td>Goeken, James A., M.D. (Retired)</td>
<td></td>
<td>University of Iowa Pathology Iowa City, Iowa</td>
</tr>
<tr>
<td>Gota, Carmen E., M.D.</td>
<td></td>
<td>Department of Rheumatology Cleveland Clinic - Center for Vasculitis Care and Research Cleveland Ohio 866.275.7496</td>
</tr>
<tr>
<td>Grayson, Peter, M.D., MSc.</td>
<td></td>
<td>National Institute of Arthritis and Musculoskeletal and Skin Diseases Bethesda, Maryland 301.451.450</td>
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<tr>
<td>Gross, Wolfgang L., M.D., Ph.D. (Retired)</td>
<td></td>
<td>University of Lübeck Dept. of Rheumatology Bad Bramstedt, Lübeck, Germany</td>
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<tr>
<td>Guillemin, Loic, M.D.</td>
<td></td>
<td>Groupe Francais d’Etude des Vascularities French Vasculitis Study Group Hospital Cochin-Paris University Paris, France</td>
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<td>Hajj-Ali, Rula, M.D.</td>
<td></td>
<td>Cleveland Clinic - Center for Vasculitis Care and Research Cleveland, Ohio</td>
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<tr>
<td>Hashkes, Philip J., M.D., MSc.</td>
<td></td>
<td>(For Pediatric Patients) Shaare Zedek Medical Center Pediatric Rheumatology Unit Jerusalem, Israel 972.2.6662624</td>
</tr>
<tr>
<td>Heeringa, Peter, Ph.D.</td>
<td></td>
<td>Department of Pathology &amp; Medical Biology, University Medical Center Groningen, The Netherlands 31.50.3610789</td>
</tr>
<tr>
<td>Hellmann, David, M.D., MACP.</td>
<td></td>
<td>The Johns Hopkins University Dept. of Medicine Baltimore, Maryland 410.550.0516</td>
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<tr>
<td>Hoffman, Gary S., M.D., MS., M.A.C.R.</td>
<td></td>
<td>Professor Emeritus Cleveland Clinic Lerner College of Medicine Center for Vasculitis Care and Research Cleveland, Ohio</td>
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<tr>
<td>Kermani, Tanaz, M.D.</td>
<td></td>
<td>Division of Rheumatology UCLA Medical Center Santa Monica, California 310.582.6350</td>
</tr>
<tr>
<td>Khasnis, Atul, M.D., MS.</td>
<td></td>
<td>Piedmont Peachtree City Rheumatology Peachtree City, Georgia 770.506.1400</td>
</tr>
<tr>
<td>Koenig, Curry, M.D., MS.</td>
<td></td>
<td>University of Utah Division of Rheumatology Salt Lake City, Utah 801.581.4333</td>
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<td>Koster, Matthew J., M.D.</td>
<td></td>
<td>Mayo Clinic Rheumatology 507.266.4439</td>
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<td>Lally, Lindsey, MD</td>
<td></td>
<td>Hospital for Special Surgery Rheumatology New York, New York</td>
</tr>
<tr>
<td>Langford, Carol A., M.D., MHS.</td>
<td></td>
<td>Cleveland Clinic - Center for Vasculitis Care and Research Cleveland, Ohio 216.445.6056</td>
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<tr>
<td>Lebovics, Robert S., M.D., FACS.</td>
<td></td>
<td>Otolaryngology/Head &amp; Neck Surgery New York, New York 212.262.4444</td>
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<tr>
<td>Lee, Augustine S., M.D.</td>
<td></td>
<td>Mayo Clinic Pulmonary and Critical Care Jacksonville, Florida 904.953.2000</td>
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<td>Levine, Stuart, M.D.</td>
<td></td>
<td>MedStar Harbor Hospital Baltimore, Maryland 410.350.3483</td>
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<td>Lorenz, Robert R., M.D.</td>
<td></td>
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<td>Mahr, Alfred, M.D., Ph.D.</td>
<td></td>
<td>Department of Internal Medicine Hospital Saint Louis Paris, France 33.142499780</td>
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<td>Maksmowicz-McKinnon, Kathleen, D.O.</td>
<td></td>
<td>Rheumatology Henry Ford Medical Group West Bloomfield, Michigan 313.916.2631</td>
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<td>Matteson, Eric L., M.D.</td>
<td></td>
<td>Mayo Clinic (Retired) Rheumatology Rochester, Minnesota</td>
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<td>Maz, Mehrdad, M.D.</td>
<td></td>
<td>Allergy, Clinical Immunology and Rheumatology KU Medical Center 913.588.6009</td>
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<td>Mcdonald, Thomas J., M.D., F.A.C.S. (Retired)</td>
<td></td>
<td>Mayo Clinic Otolaryngology Rochester, Minnesota</td>
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Giving Tuesday - It’s just around the corner!

by Beth Westbrook, VF Development Director

Are you like me when it comes to holiday shopping? I fret over whether I have chosen the right gift and if the person will like it. As we approach the holiday season, the Vasculitis Foundation has already kicked off its annual giving campaign. One of the ways you can make a vital gift toward a long-term treatment or even a cure for vasculitis is by participating in Giving Tuesday on November 27th.

Do you know how Giving Tuesday got started?
The annual event began in 2012 by two organizations in New York City the 92nd Street Y and the United Nations Foundation as a response to the commercialization and consumerism of the Thanksgiving season known as Black Friday and Cyber Monday. The movement gained momentum with press coverage and digitally driven donations. Last year Giving Tuesday raised $274 million with most gifts less than $100 per donation.

Our patient community values your contributions. When you make a gift, the VF puts it to work right away supporting research and helping people living with vasculitis. As a result, each patient’s journey becomes a shared journey with the support of the VF community.

Please consider making a monetary donation to the VF on Giving Tuesday. You will not have to think about “Will they return it?”, “Will it fit?” or “Will they like it?” You will know that the gift will be a gift of hope, of support, and of gratitude for someone living with vasculitis.

Peace and joy this holiday season,
Beth

Call me or visit the website www.vasculitisfoundation.org to learn more about Giving Tuesday.
Vasculitis Foundation Membership Campaign – JOIN!

PLEASE 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: ______________________________ State: ________________ Zip: ________________

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

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

Make the Vasculitis Foundation Your Charity of Choice!

Support the VF through your United Way or Combined Federal Campaign

More than a donation. It’s an investment.
Your United Way or CFC donation is an investment in the Vasculitis Foundation. It helps us to fulfill our mission of providing patient education and support throughout the world.

It’s also a way to help the VF with funding more research so that we can develop new diagnostic tools, less invasive treatments, and possibly a cure for the disease.

It’s simple to designate the Vasculitis Foundation as your recipient for United Way funds.
If your agency is not listed, simply complete the appropriate form (provided by your employer or local United Way) with the following information:

Vasculitis Foundation
PO Box 28660
Kansas City, MO 64188

1.816.436.8211 or 1.800.277.9474

EIN #: 43-1492959

www.VasculitisFoundation.org

Visit the CFC website at https://bit.ly/2eyDwpG to learn how you can make a donation as a federal employee.
What Do You Think?

The Rare Diseases Clinical Research Network is looking for patients with
Granulomatosis with Polyangiitis (GPA/Wegener’s)
or
Skin/Cutaneous Vasculitis or Henoch Schönlein Purpura
(HSP or IgA Vasculitis)
U.S. or Canadian-based participants only.

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

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

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

What’s Involved?

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

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

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

The Rare Diseases Clinical Research Network is an initiative of the Office of Rare Diseases Research (ORDR) National Center for Advancing Translational Sciences (NCATS) funded through a collaboration between NCATS and the National Institutes of Health.
VF Calendar of Events • 2018 - 2019

Go to our online calendar with the latest information about our upcoming events: Vasculitis Foundation
www.vasculitisfoundation.org/events/

September 8, 2018
Missouri/Kansas Chapter Meeting
▷ KU Edwards Campus
   Best Building
   12600 Quivera Rd, KS 62213

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

September 22, 2018
13th Annual Celebrating A Life: Keesha Vessell Vasculitis Walk
▷ 8:00 a.m. - 11 a.m.
▷ The welcome begins at 8:30 and the walk starts at 8:45
▷ Newnan City Veteran’s Park at 38 Jackson Street, Newnan, Georgia

October 18, 2018
VF Annual Membership Meeting
▷ 1:00 p.m.
▷ Chicago, Illinois.
▷ jakullman@VasculitisFoundation.org

November 10, 2018
2018 Vasculitis Educational Patient Conference
▷ 9:00 a.m. - 3:30 p.m.
▷ Los Angeles, CA

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

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