The 2017 International Vasculitis Symposium: A weekend of learning, engaging and connecting for patients, physicians and researchers | Ed Becker

“What’s the road ahead in vasculitis research? We need to think big. A cure for vasculitis? I say, why not? That’s the future and I think you should all be hopeful about where we’re going in this field.”

Those words from Dr. Peter Merkel resulted in cheers and applause from the more than 300 attendees at the 2017 International Vasculitis Symposium in Chicago on June 23 - 25. Merkel's presentation ended the two-and-a-half-day event that brought together patients and their families, vasculitis medical experts and researchers from 29 states, Australia, Canada, and the United Kingdom.

The theme of the symposium was to learn, connect, and engage to not only educate oneself as a patient and family member, but to also learn about participating in the many ongoing vasculitis studies that are dependent on patient involvement.

By all measures it was one of the largest VF symposia in recent history. There were a total of 48 sessions surpassing the number of presentations at the 2013, and the 2015 symposia.

It wasn’t just about offering more presentations, but centering them around the issues and topics most important to patients and their families. In fact, more than half of the total attendees were family and friends who wanted to be a part of the symposium to understand how to support and provide critical caregiving.

Providing presentations for both patients and their families was a goal from the beginning.

“For this symposium we made a special effort to learn what patients want and need to know about living with vasculitis daily,” says Joyce Kullman, Executive Director of the VF. “We reviewed past symposia surveys, we conducted informal polls on social media, and we talked to past attendees to learn how we could make this one most valuable. Based on the feedback this symposium was indeed a success on all levels.”

Dr. Dua gave an update about the 2017 International Vasculitis and ANCA Workshop during a presentation at the Vasculitis Symposium in Chicago. Photo credit: Chicago Corporate Photography and Video

ANCA Vasculitis International Conference Updates 2017
(Part 1 of 2)
By Anisha Dua, MD, MPH
Assistant Professor of Medicine, Assistant Program Director, The University of Chicago Medicine, Rheumatology

Research in ANCA vasculitis has gained significant momentum in the last decade with the discovery of new insights into disease mechanisms, targets for therapy, and it has resulted in better outcomes for patients. We have made great advances in the treatment of ANCA-Associated Vasculitides (AAVs) in the past decade, but we still have many patients who suffer from recurrent relapses, incomplete response to treatments, and complications from the disease and therapies we are using to control it.

This year, the International Vasculitis and ANCA Workshop was held in March in Tokyo, Japan and there were 451 abstracts presented from 29 different countries. The conference focused on discoveries being made in clinical care and basic science research, as well as bridging the expertise of subspecialists that are involved in caring for vasculitis patients. By integrating the research being done in different countries and across other research fields, we can further advance our ability to treat patients and minimize toxicities.

While a great deal of information was presented at this year’s conference, there were four main themes highlighted. These included:
- Classification of AAVs
- Pulmonary Limited Microscopic Polyangiitis
- Takayasu Arteritis and Giant Cell Arteritis spectrum of disease
- Eosinophilic Granulomatosis with Polyangiitis

**Classification Concerns:**
We tend to rely heavily on autoantibodies (PR3 and MPO) to help guide us in classifying patients, enroll in clinical trials, and to help us predict the risk of relapse and which organs may be involved. This is easier when a patient has a classic presentation with organ involvement and a tissue diagnosis that fits.

It becomes much more difficult when there are overlapping features, no tissue for biopsy, or an unusual
Dear Friends,

Now that our 2017 Symposium is over the staff and I are busy doing something that we particularly enjoy (especially with a symposium as successful as this past one). We review all of the symposium surveys from the attendees to find out if the event fulfilled its purpose. One theme has emerged as we read the comments. In fact, one word in particular keeps popping up. The word is Hope. Many attendees wrote that our symposium gave them a sense of hope for the future.

A key goal of the symposium was to give patients and their families an honest, hopeful picture of the exciting vasculitis research that’s currently underway.

Throughout the weekend the speakers shared updates on treatments and research efforts. In their joint presentation on Sunday, Dr. Peter Grayson and Dr. Peter Merkel outlined some of the promising clinical studies that have yielded exciting results. They also talked about better diagnostics and trials such as ADVOCATE which seeks to eliminate or reduce the use of prednisone. Or other research exploring the body’s microbiome to find clues to possible triggers of autoimmune disease.

We videotaped many of the sessions and will be making them available later this year after they have been edited.

During the Youth Engagement Program, Kate Tierney, one of the four young adults leading that session shared a motto that defines how she views her illness. Kate said, “The word ‘hope’ is an acronym. It either means, ‘Hold On, Pain Ends,’ or ‘Having Only Positive Expectations.’ I choose to focus on the latter.”

The presenters talked about the many challenges facing vasculitis patients, but the final takeaway of the meeting was that through patient involvement in clinical studies, dedicated researchers, and the focus of the VF that we can look to a brighter day.

Many thanks to ALL of the volunteers and speakers who made the weekend a success. We could not do it without your dedication and support.

We also want to thank all of you who attended the symposium and made the weekend special. We look forward to sharing much of the information in future newsletters and via the website. And, we hope you will join us for the next symposium in 2019!

Sincerely,

Joyce A. Kullman
Executive Director

Mission Statement | The Vasculitis Foundation supports and empowers our community through education, awareness and research.
Continuing with its commitment to promote early diagnosis of vasculitis, the VF awarded the Recognizing Early Diagnosis Award (V-RED) in May. The V-RED Award is presented annually to a medical professional who made a quick diagnosis of vasculitis, thus enabling the patient to receive timely and appropriate treatment, potentially sparing the patient permanent and ongoing health complications.

“The goal of the V-RED Award is to honor these healthcare professionals because they are a part of our goal to raise awareness about the need for earlier diagnosis of vasculitis,” says Joyce Kullman, Executive Director of the Vasculitis Foundation. “So often our patients fail to get an early diagnosis because vasculitis symptoms can mimic so many other conditions. We created the V-RED Award to single out those medical professionals who did catch the disease in its early stages, thus improving the outcome for the patient.”

The 2017 V-RED Awardee is Main Line Health Internist, Dr. Jennifer L. Nansteel, from MLHC Primary Care in Wynnewood, Pennsylvania. Dr. Nansteel was nominated by her patient, Cheryl Petersohn, from Bryn Mawr, Pennsylvania.

“I believe my vasculitis was caught early enough before severe symptoms had set in,” says Petersohn. “If it were not for Dr. Nansteel's skill as a diagnostician, I would have been in much greater difficulty. I am forever indebted to her. Dr. Nansteel deserves this recognition for her caring manner with which she followed through in the early days of my diagnosis. It is this combination of competency and compassion that makes her such a special physician and woman.”

Dr. Mora Recognized at Vasculitis Symposium for contribution to VF’s Early Diagnosis Award

At the Vasculitis Symposium, VF Board President, Karen Hirsch, presents Dr. Juanita Mora, MD, an allergist at the Chicago Allergy Center, with a plaque for being the inspiration of the Recognizing Early Diagnosis Award (V-RED). Mora was the physician who made a critical early diagnosis of vasculitis in Hirsch's son, Michael.

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 evasive 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
www.VasculitisFoundation.org
PO Box 28660
Kansas City, MO 64188
1.816.436.8211 or 1.800.277.9474
EIN #: 43-1492959
CFC # 64445

Visit the VF United Way / CFC web page to learn more about how your donation advance the support of patients and research worldwide: https://goo.gl/Eg9N9h
Singing Benefit Honors Kim Buckley-Bennett

On Saturday May 6, a special singing benefit was held to honor Kim Buckley-Bennett, who was diagnosed with GPA/Wegener’s in 2016, and passed away on October 12, at the age of 52.

Her daughter, Alex-Andrea Denise King, says that her dad, Bob, and brother, Jerrett, wanted to pay tribute to Kim, while also supporting the Vasculitis Foundation. “My mother loved to sing. She had a beautiful voice, and I couldn’t think of a better way to raise money in her honor,” says King. “We contacted everyone in our family, our church, and among our community of friends. It all came together and the event was a great success. We raised $1,800 to help the VF.”

Alex adds that her mother’s experience has pushed her to raise awareness. “It has been a hard journey. Learning more about the disease made me want to help others going through the same thing we went through with Mom. I don’t want any more daughters losing their mothers to vasculitis.”

Annual Eastern PA / Western NJ VF Walk Celebrates 15 Years of Supporting the VF

On Sunday, June 4, more than 60 guests put on their walking shoes to participate in the Annual Eastern Pennsylvania / Western New Jersey VF Walk at Ridley Park in Media, Pennsylvania.

Now in its 15th year, this fundraiser has raised more than $20,000 thanks to the efforts of a dedicated team of volunteer leaders.

Jack and Ruth Falkenstein, along with Sharon Sirman, and her daughter, Stephanie, have been the driving force behind the VF’s longest running fundraiser. This year, Ed Becker, director of marketing for the VF, attended the event and presented the four volunteers with a special plaque in recognition of their many years of service.

What does it take to successfully hold a fundraiser for so many years? Jack Falkenstein says they have the planning and execution down to a science. “We’ve been doing this event for so long we have the pieces in place to plan, promote, and hold this walk. Through our network of friends and family we know what works best to make it happen,” Falkenstein said. “We also appreciate the support from the VF to promote it each year.”

Another factor to the event’s popularity is the activity itself. “It’s a nice, gentle walk that’s perfect for most everyone,” says Sirman. “The site offers a covered pavilion since we hold the walk rain or shine. It just makes for a nice comfortable setting if you choose to walk or just hang out at the pavilion and chat with other folks.”

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5th Annual Rally in the Alley
Benefiting the Vasculitis Foundation
SUNDAY, NOVEMBER 12, 2017
3:00 p.m. - 6:00 p.m.

Pinstripes
1150 Willow Road
Northbrook, Illinois 60062
Cost $50 adult/$30 child
Bowling and Buffet

Register here:
https://goo.gl/jdzbEV

Put on your bowling shoes and come have fun at the “Rally in the Alley”—the fifth annual event to help “strike out” Vasculitis. This special night includes open bowling and bocce, pizza buffet, delicious desserts and an impressive silent auction featuring some of your local favorites! Hosted by Svendsen, Smith, Hirsch and Wadler families to benefit the Vasculitis Foundation. If you would like to register paying by check, please send it to: Vasculitis Foundation c/o Karen Hirsch, 1714 Wildwood Court, Glenview, IL 60025

12th Annual Celebrating A Life:
Keesha Vessell Vasculitis Walk

Put On Your Walking Shoes and Mark Your Calendar!
Saturday, September 16, 2017
Newnan City Veteran's Park at 38 Jackson Street,
Newnan, Georgia
Registration will start at 8:00 a.m.
The welcome begins at 8:30 and the walk starts at 8:45.
There is no fee. However, donations are accepted at the event. Door prizes and light, early morning snacks will be available.
Contact Diann Alford at 678-416-9155 or diannrip12@aol.com
This walk is held in memory of Keesha Vessell, a 33-year-old wife, and mother of three, who died in January 2006 from GPA/ Wegener’s. Diagnosed in August 2005, it was determined Keesha had suffered from various undiagnosed GPA symptoms for about two years. Her family started the walk in memory of Keesha and to help raise awareness of vasculitis.
LEARN:

Broad overviews and specialized topics

For many attendees the symposium was a unique opportunity to learn about the latest research developments presented by some of the world’s leading vasculitis medical experts. In addition to two general presentations (Vasculitis 101 and 102), there were numerous breakout sessions addressing the individual vasculitic diseases.

Beth Howe, a patient with Behcet’s disease and leader of Behcet’s: You Are Not Alone Facebook Group, attended the session led by Dr. Yusuf Yazici. “I found it was a place of acceptance and exceptional speakers,” says Howe. “Although there were only a few Behcet’s patients in the session it was a unique chance to learn from and engage with Dr. Yazici, who is one of the world’s few experts on this disease.”

In addition to the specific diseases, attendees could also learn about how vasculitis impacts particular body systems such as the lungs, kidneys, skin, and eyes.

Although many of the sessions focused on clinical aspects of vasculitis there were also classes that included a broader range of specialized interests. There were sessions on fertility, caregiving, nutrition, integrative medicine, mindfulness, and even a sunrise yoga class.

ENGAGE:

Bridging the patient and medical communities

For this symposium, the VF wanted to address the needs and issues directly affecting underrepresented groups such as young adults and pediatric patients. On Friday, more than 20 patients between the ages of 15 and 32 came together in a casual, round-table discussion led by Allison Lint, Ben Wilson, Brandon Hudgins, and Kate Tierney.

Parents and guardians were not included in the session so it could be an open discussion in a judgement-free setting. Many of the young patients found it to be such a cathartic experience that a second young adult session was added to the agenda.

Parents of pediatric patients also had the opportunity to ask questions of a panel comprised of pediatric rheumatologists, to learn how others deal with the special challenges of caring for a child with vasculitis.

CONNECT:

The 2017 Symposium was purposely designed to bring the medical and patient community together in a casual atmosphere outside of the lecture room. “Throughout the weekend you would often see a patient talking with one of our doctors during breaks,” says Kullman. “Although we provided Q&A sessions, our patients appreciated the chance to have one-on-one discussions with our experts. We feel this type of engagement between patient and medical professional can be extremely helpful.”

Dr. Peter Grayson agrees about this critical engagement. “As a physician and a researcher, connecting with patients at the Symposium is a fantastic way to hear the concerns that matter most, to educate patients about their disease, and to share the latest research developments,” says Grayson. “The VF Symposium is a great forum where researchers and patients can create partnerships that will continue to advance our understanding of these diseases.”

Many patients appreciated the strategic decision to arrange Saturday’s lunch tables geographically thus allowing them to meet other patients from their region. Carol, a patient from Michigan, said that she met another patient with GPA who lives only fifty miles away. She credits the symposium as a wonderful venue to form new friendships.

When the 2017 Symposium concluded on Sunday there was a mixture of exhaustion and excitement among the attendees. The final presentations by Dr. Peter Merkel and Dr. Grayson were purposely focused on the many ongoing vasculitis clinical trials, emerging treatment therapies, improved diagnosing, and worldwide efforts to improve patient lives.
ANCA presentation of the disease. Instead of forcing patients into a category, we can glean more information by combining the serotype (MPO, PR3) and the clinical/pathologic phenotype. This will allow us to categorize patients better not just based on a blood test or pathologic finding or clinical picture, but rather use all this information in trying to understand the nature of these diseases.

By being more descriptive and open to the variations in disease serologies and clinical presentations, we can learn more about the shapes that the ANCA vasculitides take and hopefully enhance our understanding of the nuances of the disease presentations and treatment options.

Professor Raashid Luqmani, Oxford University Hospitals, gave us an update on UKIVAS, a longitudinal registry in the United Kingdom and Ireland, with over 3,000 cases of vasculitis. This can be a source for making comparisons between different countries and possibly biomarker studies in the future. With the increase in the use of ANCA testing, we have been able to diagnose patients earlier, carry out more clinical trials, and improve patient outcomes and survival. But, as patients live longer with the disease, we need to be vigilant about chronic damage and comorbidities. Registries such as this one will capture this important information so that we can better study vasculitis including damage from the disease and the therapies we are using to try and control it.

**Pulmonary Limited Microscopic Polyangiitis (MPA)**

Collaboration between rheumatologists and our pulmonary colleagues has shown that there is a subset of patients who have an interstitial pulmonary disease and positive MPO-ANCA antibody—sometimes without any other manifestations of vasculitis. These patients can go on to develop other systemic manifestations of MPA and should be monitored closely for symptoms outside of the lungs.

It can be difficult to distinguish active vasculitis versus fibrotic lung disease in MPO+ patients, but this distinction is important.

Treatment of inflammation can prevent damage, but once there is already damage or fibrosis in the lungs, other agents that target fibrosis may be more effective. There are a few clues on CT imaging that are seen with more prevalence in ANCA-positive interstitial pneumonia patients, including more honeycombing and cysts compared to those with idiopathic pulmonary fibrosis. Pathologic evidence has been scarce. To date, the only known risk factor for developing full blown vasculitis in these patients is a high titer of MPO antibody.

This entity of “pulmonary limited MPA” is important to recognize because “limited” disease presentations may have implications for therapeutic management. For example, in “limited granulomatosis with polyangiitis” (findings isolated to the upper respiratory tract) methotrexate may be used to induce remission, whereas this is not effective in diffuse disease (with renal involvement). MPA patients initially presenting with exclusively lung disease may remain as “pulmonary limited MPA”, or they may go on to develop other organ disease manifestations. Identifying these subgroups and risk factors for the development of diffuse disease could have implications for screening strategies and therapeutic interventions.

Part two of this article will appear in the September/October 2017 Newsletter.

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VF Continues Medical Education Initiative with CME Course

As part of the VF’s ongoing efforts to educate health care professionals about vasculitis, we were pleased to partner with the Northwestern University School of Medicine and Division of Rheumatology, to host a half-day Continuing Medical Education (CME) course on Saturday, June 24.

“Vasculitis Update 2017” featured many of our VF Medical Consultants, including Drs. Sharon Chung, Peter Grayson, Tanaz Kermani, Peter Merkel, and Ulrich Specks. Dr. Amy Archer, director of the newly opened Northwestern University Vasculitis Clinic, moderated the session.

Topics included recognizing the role of imaging in large vessel vasculitis, understanding treatments for large vessel vasculitis and small vessel vasculitis as well as treatment options for alveolar hemorrhage. Dr. Chung discussed identifying biomarkers for disease prognosis and treatment response.

We owe the speakers a tremendous debt of gratitude. Not only did they participate in the CME course which requires extensive preparation, but they all also gave presentations and led breakout sessions throughout the Symposium weekend.

This was the second CME course sponsored by the Vasculitis Foundation this year. On April 5, we partnered with the Cleveland Clinic to host a full-day CME course in conjunction with their 2017 Biologic Therapies VII Summit.
2017 VASCULITIS SYMPOSIUM HIGHLIGHTS

Marty Oppenheimer, Keynote Address

On Friday evening, Marty Oppenheimer, our keynote speaker, shared how he created a new life after almost dying from a delayed diagnosis of EGPA/Churg Strauss. For over a year, Marty's life revolved around physical therapy, relearning basic functions and mobility, visiting nurses, doctor appointments, diagnostic tests, and hospitalizations. Marty discussed the importance of a positive attitude, setting realistic goals, having optimism, a support system, faith, and an understanding of vasculitis. Volunteerism has always been an integral part of Marty's life. He concluded his talk with encouragement for the future and a reminder to all patients to never lose hope, despite their illness.

Victor and Brenda James Testimonial

During Saturday evening's Celebration and Recognition Banquet, Victor and Brenda James shared why they support the Vasculitis Foundation because the organization has supported Victor through the ups and downs of his vasculitis. Brenda said that if there were any newly diagnosed patients in the audience they should have hope. “You are not alone in your journey with vasculitis. As we have discovered, the VF is a partner as you search for the best care and the best doctors out there.”

Recognition of Retiring Board Member, Dr. Paul Monach

Dr. Paul Monach, director of the Boston University Vasculitis Clinic, was recognized during Saturday's luncheon for his service to the VF Board of Directors. Dr. Monach retired from the board in 2016. He is a longtime VF Medical and Scientific Advisory Consultant and has served on the VF Research Committee for many years. He has been instrumental in helping grow and expand the VF Research and Fellowship Programs.

Tribute to Bob Sahs

On Saturday evening Jason Wadler, past-president of the VF Board of Directors, and VF Executive Director, Joyce Kullman paid tribute to longtime VF Board Member, Bob Sahs who passed away in April 2017.

Musical performance by Jim Peterik

The Symposium got off to a “rocky” start as Grammy winning musician, Jim Peterik, from the band, Survivor, performed some of his biggest hits to an enthusiastic audience. Peterik ended his act with his biggest hit, “Eye of the Tiger” which was featured in the movie, Rocky III.
### 2017 VASCULITIS SYMPOSIUM AWARDS AND RECOGNITION

#### 2017 Raising Vasculitis Awareness Award: Brandon Hudgins

The VF recognizes elite, record-breaking runner Brandon Hudgins, for leading the successful campaign Victory Over Vasculitis: VF Team Brandon. His passion is empowering other patients to define what a victory over vasculitis means to them on a personal level, and to set out to achieve that goal. Over the last year, Brandon has also helped raise awareness about vasculitis on a national stage through his media interviews, and personal appearances.

#### 2017 Volunteer Spirit Award: Suzanne DePaolis

Throughout the year the VF holds regional conferences or symposia and one person has attended many of these events not as a participant, but as a volunteer behind the scenes. Suzanne is one of those people who is always helping us with whatever needs to be done. She has a generous spirit and can-do attitude that is invaluable to the VF.

#### 2017 Online Patient Advocate Award: Patricia Youngross

Patricia channels her passion to help others and the VF to reach thousands of people on Facebook. Often, she will scan social media posts for questions from patients and respond to them with links to resources and information. Thanks to her efforts the VF is connecting to a wider network of patients.

### THANK YOU TO THE PRESENTERS AT THE 2017 INTERNATIONAL VASCULITIS SYMPOSIUM

We thank all the presenters who helped to make the Symposium so informative and exciting. They generously volunteered their time to bring us the latest information about vasculitis. Moreover, our presenters made themselves available to answering questions from patients throughout the weekend. We are grateful to all of them for sharing their knowledge.

Amy Archer, MD, PhD, Northwestern University
Teri Bodeman, Benefit Boost, Inc.
George Casey, MBA, V-PPRN Co-Investigator
Sharon Chung, MD, MS, University of California – San Francisco
Divi Corneec, MD, PhD, Mayo Clinic/Brest University
Anisha Dua, MD, MPH, University of Chicago
Geetha Duvuru, MD, Johns Hopkins University
Jeff Fishbein, PsyD, Fishbein & Associates, Performance Consulting
Sharyl Fishbein, Deerfield, Illinois
Marisa S. Klein-Gitelman, MD, Northwestern University
Peter Grayson, MD, PhD, NIAMS Translational Research Program
Eric Hoy, PhD, SI, ASCP, University of Texas
Tanaz Kermani, MD, PhD, University of California – Los Angeles/Santa Monica
Marisa Klein-Gitelman, MD, Northwestern University
Anjum Koreishi, MD, Northwestern University
Arti Lakhani, MD, Amita Cancer Institute
Carol Langford, MD, MHS, Cleveland Clinic
Robert Lebovics, MD, Head & Neck Surgical Group
Peter Merkel, MD, MPH, University of Pennsylvania
Robert Micheletti, MD, University of Pennsylvania

Paul Monach, MD, PhD, Boston University
Patrick Nachman, University of North Carolina
Marty Oppenheimer, Akron, Ohio
Deborah Pergament, Esq., Children’s Law Group
Rosalind Ramsey-Goldman, MD, Northwestern University
Jennifer Rodrigues, MD, PhD, McMaster University
Eric Ruderman, MD, Northwestern University
James Sosebee, Sinclair College
Ulrich Specks, MD, Mayo Clinic
Jason Springer, MD, University of Kansas
Marinka Twilt, MD, University of Calgary
Alex Villa-Forte, MD, MPH, Cleveland Clinic
Linda Wagner-Weiner, MD, University of Chicago
Yusuf Yazici, MD, New York University
Kalen Young, MA, Network Manager, V-PPRN

www.VasculitisFoundation.org
The 2017 Vasculitis Symposium: Learning, Connecting, and Engaging

We wish to thank the following photographers for capturing the true spirit of our event.

Chicago Corporate Photography and Video, Jimmy Fishbein, Owner
Ed Becker, Director of VF Marketing and Communications
Dianne Shaw
Greg Lesko

The VF thanks our sponsors for their generous support of the 2017 Vasculitis Symposium.
ABROGATE Trial Launched to Assess Abatacept for Nonsevere Granulomatosis with Polyangiitis (Wegener’s, GPA)

Multinational study builds on promising pilot results

An exciting study in granulomatosis with polyangiitis (Wegener’s) (GPA) is open to enrollment at multiple sites throughout the United States, Canada, Ireland, and several sites in the United Kingdom with anticipated sites opening throughout Europe, Mexico, Chile and Australia in the near future. The Abatacept (CTLA4-Ig) for the Treatment of Relapsing, Non-Severe GPA (ABROGATE) trial is conducted by the Vasculitis Clinical Research Consortium (VCRC) in partnership with the European Vasculitis Study Group (EUVAS) and other international collaborators.

An unmet need: Treatment of nonsevere GPA

By focusing on a treatment option for the management of nonsevere GPA, ABROGATE addresses an unmet therapeutic need. Despite advances in the treatment of GPA, 50 to 70 percent of patients continue to experience a disease relapse following successful remission induction. For many patients, nonsevere relapses can greatly impact quality of life through accrued organ damage and the need for chronic glucocorticoids. The identification of a therapeutic strategy to safely and effectively reduce nonsevere relapses would represent an important addition to the treatment armamentarium in GPA.

Building on an encouraging pilot study

ABROGATE follows up on the promising results seen in the VCRC pilot study of abatacept in 20 patients with nonsevere relapsing GPA that was funded by the National Institutes of Health. In this study, 90% improved, 80% achieved remission, and 70% reached the end of the study. 11 out of 15 patients were able to stop using prednisone to treat their GPA. Based on these encouraging results, it was felt to be important to conduct a larger study to determine more definitely the effectiveness of abatacept, which is why we are performing this study.

The essentials of ABROGATE

ABROGATE will enroll 150 patients with nonsevere relapsing GPA. Eligible participants will be randomly assigned by chance (like flipping a coin) to either receive abatacept or a placebo (inactive solution that looks like the study medicine but it doesn’t contain abatacept) injected subcutaneously (by syringe) combined with standard doses of prednisone. Patients that are already receiving other medications such as methotrexate, azathioprine (also called Imuran), mycophenolate (also called cellcept or myfortic), or leflunomide (also called arava) would continue taking the same dose of this medication throughout the study.

While on the study, if a patient’s GPA symptoms come back and you have a non-serious disease relapse or if you have not improved after 6 months of being on the study, you will have the option of receiving open label abatacept, which means that you will receive abatacept and there is no randomization and no placebo involved. The decision to receive open-label abatacept is your choice. If you decide not to receive this, you will stop all study medication treatment and be treated with the best medical approach as you and your doctor decide upon.

Further information about ABROGATE and a list of enrolling sites may be found on clinicaltrials.gov or on https://www.rarediseasesnetwork.org/cms/vcrc/Research/Studies/5527.

Clinical Trial for Patients with Granulomatosis with Polyangiitis (Wegener’s, GPA)

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 new clinical trial for patients with granulomatosis with polyangiitis (Wegener’s, GPA) in remission (had a reduced number of symptoms or no change in GPA symptoms). We would like to learn more about whether patients with GPA in remission are better off being maintained on low-dose prednisone or attempting to come off prednisone altogether when they are in remission.

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

How to join the TAPIR Trial

There are two ways to participate in the TAPIR Trial.

1. JOIN TAPIR ONLINE by visiting www.TAPIRtrial.org or by calling 1-888-443-1793
   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.

2. JOIN TAPIR BY VISITING A PARTICIPATING VCRC CLINICAL CENTER.
   If you already receive your care from a participating Vasculitis Clinical Research Consortium (VCRC) center, you can talk to your doctor about participating in TAPIR. See which clinical centers are recruiting patients for the TAPIR study by visiting: www.TAPIRtrial.org
Spotlight: Alison Fairchild

“You’ll never find rainbows if you’re looking down.”

- Charlie Chaplin

People choose different moments to reflect on their life with vasculitis. On the eve of my Swiss doctor’s retirement, I felt like it was my turn to write. I have been fighting and adapting to my particular bedmate, Wegener’s granulomatosis / GPA, for nearly 15 years.

I am a 62-year-old Scottish physiotherapist, and I have been living in Switzerland since 1980. Wegener’s struck in 2002, and I have successively suffered from lung, kidney, sinus and multiple joint problems, so I know what many of you are going through because of this disease.

Currently, I am being treated for neurological symptoms in my lower legs. Luckily, thanks to research and funding, treatment is available, but a lot of us have to deal with the side effects of medication which can be debilitating. However, my feeling is that anything that keeps us alive and kicking is definitely worth taking!

The things that have helped to keep me on track over the years are my optimism, my ability to adapt to my changing circumstances, my faith, and my sense of humour. My background as a physiotherapist helps me to know the value of exercise. I used to ski, play tennis, ride and run. Now, I can do basic yoga, nordic walking and cycling on a stationary bike.

My advice is to give anything you want to try a go, but always be patient and kind to your body, learn good postural control and don’t exhaust yourself. Learn and use correct breathing techniques to keep your body oxygenated and take advice from professionals to avoid accidents. Try to exercise for pleasure and to give yourself a sense of achievement and satisfaction. Remember that you don’t need to compete when you are in a group or feel that you have to win!

I think that maintaining strong mental well-being is very important and I have used all available help to problem solve along the way. I went to an alternative therapist in the beginning; she helped me to relax, to cry, and to feel less afraid of my body. At crucial times, a few sessions with our gentle, caring psychiatrist have helped my husband and me to deal with Wegener’s and to fear it less. My attitude is that there is no stigma attached to trying something which may improve your quality of life, especially if it makes your life easier.

I would like to end by thanking the many people who have helped and encouraged me along the way: Dr. A.J. Simpson, who fortuitously diagnosed my illness in Edinburgh and my wonderful, Swiss doctor, Annette Leimgruber, in Lausanne, who has held my hand, orchestrated appointments with other excellent medical specialists and directed my treatment since 2002.

My family in Scotland has always been there for me, as have friends, both here and all over the world. My biggest thank you goes to my wonderful husband, Peter, who is living this roller coaster ride of alternating hope and disappointment with me. He has never once complained, despite all that I have put him through, and I thank him from the bottom of my heart.

Alison Fairchild

CONNECT WITH US! We are collecting members’ email and cell phone numbers to enable us to quicker communication and to help reduce postage costs! Do we have your correct mailing address? Phone number? Please send us your contact information and we will update your record!

vf@VasculitisFoundation.org
Symposium Engages with Young Adults  
| Ben Wilson

While this July marks the third anniversary of my EGPA Vasculitis diagnosis, it was the previous month that marked a true milestone in my fight against the disease: my first trip to the 2017 International Vasculitis Symposium in Chicago, Illinois.

I initially came to the symposium as a speaker; along with Brandon Hudgins, Allison Lint, and Kate Tierney. The four of us were tasked with leading the young adult’s group session. However, by the end of the weekend, I found myself to be the one who was inspired, by a group I had no idea existed.

Our session was originally designed to be a short 45-minute chat where the four of us talked about our experiences with vasculitis. We hoped the presumed few other young adults at the symposium would speak up and ask us questions or share their concerns.

Three hours and an additional impromptu session later, the room looked nothing like a lecture hall. Instead, 25-30 of us, aging from early-teens to early-30s, formed a large circle and shared anything and everything about our journeys with vasculitis.

We bonded over our uniform struggles with high doses of prednisone -- how it wreaked havoc on our bodies, caused some level of depression or frustration, and forced us to be painfully self-aware of our outer appearance as we tried to navigate the waters of high school and college.

We talked about bad experiences with primary care doctors who didn’t know enough about vasculitis. We sympathized over having friends who didn’t understand what was wrong with us and who couldn’t comprehend our pain. Even after our session ended, we ate dinner together, then hung out by the hotel pool late into the night.

By the time it was over and we’d all followed each other on Instagram (the true sign of acceptance among millennials), I felt like a tidal wave of happiness, combined with relief, had passed over us all. As we said our goodbyes and headed home, just about all of us had the same bright expressions that said, “I can’t believe there were so many others out there just like me.”

That feeling has stayed with me since leaving Chicago last month. Because of it, I’m already thinking about the next symposium, and more importantly, seeing my new friends again. ♦

Young adults at the Symposium enjoyed two sessions where they could talk with each other about the challenges they face, and how vasculitis impacts their education, career, social life.  
Photo: Chicago Corporate Photography and Video

Meaghan Carpenter (foreground) and other young adults at the Symposium engaged in a lively and informative dialogue with each other during their session.  
Photo: Chicago Corporate Photography and Video

The Updated VF Symposium Web Page: View photos, slide shows, and video clips.  
The 2017 Vasculitis Symposium may be over, but you can find a variety of media from this exciting event.  
http://www.vasculitisfoundation.org/2017symposium/.

You can link to our Dropbox folder to view many of the symposium slide presentations.  
Watch video clips from some of the most popular presentations.  
More than 50 photos capture the spirit of the 2017 Vasculitis Symposium in our online album.
Defining a V-PPRN Study

The Vasculitis Patient Partner Research Network (V-PPRN) is the first research registry created by and for people affected by vasculitis. The network exemplifies the power of partnering with patients in research design and development. Using novel approaches to conducting vasculitis research online, we completed three studies in 2016, and recently launched the Journey Survey this past May.

The Vasculitis Pregnancy Registry, a multi-year study, is recruiting 100 female patients to learn about the impact of vasculitis on pregnancy. We have built a strong, vibrant network of 2,000 patients willing to participate in research.

The philosophy of the V-PPRN is simple: conduct high-quality research for patients WITH patients. Patients work on the development and management of data collection, research agenda, and the sharing of research findings. To uphold this philosophy and the highest standards of scientific excellence, V-PPRN investigators and patient-partners established a set of characteristics that are required to be a V-PPRN study.

Defining a V-PPRN Study

The V-PPRN promotes the advancement of research that provides reliable, useful and meaningful information to patients with vasculitis and their clinicians. A V-PPRN study must possess ALL the following characteristics:
1. Asks a research question that is important to people affected by vasculitis (patient-centered)
2. Includes significant patient engagement in all aspects of the research
3. Utilizes V-PPRN and/or PCORnet resources in a meaningful manner

Important to People Affected by Vasculitis

V-PPRN studies must be scientifically meaningful as well as relevant and important to people affected by vasculitis. The Research, Innovation, Planning and Experiments (RIPE) Working Group helps to prioritize and identify research that is important to the vasculitis community.

Patient Engagement

“Patient engagement” refers to patients having meaningful participation throughout the research process, from topic selection to design, and conduct, and reporting of research. Patient engagement is central to the V-PPRN’s governance structure, as we believe that such engagement influences research to be more patient-centered, useful, and trustworthy.

Examples of patient engagement

- Patients are involved in the review and approval of the research idea
- Patients collaborate with researchers on the design of the study
- Patients review, provide feedback, and beta-test questionnaires and electronic forms
- Patients participate in the various studies
- Patients participate in the interpretation of study results
- Patients participate in disseminating the results of the research

Utilizes V-PPRN and/or PCORnet Resources

For a study to be considered a V-PPRN study, it must use one or more V-PPRN and/or PCORnet resources, including:

- Data from the V-PPRN patient registry and/or another component of PCORnet
- Access to patients identified from the V-PPRN patient registry
- V-PPRN Working Group participation in research design and review

Dr. Peter Merkel tells the audience about the role, and goals of the V-PPRN during Saturday’s session

Photo: Ed Becker
V-PPRN Study Spotlight: The Journey of Patients with Vasculitis from First Symptom to Diagnosis

May 2017, the V-PPRN launched the stage 1 Journey survey and had an astounding 329 patients participate!

Goal of the Study

The goal of this study is to gain insight into the factors, both patient-related and professional/health system-related, that are associated with a timely or delayed diagnosis of vasculitis.

While there have been a few reports about delays in diagnosis for several types of vasculitis, the different factors contributing to that time and the perceived consequences on patients’ health remain largely unknown. It is anticipated that by examining the factors surrounding the diagnosis of vasculitis, physicians and patients will have a more detailed and sophisticated picture of the disease presentation. This knowledge could lead to earlier diagnosis and treatment, thereby helping to minimize the consequences of the disease. This issue was identified as a top question of interest among patients who submitted research ideas to the V-PPRN.

Design of the Study

This is a 2-stage survey study. The purpose of the stage 1 Journey survey was to solicit your perspective about the factors that you believe contributed to the time to diagnosis of vasculitis (delayed or expedited).

The information participants provided in the stage 1 Journey survey came to life during the data analysis and guided the questions and design of the much more detailed stage 2 survey which will launch later this summer. We hope you will participate in the stage 2 survey. You can participate in the stage 2 survey even if you did not participate in the stage 1 survey.

Learn more: vpprn.org

Learn about ADVOCATE, a Clinical Research Study for People with Two Types of Vasculitis

New ADVOCATE Trial Recruiting Patients

ANCA-associated vasculitis is a rare condition that can affect many different organ systems, and commonly involves the kidneys. Treatment of ANCA-associated vasculitis depends on the severity and activity of the disease, but often involves a combination of drugs including glucocorticoids (steroids such as prednisone) and a second drug to suppress the body’s immune system. These medicines have helped many people with ANCA-associated vasculitis. However, there is more work to be done to find treatments that work faster, help more people, and have fewer side effects.

For people who suffer from vasculitis who may want to participate in the ADVOCATE trial we would recommend you review all the information on the ADVOCATE website at http://www.advocateclinicaltrial.com.

About the ADVOCATE Trial

The purpose of the ADVOCATE trial is to learn if avacopan can provide benefits to patients by being safe and effective in improving vasculitis disease activity, kidney function, and/or quality of life. In addition to testing the effect of avacopan on improving active vasculitis, ADVOCATE will also test the effect of avacopan on preventing a recurrence of vasculitis. The ADVOCATE trial will test the safety and efficacy of avacopan for 12 months and will include approximately 300 patients across 200 medical centers in the U.S., Canada, and Europe.

You may be able to join the study if you:

• Are 18 years or older; in certain countries and study centers, patients 12-17 years old may also participate
• Have been diagnosed with one of the following kinds of ANCA-associated vasculitis
  Granulomatosis with polyangiitis, also called GPA or Wegener’s
  Microscopic polyangiitis, also called MPA
• Require the addition of cyclophosphamide or rituximab to gain better control of your disease activity
• Have not had a kidney transplant

There are other eligibility criteria that you must meet to participate. The ADVOCATE study staff can discuss these criteria with you in greater detail. Visit the “Study Locations” section of the ADVOCATE website to find a study site near you.

About Avacopan

Avacopan (previously called CCX168) is an investigational medicinal product that is being tested to learn if it will be safe and effective for the treatment of people with active 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.

ADVOCATE Webinar

Later this Fall, we will be sharing a webinar to provide more information on the ADVOCATE trial, avacopan and previous experience with the drug candidate in earlier clinical trials. The webinar will be interactive with a Question and Answer section at the end of the event.

Details about this webinar will be announced in the September/October VF Newsletter.

www.VasculitisFoundation.org
VCRC Update  | Are you a member of the VCRC Patient Contact Registry?

The Vasculitis Foundation encourages patients to participate in research whenever possible. Your participation will help researchers find better treatments and the cause and cure for vasculitis.

The Vasculitis Clinical Research Consortium (VCRC) is an integrated group of academic medical centers, patient support organizations, and clinical research resources dedicated to conducting clinical research in different forms of vasculitis. Funded by the National Institutes of Health, the VCRC is part of the Rare Diseases Clinical Research Network.

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.

Join The VCRC Contact Registry!

CURRENT VCRC STUDIES

https://www.rarediseasesnetwork.org/cms/vcrc/
The VF Store: Cool down with stylish, summer clothes

The VF Store is stocked with everything you need to be stylishly cool through the rest of the summer. Check out our new selection of tank tops, tee shirts, and ball caps!

http://vfwebstore.com

Coming soon: Watch for our newly produced DVD series. The DVDs sell for $5 plus shipping.

Current titles:
“Pumping Iron, Not Prednisone” featuring Dr. Rebecca Manno, Assistant Professor of Medicine, Division of Rheumatology, The Johns Hopkins University. She discusses the importance of incorporating some level of physical activity as a key part of managing your vasculitis.

“The 30-Year Perspective on Vasculitis” presented by Dr. Carol Langford, director of the Cleveland Clinic Center for Vasculitis Care and Research. Dr. Langford gives a comprehensive overview of vasculitis and the advances in diagnostics and treatment therapies until present day.

Visit our online store at: http://vfwebstore.com

The VF Store: Cool down with stylish, summer clothes
The VF Educational Webinar Series 2017

**Topic:** Global Vasculitis Awareness and the V-PPRN International Outreach

**When:** Tuesday, August 22, 2017 @ 12 noon, Eastern Time

**Presenters:** Joyce Kullman, Kalen Young, Ed Becker, and international vasculitis advocates

Join us for the August VF webinar when we present our first-ever global webinar that takes a look at vasculitis organizations throughout the world. Some of these international patient advocacy leaders will talk about their groups and how they engage with vasculitis patients in their country.

Kalen Young, Network Manager for the Vasculitis Patient-Powered Research Network (V-PPRN) will discuss how vasculitis patients throughout the world can become involved in the V-PPRN and in research.

We hope that our international vasculitis community will participate in this exciting and informative webinar.

To register, visit the VF Webinar web page at: goo.gl/ZzLfNF

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**SCOTLAND**
The Lauren Currie Twilight Foundation
theclarontwilightfoundation.org
VF Utah Chapter Meeting: 
The Importance of Diet and Understanding Flares | Becky Brooks

The VF Utah Chapter conducted a meeting on June 14 at the Salt Lake City Library. The meeting began with an informative presentation from Mary Mahler, a Registered Dietitian, regarding the benefits of choosing an anti-inflammatory diet.

Ms. Mahler stated regular exercise coupled with the Mediterranean diet, which includes lots of fruits and vegetables, healthy fats, and limited amounts of red meat, is a great way to reduce inflammation. She also reminded us a healthy body weight is another way to discourage inflammation. If you are interested in losing a few pounds, this diet and exercise with reduced amounts of nuts and fats will help with weight loss.

After her presentation, Dr. Curry Koening, University of Utah, Division of Rheumatology, talked about the impact of diet on vasculitis. We all agreed we would like to see the VF utilize some of the research grant funding to obtain some hard data about this topic.

We also had a group discussion about how to determine if you are having a flare, or another unrelated health issue, and when to contact your medical professional. Dr. Koening shared his recommendations when we are ill, to potentially avoid a flare before it becomes severe.

We learned a great deal about how quickly a flare can become severe, and the importance of keeping your physician aware of questionable symptoms and treatments.

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

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Please fill out form completely, detach and send to VF office.

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DUES:   ____ $35 U.S. for all members   ____ $500 U.S. Lifetime Membership
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Enclosed is my check or Please Bill My Credit Card (circle one). Visa/MasterCard/Discover/American Express

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2017 · calendar of events · 2017

August 26, 2017
Nick Pascente Memorial Golf Tournament Fundraiser
10:00 a.m. (all day with dinner at the Halftime Bar and Grill)
Prairie Isle Golf Course
2216 W State Rd, Crystal Lake, IL 60014
Golf, dinner, and raffle
Organizer:
Craig Alshouse, calshouse1@yahoo.com, 815.980.9870

August 9, 2017
Kansas/Missouri Chapter Meeting
1:00 p.m. - 3:00 p.m.
BEST Conference Center, Room 125
University of Kansas Edwards Campus
12600 Quivira Road, Overland Park, KS 66213
Denny and Ruth Hale, dhale3@kc.rr.com or 913.764.7557
Guest Speaker: To Be Announced

August 30, 2017
4th Annual Chicagoland Golf Open Fundraiser
Twin Orchard Country Club
22353 Old McHenry Rd, Long Grove, IL 60047
Organizers:
Danny Fishbein, danny@worknturn.com
Jeff Fishbein, Psy.D., jfishbein30@gmail.com

September 16, 2017
Celebrating a Life: The 12th Annual Keesha Vessell Walk
Newnan City Veteran's Park
38 Jackson St., Newnan, GA
Registration: 8:00 a.m.
Welcome: 8:30 a.m.
Walk: 8:45 a.m.
Contact Diann Alford at 678.416.9155 or diannrip12@aol.com

September 30, 2017
North Carolina VF Chapter Fall Meeting
9:30 a.m. - 2:00 p.m.
UNC Wellness Center at Meadowmont in Chapel Hill
100 Sprunt St, Chapel Hill, NC
Jill Powell, jill_powell@med.unc.edu
Speaker/Topic: To Be Announced

November 12, 2017
5th Annual “Rally in the Alley” Benefiting the Vasculitis Foundation
3:00 p.m. - 6:00 p.m.
PINSTRIPES
1150 Willow Road
Northbrook, Illinois 60062
Bowling and Buffet
Register here: https://goo.gl/jdzbEV
Organizers: Karen Hirsch 847.530.3339
Jason Wadler 773.793.6581

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

To submit items for the calendar, please contact the VF office.

The Vasculitis Foundation acknowledges an educational grant for support of this newsletter from Genentech, Inc. and Biogen, Idec.