Remembering Bob Sahs: A Passionate Vasculitis Awareness Advocate

On April 13, the VF lost one of its most passionate advocates who helped raise awareness about vasculitis, and the VF across the globe for almost 20 years. Bob Sahs came to the organization in support of his wife, who was diagnosed with Wegener’s/GPA in 1999. Interestingly, Elaine’s father also had Wegener’s and died in 2001 at the age of 89.

Bob joined the VF Board of Directors in July 2006. He served as board president for two years and chaired or served on the resource, nominating, awareness, and fundraising committees. He and Elaine were co-leaders of the Tri-State (NY, NJ, CT) VF Chapter and started the chapter at The Villages, Florida.

Bob always attended VF symposia, chapter events and special fundraisers. Although he actively participated in activities in this country, Joyce Kullman, Executive Director, remembers that he would use his global trips to bring attention to the VF.

“Bob loved to raise awareness of vasculitis and he always carried a 6-foot VF banner on his vacations to China, Africa and other exotic destinations,” says Kullman. “He always told me that he would rather carry the banner than clothes in his suitcase.”

Karen Hirsch, president of the VF Board of Directors, also remembers Bob as a tireless advocate who enjoyed his role. “Bob was a caring advocate for all with vasculitis,” says Hirsch. “He brought his extraordinary wisdom and compassion to the board and led many efforts for many years to advance the mission of the VF. Bob was funny and kind, and he will be greatly missed.”

The 2017 International Vasculitis Symposium: Meeting Patient Needs at Every Stage in their Journey

One of the challenges of creating an event like the 2017 International Vasculitis Symposium is ensuring that it’s a worthwhile experience for the widest range of patients, families, and caregivers.

There are newly diagnosed patients for whom the symposium is their introduction to the disease. Often, they are seeking basic, clinical information and an opportunity to ask lots of questions to medical experts. For others who have been managing their disease for several years, learning about more advanced issues may be necessary. Some attendees may want to know about the latest vasculitis research studies, and other patients may be seeking information on their particular form of vasculitis.

Surveys Give Clue to Patient Needs/Expectations

Balancing and meeting these expectations is especially important because patients can be in various phases of their illness. Joyce Kullman, Executive Director of the VF, says the VF Staff and Board drew from previous symposia surveys to craft an event that will hopefully help patients who are at any stage of their illness.

“We reviewed surveys from our past symposia to learn what attendees liked, disliked, or suggested as a new topic,” said Kullman. “Vasculitis patients fall into many categories or phases of their illness, and the needs for each of those stages can vary. Someone who is 25 years-old will often want information that may be less relevant to a pediatric, or a middle-aged patient. Our goal with this symposium is to offer attendees information and support that will help them wherever they are with their illness.”

Kullman acknowledges that some people who have attended past symposia may be reluctant to participate in a new one. However, the 2017 VF Symposium is designed to provide the latest research developments, advances in diagnostics and promising therapies.

“We hold a symposium every two years, but the reality is that a lot is happening during that time in the area of research and clinical advances,” explains Kullman. “If you attend this symposium you will be learning about exciting developments that weren’t around in 2015 during our last symposium.”

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Dear Friends,

May is Vasculitis Awareness Month: Learning, Engaging, and Connecting to Raise Awareness of Vasculitis


These three words form the core message for Vasculitis Awareness Month 2017. Each year the VF showcases May as a month to put the spotlight on raising awareness about vasculitis throughout the world with a single, unifying theme. This year, we wanted to make the theme simple, direct, and positive.

Patients are always asking how to be more proactive and involved in the management of their illness. We felt these three words sum it up perfectly.

Learn everything you can about vasculitis so you can make educated and informed decisions about your medical care. Engage with experts on the disease, or get involved in research studies. Finally, connect with your own network of family and friends and other patients to spread awareness about vasculitis and the impact the disease has on your life. More importantly, connect with your own doctors who may not be familiar with vasculitis.

Throughout May, the VF will provide new tools and resources to educate patients, and to help them raise awareness in their community.

The 2017 Vasculitis Awareness Poster

This poster is available both in hardcopy form, and as a downloadable PDF document on the website. We encourage you to share it with your friends, family, and doctors. We’ve also enclosed the poster in the middle of this newsletter for you to remove and take to your next doctor’s appointment!

The Updated 2017 VF Patient Guide (e-Book)

This popular publication has been updated since its introduction nearly five years ago. This e-book provides information on all of the types of vasculitis, medications, new treatment therapies, and a host of links to online resources.

May Webinar: Learning, Engaging, and Connecting Globally

In May, the VF will hold a special webinar focusing on how vasculitis organizations are working together throughout the world to raise awareness of vasculitis.

Learn more about May Vasculitis Awareness Month at: www.VasculitisFoundation.org

Sincerely,

Joyce A. Kullman
Executive Director
Register Today for the VF-Northwestern CME Course: Vasculitis 2017 Update

The Vasculitis Foundation is pleased to present the 2017 Vasculitis Update CME Course for health care professionals. Please tell your health care professionals about this educational opportunity to learn about vasculitis from our medical experts and gain CME credit!

Vasculitis 2017 Update
June 24, 2017
7:45 a.m. – 12:30 p.m.
Marriott Chicago O’Hare
8535 W. Higgins Road
Chicago, Illinois 60631

Sponsored by:
Vasculitis Foundation
Northwestern University Feinberg School of Medicine Office of Continuing Medical Education
Division of Rheumatology, Northwestern University Feinberg School of Medicine
Vasculitis Clinical Research Consortium

Audience
This continuing medical education program is designed to meet the educational needs of physicians who detect, diagnose and treat vasculitis.

Learning Objectives
At the conclusion of this activity, participants will be able to:
- Recognize the role of imaging in large vessel vasculitis
- Summarize treatment for large vessel vasculitis.
- Interpret evidence for small vessel vasculitis
- Identify treatment options for alveolar hemorrhage
- Identify biomarkers for disease prognosis and treatment response

Utilizing Biomarkers in Vasculitis
Sharon Chung, MD, MS
Assistant Professor of Medicine
University of California San Francisco

Imaging in Systemic Vasculitis
Peter Grayson, MD, PhD
Vasculitis Translational Research Program - NIAMS

Management of Alveolar Hemorrhage
Ulrich Specks, MD
Professor of Medicine
Mayo Clinic

Management of ANCA Associated Vasculitis
Peter Merkel, MD, MPH
Professor of Medicine
University of Pennsylvania

Management of Large Vessel Vasculitis
Antoine Sreih, MD
Assistant Professor of Medicine
University of Pennsylvania

Question & Answer Session
Lunch and Learn about the Vasculitis Clinical Research Consortium

Fees
Physician: $150.00 | Clinical Staff: $100.00 | Trainee: Free
Register: http://www.medicine.northwestern.edu/divisions/rheumatology/research/vasculitis.html
For more information: 312.503.8003
The VF Patient and Caregiver Conference, Cleveland Clinic

Dr. Carol Langford talks about the newest vasculitis research during the VF Patient and Caregiver 1/2 Day Conference, Tuesday, April 4 in Cleveland, Ohio. More than 80 attendees learned about the various types of vasculitis, how it is treated, and new research advances in diagnosing and treating vasculitis.

North Carolina Meeting

The North Carolina/Raleigh VF Chapter met on April 1 and featured a special presentation “How Does Your Doctor Think: Getting the Most from Your Visit” led by Dr. Will Pendergraft, Associate Professor of Nephrology at the University of North Carolina. Dr. Pendergraft also discussed the latest research results that he learned at the 18th International ANCA Workshop in Toyko, Japan.

VF Beer Tasting Fundraiser Raises over $4,000

More than 50 guests raised over $4,000 at the VF Beer Tasting Fundraiser, March 12, Imperial Oak Brewing, Willow Springs, Illinois.
15th Annual Eastern PA/Western NJ Vasculitis Walk

JOIN US • SUNDAY, JUNE 4, 2017
Registration starts at 11 a.m. • Walk at Noon
Ridley Creek State Park, #17
1023 Sycamore Mills Rd., Media, Pennsylvania 19063

RAIN OR SHINE
Come by yourself, bring a friend or your family!
• Bring your lunch, grill available
• Playground and Restroom on Site
• Pets welcomed on a leash
• FREE TSHIRT

GREAT DOOR PRIZES
This walk supports the following diseases:
• Behcet’s disease
• Central Nervous System
• Churg-Strauss Syndrome
• Cryoglobulinemia
• Giant Cell Arteritis
• Henoch-Schonlein purpura
• Hypersensitivity Vasculitis
• Microscopic Polyangitis
• Kawasaki disease
• Polyarteritis Nodosa
• Polymyalgia Rheumatica
• Rheumatoid Vasculitis
• Takayasu’s Arteritis
• Wegener’s Granulomatosis (GPA)

If you can’t attend the walk but would like to donate please make your check out to:

VASCULITIS FOUNDATION
P.O.Box 28660
Kansas City, MO 64188
1.800.277.9474

Contact: Sharon Sirman • 610.836.2455
Ruth or Jack Falkenstein • 484.461.6156

Charity Magic Show Benefiting the Vasculitis Foundation

SUNDAY, MAY 21 @ 6:00 p.m.
Sunset Hills Community Center
3915 S. Lindbergh Blvd., St. Louis, MO, 63127
Admission: Donations will be accepted at the door. Proof of online donation to the VF will also be accepted. For more information contact: Amanda Lindsey
amandalindseymagic@gmail.com

Youth Engagement A Key Part of the 2017 Vasculitis Symposium | Ed Becker

A major strategy for the Vasculitis Foundation in 2017 is a deeper engagement with a key demographic in the vasculitis community – young adults with vasculitis. During the 2017 International Vasculitis Symposium in Chicago, the VF will be particularly focusing on this group which loosely includes kids in their teens and young adults through their late twenties.

Joyce Kullman, Executive Director, says that providing special sessions for young adults dealing with vasculitis was always a critical consideration as the symposium was planned out months ago. She says feedback on social media, and on previous symposia surveys showed the needs of young adult patients are sometimes overlooked.

“We created a session that will be led by young adults, for young adults. We also plan to have a separate session at the same time for our parents and guardians. Both of these groups are so important and have their own issues and concerns,” says Kullman. “It’s important to have an atmosphere where our younger patients can talk to their peers about what it means to be a young adult with vasculitis. There are some outstanding youth leaders in our community who can serve as mentors to these young people dealing with vasculitis.”

One of those leaders is Allison Lint, a talented professional violinist whose passion is to raise awareness about vasculitis with a particular interest in helping young adult patients. “I’ve now been through high school, college, and almost the entire decade of my 20’s since being diagnosed, and finally feel mentally and emotionally in touch with the roller coaster that is chronic illness,” explains Lint.

“When I’m committed to guiding teens and young adults down this crazy, unconventional path so that they too can reach a place of peace and acceptance – no matter what stage of illness they encounter. You can’t beat vasculitis, but you can live with it better than you might think possible!”

“...and no matter how much research I do on my own, a single sentence from one of the vasculitis experts that present at these symposiums may totally change the course and outlook of my treatments.”

Suzanne

HAVE CHAPTER NEWS you’d like to share? Contact the VF office at 816.436.8211 or 800.277.9474 or vf@VasculitisFoundation.org
2017 INTERNATIONAL VASCULITIS SYMPOSIUM
JUNE 23-25, 2017
Chicago Marriott O’Hare | 8535 West Higgins Road, Chicago, Illinois  60631

REGISTRATION FEE
The Registration fee includes meals (Friday afternoon break, evening dessert reception, Saturday breakfast, morning break, lunch, afternoon break, banquet, Sunday breakfast and morning break), educational materials, handouts and admittance to educational sessions and exhibit area, refreshment breaks and a VF Symposium 2017 t-shirt!

US $200 for VF members
US $230 for non-VF members
Please contact the VF office to confirm your membership status.
Register online: https://goo.gl/u5SBeX
Or, call the VF office to register by phone: 816.436.8211
Pre-registration is required! The deadline for registering is Saturday, June 17, 2017.

Hotel Headquarters:
Chicago Marriott O’Hare,
8535 West Higgins Road, Chicago, IL 60631
3 miles from O’Hare International Airport
Room block available June 21 – 26, 2017 (Room block is limited so book now.)
Room Rate: $119 per night plus taxes (Deadline is May 31, 2017 to reserve under VF room block)
Reserve online: http://www.marriott.com/hotels/travel/chiap-chicago-marriott-ohare/
Phone: 773.693.4444

Note: Pediatric Patients: Only pediatric vasculitis patients are permitted to attend symposium sessions and a parent or legal guardian must accompany any patient 15 years of age or younger to the sessions.

2017 International Vasculitis Symposium Preliminary Schedule | FRIDAY, JUNE 23, 2017

<table>
<thead>
<tr>
<th>10:00 a.m. - 8:00 a.m.</th>
<th>INFORMATION DESK OPEN</th>
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| 1:00 p.m. - 1:45 p.m. | BREAKOUT SESSION I
Please choose one session to attend: |
|-----------------------|------------------------|
| Breakout Session | Vasculitis 101
For Newly Diagnosed Patients – How to Symposium!
Alex Villa-Forte, M.D., Cleveland Clinic |
| Breakout Session | Vasculitis 201
Experienced Patients - What’s New for You?
Peter A. Merkel, M.D., University of Pennsylvania |
| Breakout Session | Pediatric Vasculitis – Parents & Children
(this session will meet from 1:00 - 4:00 p.m.)
Marinka Twilt, M.D., The University of Calgary, Pediatrics Rheumatology
Linda Wagner-Weiner, M.D., University of Chicago Pediatrics Rheumatology
Marisa S Klein-Gitelman, M.D., Northwestern University Pediatrics Rheumatology |

| 2:00 p.m. - 4:00 p.m. | BREAKOUT SESSION II
Overview of Specific Diseases |
|------------------------|------------------------|
| These sessions provide the opportunity for patients diagnosed with the same types of vasculitis to gather in smaller groups for discussions on treatments and side affects with our vasculitis experts. All of the sessions will include time for Q&A. The final groups will be arranged based on the number of attendees.
Please choose one session to attend: |
| Breakout Session | Behcet’s Disease
Yusuf Yazici, M.D., NYU Langone Medical Center
Rob Micheletti, M.D., University of Pennsylvania |
| Breakout Session | Eosinophilic granulomatosis with polyangiitis
(Churg-Strauss Syndrome)
Paul Monach, M.D., Ph.D., Boston University
Antoine Sreih, M.D., University of Pennsylvania |

| 4:15 p.m. - 5:00 p.m. | BREAKOUT SESSION III - Special Interests
Please choose one session to attend: |
|------------------------|------------------------|
| Breakout Session | Introducing the Northwestern Vasculitis Clinic
Amy Archer, M.D., Northwestern University Memorial Hospital |
| Breakout Session | Parents’ Meeting without Patients
Maninka Twilt, M.D., The University of Calgary, Pediatrics Rheumatology
Linda Wagner-Weiner, M.D., University of Chicago Pediatrics Rheumatology
Marisa S Klein-Gitelman, M.D., Northwestern University Pediatrics Rheumatology |
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<tr>
<th>Breakout Session</th>
<th>Social Media Round Table for Facebook Vasculitis Group Moderators</th>
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Friday Schedule continued on page 7
FRIDAY SCHEDULE continued from page 6

Breakout Session
Young Adults (15-22) – patients only, no parents/guardians
Allison Lint, Ben Wilson, Brandon Hudgins (moderators)

Breakout Session
Youth Moviemaking without their Parents
Ed Becker, Vasculitis Foundation

5:00 p.m.
DINNER WITH YOUR FELLOW ATTENDEES!
Groups will be organized for attendees wishing to have dinner with other people with the same form of vasculitis. The Rosemont’s Mini Mile of Entertainment offers a variety of restaurants! www.Rosemont.com

7:30 p.m.
DESSERT RECEPTION
Welcome and Introductions and Keynote Address
Join us for dessert and the opportunity to visit with other attendees and hear a positive and powerful talk about living well with vasculitis.

PRELIMINARY SCHEDULE | SATURDAY, JUNE 24, 2017

6:00 a.m.
Sunrise Yoga

7:00 a.m.
Continental Breakfast

- 8:00 a.m.

8:00 a.m.
- 11:00 a.m.
MORNING SESSION IN THE BALLROOM
Welcome and Introductions
Karen Hirsch, President, VF Board of Directors
Practicing Mindfulness
James Sosebee, Sinclair College

Dermatology/Skin Involvement in Vasculitis and the 2017 ARAMIS Study
Robert Micheletti, M.D., University of Pennsylvania
Research and Fellowship Advances Funded by the Vasculitis Foundation
Jason Springer, M.D., University of Kansas
Pain Management and Health Promotion
Paul Monach, M.D., PhD., Boston University
The Role of Genetics in Vasculitis
Sharon Chung, M.D., MAS, University of California - San Francisco

11:00 a.m.
- 12:00 noon
BREAKOUT SESSION IV
Please choose one session to attend:

Breakout Session
Ear/Nose/Throat Involvement in Vasculitis
Robert Lefebvres, M.D., Head & Neck Surgical Group

Breakout Session
Inflammatory Eye Disease
Anjum Koreishi, University of Chicago

Breakout Session
Kidney Involvement in Vasculitis
Geetha Duvuru, M.D., Johns Hopkins University
Patrick Nachman, M.D., University of North Carolina

Breakout Session
Practicing Mindfulness: Hands-on Practice
Tanaz Kermani, M.D., University of California - Los Angeles

Breakout Session
Steroids 101
Amy Archer, M.D., Northwestern University Memorial Hospital

12:00 p.m.
LUNCH
- 1:00 p.m.
Vasculitis Patient-Powered Research Network (V-PPRN) Update & Q&A
Peter A. Merkert, M.D., MPH, University of Pennsylvania
George Casey, MBA, Co-Investigator
Kalyn Young, V-PPRN Network Manager

2:00 p.m.
- 2:45 p.m.
BREAKOUT SESSION V - New Disease Specific Therapies and Research For:
Please choose one session to attend:

Breakout Session
Eosinophilic granulomatosis with polyangiitis (Churg-Strauss Syndrome)
Paul Monach, M.D., Ph.D., Boston University

Breakout Session
Giant cell arteritis/Polymyalgia Rheumatica/Takayasu’s arteritis
Tanaz Kermani, M.D., University of California - Los Angeles
Jason Springer, M.D., University of Kansas

Breakout Session
Granulomatosis with polyangiitis (GPA/Wegener’s) and Microscopic Polyangiitis
Ulrich Specks, M.D., Mayo Clinic

Breakout Session
Orphan Vasculitides: Cogan’s syndrome, Cryoglobulinemic vasculitis, IgA vasculitis (Henoch-Schonlein purpura), Primary Central Nervous System vasculitis, Polyaneritis nodosa, Urticarial vasculitis and other cutaneous vasculitis
Alex Villa-Forte, M.D., MPH, Cleveland Clinic Vasculitis Clinic

2:45 p.m.
- 3:00 p.m.
AFTERNOON BREAK

3:00 p.m.
- 3:45 p.m.
BREAKOUT SESSION VI -
Please choose one session to attend:

Breakout Session
Balancing Life, Work and Vasculitis
3-Patient Panel

Breakout Session
Caregiving for Family Members Juggling Family, Career, and Vasculitis
(This session is for family members only, no patients please)
Jeff Fishbein, Psy.D., and Sharyl Fishbein

Breakout Session
Caregiving for Pediatric Patients
(This session is for parents and guardian only, no patients please)
Marinka Twilt, M.D., The University of Calgary

Breakout Session
Is it Time for Disability
Teri Bodeman, Benefit Boost, Inc.

Breakout Session
Lung Involvement in Vasculitis
Ulrich Specks, M.D., Mayo Clinic

BREAKOUT SESSION VII
Please choose one session to attend

Breakout Session
Caregiving for Senior Citizens
(This session is for family members only, no patients please)
Jeff Fishbein, Psy.D., and Sharyl Fishbein

Breakout Session
Fertility Considerations for Patients with Vasculitis

Schedule continued on page 8
Symposium Speakers List

Amy Archer, MD • Northwestern University
George Casey, MBA • V-PPRN Co-Investigator
Sharon Chung, MD • University of California - San Francisco
Geetha Duvuru, MD • Johns Hopkins University
Anisha Dua, MD • University of Chicago
Jeff Fishbein, PsyD • Fishbein & Associates, Performance Consulting
Sharyl Fishbein
Peter Grayson, MD • NIAMS Translational Research Program
Tanaz Kermani, MD • University of California - Los Angeles
Anjum Koreishi • University of Chicago
Carol Langford, MD • Cleveland Clinic
Robert Lebovics, MD • Head & Neck Surgical Group
Peter Merkel, MD • University of Pennsylvania
Robert Michelelli, MD • University of Pennsylvania
Paul Monach, MD • Boston University
Patrick Nachman • University of North Carolina
Eric Ruderman, MD • Northwestern University
Ulrich Specks, MD • Mayo Clinic
Jason Springer, MD • University of Kansas
Tony Srieh, MD • University of Pennsylvania
Marinka Twilt, MD • University of Calgary
Alex Villa-Forte, MD • Cleveland Clinic
Yusuf Yazici, MD • New York University
Kalen Young, MA • V-PPRN Network Manager

“My wife and I have attended two prior symposiums, one in Philadelphia and one in Jacksonville. We are already registered for the Chicago symposium to be held in June. We look forward to making new friends, attending breakout sessions for the latest information on my illness, and learning about new studies or trials. At each event, we have gained greater knowledge about vasculitis and GPA.”

Victor James

12 REASONS TO ATTEND the 2015 INTERNATIONAL VASCULITIS SYMPOSIUM

Attendees from previous International Vasculitis Symposia have shared their comments, and we want to share them with you. REGISTER NOW!

1 ➔ Good topics and good program.
2 ➔ Awesome information.
3 ➔ I’m not alone anymore.
4 ➔ Very informative, even entertaining.
5 ➔ Great. Very informational. Broke it down to our level.
6 ➔ Research talks offered me hope that things will be okay.
7 ➔ The entire event was incredibly well organized.
8 ➔ As a newly diagnosed patient, it was great to see others who’ve been around for awhile doing well. They inspired and reassured me.
9 ➔ My first time to attend. Good to hear people’s stories; most excellent to have so many leaders in one place.
10 ➔ Value was better than the registration price!
11 ➔ The absolute best part was how accessible the doctors were!
12 ➔ Wonderful! Pertinent! Innovative!
REGISTRATION FORM
MARRIOTT CHICAGO O’HARE  •  8535 W HIGGINS RD  •  CHICAGO, IL 60631
TEL: 773.693.4444
REGISTRATION DEADLINE: JUNE 17, 2017

REGISTRATION
ONLINE: https://www.giftool.com/registrar/ShowEventDetails?ID=1232&EID=23610
FAX: Please complete form and fax to: 816.436.8211
MAIL: Please complete form and mail to:
Vasculitis Foundation, PO Box 28660, Kansas City, MO 64188-8660
PHONE: Please call the VF office to register: 800.277.9474

Registration fee includes: Meals (Friday afternoon break, evening dessert reception, Saturday breakfast, morning break, lunch, afternoon break, banquet, Sunday breakfast and morning break), educational materials, handouts, and admittance to educational sessions and exhibit area, and VF Symposium 2017 t-shirt.

HOTEL: If you plan to stay at the Marriott, you will need to book your own room. Please reference the Vasculitis Foundation for our special room block. $119 + taxes/night https://goo.gl/KciPzQ or 773.693.4444

FIRST ATTENDEE
First Name ___________________________ MI _______ Last Name ___________________________
Address _____________________________ City _____________________________ State _____ ZIP ______
Country _____________________________ Phone _____________________________ Cell ______________
Email ________________________________
Please check: _____ Patient (Disease ____________________________________________ ) _____ Family/Friend _____ Medical Professional
Symposium t-shirt size: _____ Small _____ Medium _____ Large _____ X-Large _____ XX-Large
In case of emergency, please contact ________________________________
Please list any special needs (dietary, other) you have ____________________________________________

SECOND ATTENDEE
First Name ___________________________ MI _______ Last Name ___________________________
Address _____________________________ City _____________________________ State _____ ZIP ______
Country _____________________________ Phone _____________________________ Cell ______________
Email ________________________________
Please check: _____ Patient (Disease ____________________________________________ ) _____ Family/Friend _____ Medical Professional
Symposium t-shirt size: _____ Small _____ Medium _____ Large _____ X-Large _____ XX-Large
In case of emergency, please contact ________________________________
Please list any special needs (dietary, other) you have ____________________________________________

REGISTRATION FEE
No. of (member) attendees _____ x 200.00 = ____________ TOTAL ______________
No. of (non-member) attendees _____ x 230.00 = ____________ TOTAL ______________

PAYMENT INFORMATION
Paying by check _____ PAYMENT must be received no later than June 17, 2017.
Visa _____ MasterCard _____ Discover _____ American Express _____
Name on Card ___________________________ Card # ____________________________
Billing Address (if different from above) _________________________________________
Expiration Date ________________ TOTAL ______________
Signature ______________________________

CONFIRMATION: Please bring a copy of your registration confirmation to the symposium.
SUBSTITUTIONS: If a registrant is unable to attend, substitutions are welcome.
REFUNDS: Refund requests must be made in writing and MUST be received no later that June 17, 2017. After that time, we are sorry that no refunds can be made for any reason.
pediatric patients: Only pediatric vasculitis patients are permitted to attend symposium sessions and a parent or legal guardian must accompany any patient 15 years of age or younger to the sessions.
This issue we profile a teenager with vasculitis: 14-year-old Harrison Whetzel from Charlotte, North Carolina, who was diagnosed with GPA/Wegener’s in November 2015. Over the past 18 months, Harrison has fought through four different sinus surgeries and had tubes put in his ears and tear ducts to try alleviating the constant sinus discomfort that began the summer before his 8th grade year of school.

Harrison is an accomplished swimmer who has enjoyed a wealth of success in the pool. He posted the best time in the state for his U12 time classification, competing in the backstroke. He also swam freestyle, breast stroke, and butterfly for New South Swimming, a year-round competitive swim team in Charlotte.

As his 8th grade swimming season began, Harrison tried to stay in the pool when his symptoms started and was even able to swim after his first surgery. But the symptoms got progressively worse. “It became hard to swim,” Harrison says. “The pain was too much, and I couldn’t really focus.” After undergoing a second surgery in October 2015, Harrison hung up his swim cap for the rest of the winter while he and his parents tried to figure out what was wrong.

Luckily for the Whetzel family, Dr. Eric Mair at the Charlotte Eye Ear Nose and Throat Clinic (CEENTA) would provide some answers. In November 2015, Dr. Mair noticed a hole in Harrison’s septum and took some tissue to be biopsied, which ultimately led to a diagnosis. Harrison’s father, Doug, says he got a call late on a Friday night from Dr. Mair, who explained that Harrison had Wegener’s granulomatosis.

At that point, Harrison started on a two-year dose of Methotrexate, along with 60 mg of prednisone per day to quell his symptoms. He was also taken out of school for the rest of 8th grade to avoid getting ill on the high doses of medication.

For the most part, the next year went well for Harrison. He was able to wean completely off prednisone and was handling the Methotrexate fairly well. He returned to school, finishing 8th grade and got back in the swimming pool in the summer to prepare for high school tryouts in the fall of 2016.

But as many vasculitis patients can attest, there were still some frustrating times for Harrison and his family while trying to deal with the disease. Despite getting back into swimming shape for his freshman year at Ardrey Kell High School and performing well enough in tryouts to earn a spot on the high school swim team, Harrison was left off the roster. “It was just a real bummer for everyone,” Doug, explains. “Harrison had a weekly chemo shot the day before tryouts, but he was still in the pool the next afternoon, and posted the ninth-best freestyle time of anyone there.”

Then in January, some of Harrison’s symptoms started coming back as he started to feel like the Methotrexate was wreaking havoc on his body. By last month, he switched to online classes, and he went back on prednisone. His doctors also had him switch off Methotrexate and onto Imuran, and they are hopeful his body reacts better to the new drug.

Despite the ups and downs, Harrison has stayed optimistic and hopes to swim again this summer. “Ultimately, I’ll still plan on trying out for the swim team again,” he says. “It would mean a lot to make the team after all I’ve been through.”

Outside of his immediate high school goals, Harrison wants to become a youth ambassador for the Vasculitis Foundation to help promote awareness about the disease and to raise funding for vasculitis research in the Charlotte area.

Part of that desire stems from a lack of understanding about the disease from Harrison’s friends; Doug echoes those sentiments as well. “I think people see a young kid like Harrison who looks healthy on the outside, so they don’t have any idea what he’s been going through and the impact of [the disease].”

As Harrison continues his fight against vasculitis, he hopes to attend this summer’s VF Symposium in Chicago with his dad.

Ben Wilson
Play-By-Play Broadcaster & Reporter - KRES Radio
http://staatalent.com/client/ben-wilson/
http://www.benwilsonbroadcasting.com/
Detailing Her Journey with Vasculitis Through Writing | Ed Becker

For Anna Fieldsend, the initial symptoms couldn't have come at a worse time. At 19 years-old, Anna was in peak physical condition as she prepared for a career as a linguist in the British Military's Intelligence Corps.

“We thought it was chronic sinusitis but the symptoms kept getting worse. I’m stubborn and pushed on with life the best I could, but within a couple of weeks I was destroyed and began to deteriorate rapidly,” Anna says.

When she finally got the diagnosis of GPA/Wegener’s, Anna said she was overcome with a mixture of feelings. She recalls reaching a point of resignation and not caring so much as to the type of illness; she simply wanted to feel better. Although relieved to finally get a diagnosis, two words from the doctor’s explanation of how the vasculitis would be treated caused her concern.

“I was barely conscious when the doctors sat by my bed and explained everything to me. They told me the disease’s long and complicated name (Granulomatosis with polyangitis, GPA/Wegener’s), what it was doing to my body, and how they would treat it, but the only information that my brain truly registered were the words ‘chemotherapy’ and ‘possible infertility’, says Anna.

“I have always wanted to be a mom so hearing those words made me break down and burst into tears. Explaining to friends and family was hard as I didn’t quite know where to start! My parents were confused and scared but extremely supportive.”

Anna spent six weeks in the hospital where they stabilized her condition, and began treating her with plasmapheresis, IV cyclophosphamide, and methylprednisolone. However, it was ultimately Rituxan that proved to be the most effective treatment.

“Rituxan only came along eight years after my diagnosis, and at that point I had gone through every drug out there with no success. Everything that the doctors tried would work for a while then I would relapse again. Each time, more and more damage was being done. Finally, Rituxan changed everything. It was slow-acting but within two years I was in full remission,” Anna says.

Accepting the “new normal” that comes with vasculitis has been one of her primary challenges, but she keeps a positive outlook. One of her outlets to share her story has been writing a popular blog entitled, “The Beautiful Flight: Living with Vasculitis”.

“I’ve never been a writer, but recently I had an urge to finally get my thoughts down on paper. I never really stopped to process what my family and I went through during those years, and I quickly found that writing this blog has helped a lot,” explains Anna. “I know we are all different from each other but I know that for me, it would have helped to see a little light at the end of the tunnel by knowing that with the right help and medication, there can be a healthy life after vasculitis.

You can read more detail about Anna’s experience at her blog: https://annefieldsend9.wixsite.com/vasculitis/single-post/2017/01/19/The-diagnosis-Part-1
V-PPRN Update

The Vasculitis Patient-Powered Research Network (V-PPRN) promotes the advancement of research that provides reliable, useful and meaningful information to patients with vasculitis and their clinicians. The V-PPRN is a collaboration among patients, patient advocacy organizations, academic clinical investigators, expert clinicians, biomedical informaticians, qualitative and quantitative methodologists, and funding organizations all dedicated to conducting high-quality clinical research in vasculitis aimed at addressing key scientific and clinical issues considered of high-priority to both patients and physicians.

The V-PPRN is a member network of the Patient-Centered Outcome Research Network (PCORnet). PCORnet is an innovative initiative of the Patient Reported Outcomes Research Institute (PCORI).

It is designed to make it faster, easier, and less costly than traditional research by harnessing the power of large amounts of health data and patient partnerships.

The V-PPRN maintains an on-line research registry with patients with all forms of vasculitis providing clinical data about their condition. The type of information collected through the V-PPRN portal includes data elements relevant to diagnosis, disease extent, medications, demographics, healthcare team, and patient-reported outcomes.

MEET THE TEAM BEHIND THE NETWORK:

The V-PPRN would like to give you a special introduction to the researchers working diligently behind the scenes. We hope to continue to reduce the distance between researchers and patients – introducing you to the many faces you don’t see is important.

Peter A. Merkel MD, MPH (Co-Principal Investigator), is the Principal Investigator (PI) of the Vasculitis Clinical Research Consortium, the Chief of Rheumatology and Professor of Medicine and Epidemiology at the University of Pennsylvania, and a Senior Scholar within the Penn Center for Clinical Epidemiology and Biostatistics.

**HIS WOW FACTOR:** He is an internationally-recognized clinical and translational investigator in vasculitis whose projects have included, often as the principal investigator:

- patient-orientated clinical investigation
- outcome measure development
- clinical trial design and conduct
- clinical epidemiology

**WHY WE LOVE HIM:** Dr. Merkel is a longstanding advocate of patient empowerment and education; he is an extremely active member of the Vasculitis Foundation. He has extensive experience in leading large groups of investigators, complex research studies, and working directly with patients as research partners.

George Casey, MBA (Co-Principal Investigator) serves on the Board of Directors of the Vasculitis Foundation as the Treasurer.

**HIS WOW FACTOR:** George is a collaborative leader and problem solver aligning clients with technology and process. His specialties include predictive analytics, marketing automation, CRM, and ERP.

Jeffrey P. Krischer, PhD, is a Professor and Head, Division of Biostatistics and Informatics; Director, Pediatrics Epidemiology Center, Department of Pediatrics, University of South Florida; Principal Investigator of the Data Management and Coordinating Center for the NIH-supported Rare Diseases Clinical Research Network.

**HIS WOW FACTOR:** Dr. Krischer has more than 25 years’ experience in the design and conduct of multi-institutional epidemiological studies and clinical trials. Over the last 10 years, Dr. Krischer has served as the lead biostatistician and Principal Investigator of the DMCC for the Rare Diseases Clinical Research Network.

**WHY WE LOVE HIM:** He is expert in the application of web-based tools for clinical studies. He is responsible for the design of federated databases for integration of clinical data from multiple sources, including patient provided outcomes. His team promulgated the use of data standards to ensure the comparability and utility of data elements across databases.

Antoine G. Sreih, MD is an Assistant Professor of Medicine in the Division of Rheumatology at the University of Pennsylvania.

**HIS WOW FACTOR:** Dr. Sreih is a core faculty member of the Penn Vasculitis Center and the Vasculitis Clinical Research Consortium. Dr. Sreih has specific interests continued on page 13
VF Hires Joel Massel to Grow Resources and Optimize Outreach to Vasculitis Community

The Vasculitis Foundation has hired Joel Massel as Chief Development Officer. Massel is the founder of Creative Management Services (CMS), a company specializing in helping non-profit organizations achieve greater fundraising goals, develop effective strategic planning, and enhance advocacy.

Massel has an extensive background working with health-related organizations including the Pulmonary Fibrosis Foundation, the Institute of Medicine of Chicago, the Foundation for Hearing and Speech Rehabilitation; and the Chicago Asthma Consortium.

Creating and implementing a strong, strategic vision is a key to survival for most non-profit organizations, explains Massel. He will help the VF lay out a strategic blueprint to find new funding resources, and optimize the organization's mission of providing education, support and research.

"Over the past decade, successful organizations have become more strategic and focused on Return on Investment (ROI)," Massel explains. "A strong development strategy will support the efforts of the entire vasculitis community—patients, caregivers, professionals, and industry. Achieving our goals requires an enormous commitment. Resources are needed to support research, provide patient resources, and advocate for the thousands of individuals and caregivers impacted by vasculitis."

Generous Donation Funds Second Year of Research Study

Chris Cox-Marinelli, MD | Chair, VF Research Committee

The Research Committee of the Vasculitis Foundation would like to thank our generous donors, Mr. and Mrs. Ben and Kathy Johnson, for donating the necessary monies to fund the second year of a two-year research study proposed by Dr. Divi Cornec and Dr. Ulrich Specks, Mayo Clinic.

Dr. Specks was co-primary investigator for the RAVE Study which ultimately brought rituximab as frontline treatment for GPA/Wegener’s and Microscopic polyangiitis (MPA). The new research project hopes to refine even further those who would most benefit from rituximab by more precisely defining the role of PR-3 ANCA in GPA vasculitis and its response to rituximab intervention.

The second year of the study will expand to our French compatriots in Brest, France, and will help support a new vasculitis center. Mr. and Mrs. Johnson donated this money in appreciation of the outstanding and compassionate care they have received from Dr. Specks for Kathy’s EGPA/Churg-Strauss. They have also generously donated funds to support two ongoing EGPA research studies.

We thank them for their generosity and support to find the cure for vasculitis.

"The knowledge I gained at a VF Symposium helped my quality of life after my diagnosis. The opportunity to connect with others with my rare disease, and engage with the mission of the Vasculitis Foundation to support through education, awareness and research is an opportunity that I am forever grateful."

Grace Eisen

Tanaz Kermani, MD, MS is the Director of the Vasculitis Program at UCLA. She grew up in Mumbai and moved to the United States in 1996 after graduating high school to pursue higher education. She completed her training in Internal Medicine, Rheumatology at the Mayo Clinic in Minnesota including a two-year Vasculitis Clinical Research Consortium Fellowship. She joined the UCLA Health’s Division of Rheumatology in 2012.

HER WOW FACTOR: She has expertise in vascular ultrasound for evaluation of patients with suspected giant cell arteritis. She is an active member of the vasculitis research community, with multiple ongoing national and international collaborations with vasculitis patient advocates and medical experts. She has published several vasculitis research studies.

WHY WE LOVE HER: Dr. Kermani is deeply concerned and invested in the well-being of her patients. Her approach is to listen to her patients, and provide them with the best treatment options so she and the patients can make joint decisions concerning the best way to proceed. Dr. Kermani plays a key role in reviewing and developing research projects and data entry systems within the V-PPRN.

These are the faces of the researchers who work tirelessly to increase the understanding of vasculitis, find better treatment options, and improve the lives of patients through research. Stay tuned for the next VF Newsletter to meet the patients who partner with our researchers to develop the V-PPRN’s research protocols.
New Enrolling: A Randomized Multicenter Study for Isolated Skin Vasculitis (ARAMIS)

New study to evaluate different treatments for patients with skin vasculitis has launched!

The Vasculitis Foundation is pleased to support the ARAMIS Study with a one-year grant of $50,000.

For Diseases
- Isolated cutaneous small-vessel (SVV)
- Isolated cutaneous medium-vessel vasculitis (MVV)
- Cutaneous polyarteritis nodosa (cPAN)
- IgA vasculitis (Henoch-Schönlein purpura, IgAV)

Background
Vasculitis is the swelling or inflammation of your blood vessels. There are many forms of vasculitis, and the cause is unknown for most types of vasculitis. Vasculitis can be isolated to a single body part, or it can involve many different parts of the body or organs. Vasculitis frequently affects the skin and causes different kinds of rashes (lesions).

Because no research studies have provided answers to the question of what therapy for skin vasculitis is best, treatment decisions for patients with skin vasculitis are made based upon the treating doctor's experience and expert opinions. The doctors involved in this study are hopeful that the information gathered from this study will help doctors and patients understand what the best treatment options are for patients with skin vasculitis. This study will compare the effectiveness of the three different drugs for the treatment of skin vasculitis, look at how patients respond to the study drugs, and see if there are characteristics that predict which patients will respond to which drugs.

About this Study
About 90 people with skin vasculitis will take part in this study. If you take part in this study, you will be asked to complete a minimum of 6 study visits at the study site. The number of visits will depend upon which stage you enroll into the study and how your skin vasculitis responds to the treatments. You may be in this study for up to 18 months.

This study has two stages, Stage 1 and Stage 2. The study ends after Stage 2. Each Stage is up to 6 months long.

Qualifying for Social Security Disability Benefits with Vasculitis | Deanna Power

Vasculitis comes in a variety of forms and severities. While some people with the disorder experience mild, manageable symptoms, others with widespread or severe vasculitis may find it hard to work or complete daily tasks.

If your vasculitis prevents you from working, then Social Security disability benefits may be an option. The Social Security Administration (SSA) offers financial resources for people who are unable to earn income.

Programs Available: SSDI and SSI
Before beginning your application, it is important to know which disability benefits program may be best for you. Depending on your work history, current income, and age, you may qualify for one (or both) of the following programs.

- SSDI
  Social Security Disability Insurance (SSDI) is for people with a work history. This program is typically reserved for people over 18 who have worked regularly, but are no longer able to because of their disability’s severe symptoms.
  To qualify, the SSA must see that you have contributed enough “work credits” (taxes paid through work) in comparison to your age. For example, a 38-year-old applicant needs 20 credits (5 years of work) in order to qualify, while a 58-year-old applicant needs 36 credits (9 years of work) to qualify. SSDI recipients get monthly benefits in proportion to the amount they made in their working years, as well as Medicare coverage.

- SSI
  Supplemental Security Income (SSI) is for people without a work history, who are unemployed, or who are under 18. To qualify here, applicants must make below a certain amount of money each month to show severe financial need. Individual applicants can earn up to $735/month and still qualify, while couples can earn up to $1,103/month. However, in an effort to encourage continued

continued on page 17
Vasculitis Clinical Research Consortium (VCRC) Announces New Study
Clinical Transcriptomics in Systemic Vasculitis (CUTIS)

Status: Recruiting

The purpose of this study is to take skin biopsy samples from participants with skin (cutaneous) vasculitis to see what vasculitis is doing to the skin. The doctors in this study would like to describe the impact of vasculitis on the skin and to investigate the differences between the different types of skin vasculitis. The research team hopes that this study will develop information about skin vasculitis that will allow researchers to learn about the causes, the disease process and potential treatments for skin vasculitis.

For Diseases

- Cryoglobulinemic vasculitis (CV)
- Drug-induced vasculitis
- Eosinophilic granulomatosis with polyangiitis (EGPA)
- Granulomatosis with polyangiitis (GPA)
- IgA vasculitis
- Isolated cutaneous vasculitis
- Microscopic polyangiitis (MPA)
- Polyarteritis nodosa (PAN)
- Urticarial vasculitis

Background

Vasculitis is the swelling or inflammation of your blood vessels. There are many forms of vasculitis, and the cause is unknown for most types of vasculitis. Vasculitis can be isolated to a single body part, or it can involve many different parts of the body. Vasculitis frequently affects the skin and causes different kinds of rashes (lesions).

About this Study

About 56 people with vasculitis will take part in this study at approximately 20 medical centers across North America. All participants will be asked to complete one visit. Some participants may be asked to return for another visit 6 months after the first visit to confirm the vasculitis diagnosis. At the first visit, you will be asked to provide information about your medical history, the current medication you are taking for your vasculitis, and you will be asked to have a photograph taken of the skin lesions you have that are related to your vasculitis. At this initial visit, you will also be asked to provide a skin biopsy sample on a skin lesion that is between 24–36 hours old or is not older than one week. If you have more than one skin lesion, you will be asked if the doctor can take two skin biopsy samples. One will be used for this study and the other will be evaluated as part of your standard care. You will also be asked to provide blood samples for research.

How to participate

In order to participate in a study, you must personally contact the study coordinator of any of the participating institutions by phone or by e-mail. Please use the information below to inquire about participation.

University of Pennsylvania, Philadelphia
Study Coordinator: Christopher Snider, MPH
E-mail: Christopher.snider@uphs.upenn.edu
Phone: 215.662.6597

NEW! VF 2017 AWARENESS T-Shirt available at our Webstore!
Go to http://vfwebstore.com/. Show your support for VASCULITIS AWARENESS!

“T'm planning to attend the VF Symposium this June because they will offer sessions specifically for young patients. As a young adult with vasculitis, I know that it can be a somewhat isolating and a difficult experience with a limited amount of information available as to the disease's effect over a long period of time.

I would certainly encourage any young adult with vasculitis to attend the symposium to help connect with their peers and continue educating themselves on the intricacies of this complicated disease.”

Ben Wilson
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

AORTITIS
5507: VCRC Longitudinal Protocol for Aortitis
5511: Tissue Repository Protocol

BEHÇET’S DISEASE
5535: VCRC Validation of Patient-Reported Diagnostic Data

CRYoglobulinemic Vasculitis (Cryoglobulinemia)
5563: Clinical Transcriptomics in Systemic Vasculitis (CUTIS)

CUTANEOUS VASCULITIS
5511: Tissue Repository Protocol
5562: A randomized multicenter study for isolated skin vasculitis (ARAMIS)
5563: Clinical Transcriptomics in Systemic Vasculitis (CUTIS)

DRUG-INDUCED VASCULITIS
5563: Clinical Transcriptomics in Systemic Vasculitis (CUTIS)

EOSINOPHILIC GRANULOMATOSIS WITH POLYANGIITIS/CHURG-STRAUSS
5506: Longitudinal Protocol for EGPA/Churg-Strauss
5510: VCRC Genetic Repository One-Time DNA Study
5511: Tissue Repository Protocol
5535: VCRC Validation of Patient-Reported Diagnostic Data
5563: Clinical Transcriptomics in Systemic Vasculitis (CUTIS)

GIANT CELL (TEMPORAL) ARTERITIS (GCA)
5502: Longitudinal Protocol for GCA
5510: VCRC Genetic Repository One-Time DNA Study
5511: Tissue Repository Protocol
5535: VCRC Validation of Patient-Reported Diagnostic Data

GRANULOMATOSIS WITH POLYANGIITIS (WEGENER’S/GPA)
5505: Longitudinal Protocol for GPA/Wegener’s
5510: VCRC Genetic Repository One-Time DNA Study
5511: Tissue Repository Protocol
5515: VCRC Imaging Protocol for Magnetic Resonance and Positron Emission Tomography in Large-Vessel Vasculitis (TAK): Development as Clinical Trial Outcome Measures
5535: VCRC Validation of Patient-Reported Diagnostic Data
5563: Clinical Transcriptomics in Systemic Vasculitis (CUTIS)

URTICARIAL VASCULITIS
5563: Clinical Transcriptomics in Systemic Vasculitis (CUTIS)

POLYARTERITIS NODOSA (PAN)
5504: Longitudinal Protocol for PAN
5510: VCRC Genetic Repository One-Time DNA Study
5511: Tissue Repository Protocol
5535: VCRC Validation of Patient-Reported Diagnostic Data
5562: A randomized multicenter study for isolated skin vasculitis (ARAMIS)

TAKAYASU’S ARTERITIS (TAK)
5503: Longitudinal Protocol for TAK
5510: VCRC Genetic Repository One-Time DNA Study
5511: Tissue Repository Protocol
5515: VCRC Imaging Protocol for Magnetic Resonance and Positron Emission Tomography in Large-Vessel Vasculitis (TAK): Development as Clinical Trial Outcome Measures
5535: VCRC Validation of Patient-Reported Diagnostic Data

MICROSCOPIC POLYANGIITIS (MPA)
5505: Longitudinal Protocol for GPA/Wegener’s and MPA
5510: VCRC Genetic Repository One-Time DNA Study
5511: Tissue Repository Protocol
5535: VCRC Validation of Patient-Reported Diagnostic Data
5563: Clinical Transcriptomics in Systemic Vasculitis (CUTIS)

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work, only half of all income earned through jobs is counted towards these totals, meaning many SSI recipients make more than these amounts and still qualify. Applicants under 18 are evaluated by the income of their parents or guardians.

If you are unsure whether or not you qualify for a program, you can consult the SSA’s website or speak with an official at your local Social Security office.

**Medical Requirements**

Regardless of whether you’re applying for SSI or SSDI, the SSA can only provide benefits to applicants who demonstrate “total and permanent disability”. This phrase describes any person whose condition is a) severe enough to prevent them from performing normal tasks safely, and b) is expected to last for at least 12 months or result in death. When an SSA reviewer looks over an application, they evaluate these factors by consulting the “Blue Book” — a collection of all SSA-approved disorders.

To see if your vasculitis may qualify, we must consult Section 14.00 of the Blue Book: “Immune Disorders.” Here, it states that applicants with vasculitis can qualify if:

- Your vasculitis affects two or more organs/body systems, with one body system being affected to at least a moderate degree, as well as at least two of the constitutional signs (severe fatigue, fever, malaise, or involuntary weight loss)

**OR**

- repeated manifestations of systemic vasculitis, with at least two of the typical symptoms (severe fatigue, fever, malaise, or involuntary weight loss) as well as at least one the following: limitations of daily living, limitations of social functioning, or limitations in completing tasks in a timely manner due to problems with pace, persistence, or concentration.

For example, you might be able to qualify if the fatigue from your vasculitis keeps you from working (you’re too tired to drive, unable to take public transportation, stairs become a challenge, etc.)

Because these qualifications can be subjective, it is important to provide as much medical evidence as possible when applying. For vasculitis, tests like tissue biopsies, angiography tests, MRIs, CT scans, and general blood work are most beneficial in demonstrating symptoms. Hospitalization history, medication lists, therapy session notes, or physician’s notes can also have a large impact on the SSA’s decision. In general, the more evidence you provide on your application, the more likely you will medically qualify for benefits.

**Starting the Social Security Application**

SSI applications can only be filled out in-person at your local Social Security office. However, online resources (such as income calculators, information pages, and necessary document lists) are also available to help you prepare and expedite the in-person application. Applicants under 18 will also need to fill out official documentation on the SSA’s website to allow their physicians to forward medical history for their application.

The average applicant is approved in around five months.

Deanna Power  
Director of Outreach, Disability Benefits Help  
drp@ssd-help.org•

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**JOIN THE V-PPRN TODAY!**  
www.vpprn.org

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**VCRC | continued from page 16**

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Vasculitis Experts Teaching Medical Professionals about Vasculitis

More than 200 rheumatologists, nephrologists, pulmonologists, dermatologists, neurologists, allergists, immunologists, and advanced practice clinicians interested in vasculitis attended this Continuing Medical Education (CME) course on April 5 at the Cleveland Clinic.

During the day long session, they learned about the latest information on diagnosing and treating vasculitis.

Session instructors included: Dr. Peter Merkel, Dr. Carol Langford, Dr. Kenneth Warrington, Dr. Michael Wechsler, and Dr. Rula Hajj-Ali.

The sessions were recorded, and will be made available as online CME courses for other medical specialists in the future.

The VF contributed $10,000 to help the Cleveland Clinic produce this vasculitis CME series. It’s part of the VF’s commitment to help educate medical professionals who may be the first ones to see a patient and to hopefully know about vasculitis to make an earlier diagnosis.

The Primary Vasculitides: Best Practices and Future Advances CME session was held at the Intercontinental Hotel in Cleveland, Ohio on April 5.

Photo by Ed Becker

The Primary Vasculitides: Best Practices and Future Advances CME session was held at the Intercontinental Hotel in Cleveland, Ohio on April 5.

IN MEMORIAM

THANK YOU to all those who made donations to the VF in memory of a loved one.

Dennis Gene Bryan  Ryan Bunck  Joseph T. Buckley  Roy Chao  Eliseo Gomez  Richard Goulet  Terry Grant  Janice Jolly  Susan Kalmar  


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The Road Map To Wellness Educational Webinar Series 2017

Topic: Pumping Iron, Not Prednisone

Thursday, April 27, 2:00 p.m. (Eastern)

Presenter: Rebecca Manno MD, MHS, Assistant Professor of Medicine and Assistant Director of the Johns Hopkins Vasculitis Center

Register: http://tinyurl.com/kvd3bmb

Trying to maintain a consistent exercise regimen while dealing with the effects of vasculitis can be extremely frustrating. How much is too much exercise? What special precautions should be taken to avoid injury?

Dr. Rebecca Manno will discuss these key questions during the webinar. “This presentation will review why exercise is beneficial for the treatment of inflammatory diseases and the evidence which supports such activity,” says Dr. Manno. “I’ll look at a practical approach to prescribing exercise in chronic, musculoskeletal conditions. We will also discuss strategies to overcome barriers to exercise in vasculitis.”

Dr. Manno is an Assistant Professor of Medicine and Assistant Director of the Johns Hopkins Vasculitis Center at the Johns Hopkins University School of Medicine. Her research interests are focused on the intersection of aging and rheumatic diseases and the application of resistance exercise for patients with inflammatory disease (namely rheumatoid arthritis and vasculitis) to improve body composition, strength, function and decrease inflammation.

The webinar will be recorded and placed in the library for later viewing.

Rebecca Manno, MD, MHS

Photo by Ed Becker
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$15 each - Child and Adult Sizes Available

Enjoy a 20% DISCOUNT on jackets, visors and caps!

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Keith and Cava Ronsaville  
Max Sell  
Dixie Selvidge  
Travis Sizemore  
Tom Stokes  
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Stephanie Taylor  
Pamela Pekerman and Stanislaw Tenenbayev  
Carol Thompson  
Mary and Bruce Torgler  
United Way, Buffalo and Erie County  
Jan Van Wazer  
Anne Vartersian  
Michael and Victoria Wallace  
Angela Warren  
Rex Wisner

“The VF Symposiums are unmatched resources for learning about vasculitis. As a new patient, you can learn all the basics of vasculitis. As an experienced patient you can get updates on the latest in research and treatment. Whether you’re new or experienced, the opportunity to talk with other patients and the doctors is amazing!”

Elaine Holmes

VICTORY OVER VASCULITIS: VF Team Brandon Challenges People to Define it, Do it, and Share it

What is your victory over vasculitis?

This is the question that is posed to the members who have joined Brandon Hudgins’ Facebook Group. Since January the group has grown to more than 115 members.

Each week, people post updates, photos, or video showing themselves achieving their own victory.

Brandon Hudgins says the idea of “victory” means achieving a goal despite the vasculitis. It also means something different to every person.

“Some people may complete a race. For someone else, going to the gym twice a week is a win,” says Hudgins. “And honestly, simply playing with your grandkids for an hour despite feeling lousy might be a victory. It’s all very personal, but the goal of our group is to encourage people to define it, do it, and then share the news with everyone.”

Also, Brandon Hudgins will be attending the 2017 Vasculitis Symposium in Chicago. Hudgins, along with several other individuals will be leading a special session focusing on the needs and challenges of young adults with vasculitis.

Join Victory Over Vasculitis: VF Team Brandon:

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Note: Due to space constraints, we are no longer listing area contacts. Area contacts are listed on the VF website or call the VF office for assistance.

www.VasculitisFoundation.org

continued on page 22
Recommended Reading

The Heart in Rheumatic, Autoimmune, and Inflammatory Diseases
Pathophysiology, Clinical Aspects and Therapeutic Approaches

Edited by: Udi Nussinovitch, MD PhD
Rambam Health Care Campus, affiliated with the Technion Institute of Technology, Israel
ISBN: 978-0-12-803267-1
Feb 28, 2017 | $180.00 | Hardback | 766 pp
Publisher: www.elsevier.com

Autoimmune rheumatic diseases can affect the coronary vessels, myocardium, pericardium, heart valves and the conduction system. The diagnosis of these unique cardiac complications necessitates medical awareness and a high index of suspicion. The book aims at providing the readers with a state-of-the-art collection of up-to-date information regarding clinically important topics based on experts’ perspectives.

This book is the result of an extended coordinated collaboration of 154 distinguished scientists from 31 countries around the globe.

Key Features
- A review of common as well as unusual (yet clinically significant) medical cardiac complications of prevalent rheumatic, autoimmune and inflammatory diseases.
- Focuses on aspects of pathophysiological processes, clinical presentations, screening tests, prognostic implications and novel therapeutic approaches.
- Presents an up-to-date “level of evidence” and “strengths of recommendations” for suggested therapies and reviews all randomized clinical trials, meta-analyses and other supporting published clinical findings.

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May 1-31, 2017
VASCULITIS AWARENESS MONTH
vf@vasculitisfoundation.org

May 6, 2017
Benefit Singing
in Honor of Kim Buckley-Bennett
6:00 p.m.
Greasy Creek Freewill Baptist Church
3169 Shelby Dry Fork
Shelbiana, KY 41562
Bob Bennett, truckerpacrat52.rb

May 13, 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: Dr. Jason Springer,
KU Vasculitis Clinic

May 20, 2017
2nd Annual Rocking Bar H Spaghetti Western Dinner
6:00 p.m.
Neuauwukum Grange Hall
38402 180th Ave SE
Auburn, WA 98092
Brook Hickle
brook.hickle@gmail.com

May 21, 2017
Charity Magic Show Benefit for VF
6:00 p.m.
Sunset Hills Community Center
3915 S Lindbergh Blvd
St. Louis, MO 63127
Amanda Lindsey
amandalindseymagic@gmail.com

May 24, 2017
Dine & Share Invitation Fundraiser
(15% of all food sales go to the VF)
Nick Pascente Memorial
5:00 p.m. - 9:00 p.m.
BuddyZ McHenry
1138 N. Green St.
McHenry, IL 60050
Craig Alshouse, 815.980.9870,
calshouse1@yahoo.com

June 4, 2017
15th Annual Eastern PA/Western NJ Vasculitis Walk Fundraiser
Registration 11:00 a.m.
Walk at Noon
Ridley Creek State Park
Shelter #17
1023 Sycamore Mills Road
Media, PA 19063
Sharon Sirman, 610.836.2455 or
ssirman714@gmail.com
Ruth or Jack Falkenstein
484.461.6156

June 14, 2017
VF Utah Chapter Meeting
SLC Main Library, Room B
Becky Brooks, vfutah11@gmail.com

June 23-25, 2017
2017 INTERNATIONAL VASCULITIS SYMPOSIUM
Marriott Chicago O’Hare
8535 West Higgins Road
Chicago, Illinois 60631
http://www.vasculitisfoundation.org/2017symposium/

June 24, 2017
Northwestern-VF CME Course:
Vasculitis 2017 Update
7:45 a.m. - 12:30 p.m.
Marriott Chicago O’Hare
8535 W. Higgins Road
Chicago, Illinois 60631
For Healthcare Professionals
Registration is required:
medicine.northwestern.edu/divisions/rheumatology/research/vasculitis.html
Physician: $150.00
Clinical Staff: $100.00
Trainee: Free
rheumatology@northwestern.edu
312.503.8003

August 26, 2017
Nick Pascente Memorial Golf Tournament Fundraiser
10:00 a.m.
Prairie Isle Golf Course
2216 W State Rd
Crystal Lake, IL 60014
Golf, dinner, and raffle
Craig Alshouse,
calshouse1@yahoo.com,
815.980.9870
Dave Schwanebeck

August 30, 2017
4th Annual Chicagoland Golf Open Fundraiser
Twin Orchard Country Club
22353 Old McHenry Rd
Long Grove, IL 60047
Danny Fishbein, danny@worknturn.com or 312.305.1021
Jeff Fishbein, Psy.D.,
jjfishbein30@gmail.com

November 12, 2017
3:00 p.m. - 6:00 p.m.
5th Annual “Rally in the Alley” Benefiting the Vasculitis Foundation
Pinstripes
1150 Willow Rd
Northbrook, IL 60062

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.