4th Annual Chicagoland VF Golf Open: Impacting Vasculitis Research and Patient Care in Chicago

In 2013 when he was diagnosed with non-systemic microvasculitis, Dr. Jeffrey Fishbein and his family decided they wanted to raise both awareness and funds for vasculitis research. Fishbein said the easy part was determining what type of fundraiser they wanted to do.

“We chose golf because it has been in our family since childhood,” says Fishbein. “We grew up near Twin Orchard Country Club, and the passion all of us feel for this game gets stronger by the year. It is where our friends are and where all the support has been. What started as a simple and small idea turned into an event none of us really predicted would occur, which was an outpouring of support from friends, family, and corporations.”

To date, their golf event has raised more than $500,000 for the Vasculitis Foundation. The monies have resulted in helping to establish a new vasculitis center at Northwestern University Feinberg School of Medicine’s Department of Medicine.

This program, a collaboration with the Vasculitis Foundation, supports clinical and translational research into the epidemiology and treatment of vasculitis. The Northwestern Vasculitis Clinic is headed by Amy Archer, MD, PhD. Fishbein says the Annual Chicagoland VF Golf Open helps to support Dr. Archer’s work.

“In the last two months alone, Dr. Archer has had over 40 appointments with patients diagnosed with vasculitis,” says Fishbein. “They are about to open a dedicated half-day vasculitis clinic downtown and are also having smaller dedicated vasculitis clinics in Glenview. Many of the funds raised at this golf outing have enabled us to keep Dr. Archer running the program.”

Jeff is already looking towards the 2018 fundraiser. “We need to keep making it feel fresh and exciting, and we need to make sure that everyone who contributes knows the unbelievable impact they make on the foundation and the use of the funds to date.”

ANCA Vasculitis International Conference

Updates 2017 (Part 2 of 2)

By Anisha Dua, MD, MPH
Assistant Professor of Medicine, Program Director, The University of Chicago Medicine, Rheumatology

Editor’s note: This is the second of a two-part series discussing information presented at the 2017 International Vasculitis and ANCA Workshop in March in Tokyo, Japan. The first part of the article was published in the July/August newsletter and reviewed research presented on ANCA vasculitis and pulmonary limited Microscopic Polyangiitis (MPA). This part of the article discusses Takayasus and Giant cell arteritis.

Takayasus (TAK) and Giant Cell Arteritis (GCA) - Spectrum of Disease?

Early recognition and diagnosis of vasculitis leads to prompt management and better patient outcomes. Currently the delay to diagnosis is significant (258 days in TAK and 56 days in GCA) and there are overlapping clinical features including weight loss, fatigue, fevers, claudication and angiograms (blood vessel studies) with stenosis (areas of narrowing). As a community, we are re-appraising the ACR classification criteria for TAK and GCA to try and improve our accuracy in recognizing and diagnosing these patients.

Dr. Tanaz Kermani, director of the UCLA Vasculitis Program, discussed the many overlapping features of GCA and TAK, but noted some important distinctions that can help us in properly classifying these patients. GCA and TAK are similar in that they affect branches of the aorta and while GCA classically affects older individuals, and TAK affects younger adults, there is a gap of people in the middle (age 40-50).

Clinically it has been easier to diagnose GCA because the headache symptom is more common, with higher inflammatory markers and more polymyalgia symptoms. Some important differences between TAK and GCA include that TAK patients tend to have more lower extremity claudication and more damage and bruits on exam with a larger number of vascular beds affected. Patients with TAK are often females (9:1) and of Asian/Turkish descent. GCA tends to affect Caucasians and there is a female predominance, about 2:1. There are also some genetic distinctions between these two diseases.

continued on page 9
Dear Friends,

The Vasculitis Foundation achieved some tremendous milestones in 2017. In the coming weeks, we will be sharing with you our most significant accomplishments and how they directly impacted you, whether you are a patient, family member, caregiver, physician, or researcher.

While the VF’s contributions to improving the lives of patients with vasculitis have been significant this year, our goals, as always, remain high. We work on your behalf to achieve faster diagnoses, better treatments, and, ultimately, a cure for all forms of vasculitis.

Training new clinician-investigators

We are pleased to introduce Dr. Kaitlin Quinn, one of our 2017-2018 VCRC-VF Fellows, to readers on page 7. Dr. Quinn is a junior faculty member in the Division of Rheumatology, Immunology and Allergy at Georgetown and will complete her fellowship at the National Institutes of Health. One of her research goals is to look at how positive-emission tomography (PET) scans can impact the diagnosis and treatment of vasculitis.

Educating our community

An example of programmatic growth is the recent launch of a project to update and expand our educational materials. Our patient population is diverse - scattered around the world, and includes people of all ages, economic and socioeconomic backgrounds, and educational levels. The VF is committed to providing educational materials that reflect and speak to the diversity of our patient population by leveraging the many ways people learn and many resources for learning.

Educating health care professionals

Over 250 health care professionals attended two different continuing medical education (CME) courses partially funded by the VF in partnership with the Cleveland Clinic and Northwestern University this year.

Raising awareness, creating understanding

There are countless ways to help other members of the vasculitis community. Please accept our tremendous appreciation for all your efforts over the past year. Whether you joined the V-PPRN, led a support group, participated on social media, attended a regional conference, watched a webinar, shared your story at the symposium, organized an awareness campaign, hosted a fundraising event, or made a donation, you have made a difference in the lives of thousands of individuals with vasculitis and their families.

Every contribution, every effort, large and small, helps to improve the quality of life for everyone impacted by vasculitis both in your neighborhood and around the world.

Thank you.
Sincerely,

Joyce A. Kullman
Executive Director

Mission Statement | The Vasculitis Foundation supports and empowers our community through education, awareness and research.

The Vasculitis Foundation

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Mission Statement | The Vasculitis Foundation supports and empowers our community through education, awareness and research.

The Vasculitis Foundation is most grateful to authors who have shared their personal experiences with vasculitis in the newsletter. The reader should be aware that these contributions are personal reflections by the writer and do not represent medical scientific statements. Therefore, such information while being accurate perceptions of the writer, may not be scientifically accurate and may not apply to other patients.
The VF Educational Webinar Series 2017

Topic: Vaccines and Vasculitis
Speaker: Eric M. Ruderman, MD, Associate Chief, Clinical Affairs, Division of Rheumatology Northwestern University Feinberg School of Medicine
Date: Thursday, October 12, 2017
Time: 9:00 a.m. CDT

Register: https://attendee.gotowebinar.com/register/5266106928493366787

Dr. Ruderman joined the faculty at Northwestern University in 2000, where he is currently a professor of medicine and associate chief for clinical affairs of the rheumatology division. His primary responsibilities include patient care, fellowship teaching, clinical administration, and management of clinical trials in rheumatoid arthritis and other forms of inflammatory arthritis.

It is important that patients with vasculitis talk with their physician about what vaccines they should receive. Dr. Ruderman originally gave this presentation at the 2017 Vasculitis Symposium this past June. There will also be time for Q&A with the audience.

Editor’s Note: The webinar will be recorded and archived in the VF Webinar Library on the website for later reviewing.

Support the VF through AmazonSmile Program

Just in time for your holiday shopping!

AmazonSmile is a simple and automatic way for you to support the Vasculitis Foundation every time you shop, at no cost to you. When you shop at smile.amazon.com, you’ll find the exact same low prices, vast selection and convenient shopping experience as Amazon.com, with the added bonus that Amazon will donate a portion of the purchase price to the Vasculitis Foundation.

How do I shop at AmazonSmile?
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Yes, you use the same account on Amazon.com and AmazonSmile. Your shopping cart, Wish List, wedding or baby registry, and other account settings are also the same.

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On your first visit to AmazonSmile, select the Vasculitis Foundation to receive donations from eligible purchases before you begin shopping.

How much of my purchase does Amazon donate?
The AmazonSmile Foundation will donate 0.5% of the purchase price from your eligible AmazonSmile purchases. The purchase price is the amount paid for the item minus any rebates and excluding shipping & handling, gift-wrapping fees, taxes, or service charges. From time to time, we may offer special, limited time promotions that increase the donation amount on one or more products or services or provide for additional donations to charitable organizations. Special terms and restrictions may apply.

Make VF your Charity of Choice: 2017 United Way Workplace Campaign

The 2017 United Way Workplace Campaign is underway in thousands of companies throughout the United States. If you participate in the United Way Campaign, we ask that you make the Vasculitis Foundation your charity of choice.

The Vasculitis Foundation is a registered 501 (c) (3) nonprofit. To designate the VF for your United Way support, please complete the appropriate form (provided by your employer or local UW agency) 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

For more information, visit: http://www.vasculitisfoundation.org/donate/united-way-giving/

Combined Federal Campaign

The Vasculitis Foundation has been accepted to participate in the 2017-2018 Combined Federal Campaign. If you are an employee of the federal government, postal service, or a member of the United States armed forces, you can now designate your gifts and pledges during the Combined Federal Campaign (CFC) to the Vasculitis Foundation. Our national code is 64445.

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How much of my purchase does Amazon donate?
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Combined Federal Campaign

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**All Ireland Vasculitis Conference 2017**

Saturday - Sunday, October 28-29, 2017  
The Royal Marine Hotel  
Dun Laoghaire, Ireland

Come along and join us for our sixth All Ireland Vasculitis Conference, where you will have an opportunity to meet others living with similar symptoms and day to day issues. This year we plan to have talks and feedback from those affected by Vasculitis, Specialist Consultants involved in Vasculitis treatment, and updates in developments in the Vasculitis world. The cost of the conference are being subsidised with fundraising by members throughout the year. Lunch and refreshments are included. Come along and learn more about living well with the Vasculitis diseases from others in a similar situation and the specialists. Anyone affected with similar auto immune diseases and interested healthcare professionals welcome. We look forward to seeing you there. B&B available at the Royal Marine at a special rate for attendees €140 double/twin, €130 single, but needs to be booked by September 23rd 2017.

[https://www.eventbrite.co.uk/e/all-ireland-vasculitis-conference-2017-tickets-36320685147](https://www.eventbrite.co.uk/e/all-ireland-vasculitis-conference-2017-tickets-36320685147)

Contact: Julie Power, juliepower@btinternet.com •

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**Cindy Todd: Combining Love of Hiking and Writing to Raise Awareness about Behcet’s Vasculitis**

On her Twitter feed Cindy Todd describes herself as author, backpacker, and abstract artist. She has combined these interests into an outlet for raising awareness about Behcet’s disease. She was diagnosed in August 2011, although her symptoms began in 2008.

Todd also has a personal interest in suicide prevention and has discussed how the challenges brought on by vasculitis also forced her to deal with the issue of suicide.

Here is an excerpt from Todd’s recent essay about her trek through Yosemite:

“OK, let me start out by saying that I have Behcet’s Disease (rare autoimmune disease). And yes, I’ve contemplated suicide during a certain stage of my life. So, it was important to me to try to increase awareness for these two causes. I completed my backpacking trip and was pleased with the conversations that I had with other people about Behcet’s and suicide prevention. I’m proud of my mission! I’ve had tremendous support from all over the world! I’m so grateful for the donations and the words of support that I’ve received from my sponsors. It’s been a truly special experience.”

Editor’s Note: Cindy’s complete essay, "Mammoth Lakes to Tuolumne Meadows - Backpacking for Behcet’s Disease Awareness & Suicide Prevention" will appear in the September issue of VF E-News.

You can subscribe for VF E-News at:  

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**Recommended Reading**

**Granulomatosis With Polyangiitis (GPA) and Microscopic polyangiitis (MPA): Your Questions, Expert Answers.**

By Dr. Jonathan Scott Coblyn, Director, Clinical Rheumatology, Brigham and Women’s Hospital, Boston

This is the first book written specifically for GPA and MPA patients and covers signs, symptoms, diagnosis, treatment options, complications, relapse and remission. The book also discusses how to communicate effectively with your health care providers.

If you would like a free copy of the book, please email the VF at vf@vasculitisfoundation.org or call 816.436.8211. •
5th Annual Rally in the Alley
Benefiting the Vasculitis Foundation
SUNDAY, NOVEMBER 5, 2017
3:00 p.m. - 6:00 p.m.

PINSTripes
1150 Willow Road
Northbrook, Illinois 60062
Adult $75/each
Child $25/each
Family of Four $200
Bowling and Buffet

REGISTER TODAY:
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
Questions? Karen Hirsch 847-530-3339 • Jason Wadler 773-793-6581
Krista Smith 847-812-1210 • Steve Svendsen 847-868-9278.

The Victory Over Vasculitis 3v3 Basketball Tournament held on August 5, in Medford, Massachusetts, raised $5,000 for the VF. This was the first year for the basketball tournament. Patrick Lane, the event’s organizer wrote, “We battled through the rain, but had a great turnout and everyone had fun!”
Facebook Live with Allison Lint

Tune into the Violin for Vasculitis Facebook page (www.facebook.com/v4vinc) to connect with Allison as she discusses life with a rare disease and entertains with live music!

Sundays at 8:00 PM, EST, are geared towards patients of rare disease as we discuss symptoms, medications, diet, exercise, travel, and managing life after a diagnosis of vasculitis.

Thursdays at 8:00 PM, EST are open to the public for a recital feed. Enjoy a casual violin performance and request your favorite tunes!

To join: Simply visit the Facebook page (www.facebook.com/v4vinc) and look for the live video at the top. Click “Join Now,” then use the comment box to communicate live with Allison.

BONUS: Win prizes during the Thursday sessions for guessing correctly in a “Name That Tune” segment!

Vasculitis Foundation Canada (VFC) Announces the 2017 Fall Speaker and Lecture Program:

Staying Well with Vasculitis

VFC 2017 Fall Lectures - Saturday, October 28, 2017
Toronto Western Hospital
399 Bathurst Street
Toronto, Ontario
West Wing 2nd floor Auditorium and Conference Room - WW2-401

VFC is pleased to advise the theme for this fall’s lectures will be Staying Well with Vasculitis. It is an appropriate theme because patients, doctors, researchers and all members of the vasculitis family still need to come together and focus on getting well and staying well with vasculitis. Much more can be done, and with your participation we’ll continue to help improve your care, we will find new ways to control vasculitis and of course, together we will find the cause, and the ultimately the cure.

Presenters will include:
Dr. Christian Pagnoux (Rheumatology/CanVasc),
Dr. Rowena Ridout, (Endocrinology, Associate Director Osteoporosis Clinic TGH),
Dr. Katherine Siminovitch (Vasculitis Genetics),
Dr. Jennifer Rodrigues (Nephrologist & VERITAS study).

Registration begins at 9:15AM. The lecture program gets underway at 10:00AM.
As in past years some DNA study samples may be collected. Stay tuned for more information on the various lab collections which may apply to you.
Lecture Registration is FREE for VF Canada members, (whose memberships are current!), non-members can attend by becoming a member with a $20 Canadian membership, or a dual Canada/U.S. membership for $60. Please note: a valid passport is required for all visitors to Canada.
The full lecture program and registration information will be posted soon, please check www.vasculitis.ca for the most current information and for details on how to register.
Kaitlin Quinn, M.D., Awarded 2017 VCRC-VF Fellowship
| Kurt Ulman, Medical Writer

Kaitlin Quinn, MD, is the recipient of the 2017 VCRC-VF Fellowship. She received her medical degree from New York Medical College in Valhalla, New York. She completed her Internal Medicine residency and a two-year Rheumatology fellowship training program at MedStar Georgetown University Hospital in Washington, D.C. Dr. Quinn is currently serving as a junior faculty member in the Division of Rheumatology, Immunology and Allergy at Georgetown.

“Vasculitis initially sparked my interest in rheumatology,” she said. “I rotated through the rheumatology consult service as a medical intern. The most fascinating part of the rotation for me was the complexity of these patients.”

She sees many research and clinical opportunities in this area. The fellowship will help deepen her understanding of the disease and give mentorship opportunities needed to broaden her clinical skills and enable her to conduct investigational research.

PET Scans in Diagnosis and Treatment

One of Dr. Quinn’s goals is to look at how positive-emission tomography (PET) scans can impact the diagnosis and treatment of vasculitis. PET scans use a small amount of radioactive material attached to glucose to find areas of the body that are biologically active, such as inflamed vessels in the case of vasculitis.

Currently, it can be difficult to determine if a patient’s vasculitis is active. Normal laboratory values can be seen even when the disease isn’t in remission. The aim of this research is to give clinicians another diagnostic tool to help guide treatment decisions in patients with vasculitis.

“A key part of the fellowship is to allow further development of my clinical skills and management of vasculitis patients,” said Dr. Quinn. “The fellowship allows for professional growth and accretion of skills with the hope that I will eventually assume leadership of the vasculitis clinic at Georgetown and one day expand it to a formal vasculitis center that can participate in clinical trials.”

Dr. Peter C. Grayson is head of the Vasculitis Translational Research Program (VTRP) at The National Institute of Arthritis and Musculoskeletal and Skin Diseases, a part of the National Institutes of Health in Bethesda, Maryland. He is serving as Dr. Quinn’s mentor during the Fellowship.

Unique Fellowship

“There is a lot about Dr. Quinn’s fellowship that is unique,” said Dr. Grayson. “The NIH program frequently performs research studies on patients with vasculitis who otherwise receive clinical care in the vasculitis clinic at Georgetown run by Dr. Thomas Cupps. Dr. Quinn’s fellowship will further strengthen the collaboration between our institutes and will help her to expand vasculitis-focused research initiatives at Georgetown.”

Dr. Cupps is preparing to transfer patients to Dr. Quinn’s vasculitis clinic. The fellowship is a way to prepare Dr. Quinn to not only continue the clinic, but to build on Dr. Cupps’ work and elevate it to the next level as a vasculitis center.

“She will spend some of her time working at the VTRP, seeing patients and participating in research,” said Dr. Grayson. “This will give her more time to be a student of vasculitis on both the clinical and the research level.”

Dr. Quinn’s research projects should help enhance vasculitis treatment and research. Currently, imaging assessment of patients with large vessel vasculitis is difficult because there are no standardized guidelines.

“A major goal of Dr. Quinn’s project is to generate data that will inform the development of imaging studies guidelines in large vessel vasculitis,” said Dr. Grayson. “By studying the strengths and limitations of specific imaging modalities, including PET scans and angiography, we hope to provide guidance to physicians on how to use these tests effectively for clinical care purposes. We also want to test if imaging studies are useful as outcome measures in clinical trials.

The support of the VF gives us an opportunity to test how medications used to treat vasculitis affect both how a patient feels and how their blood vessels look on imaging studies.”

The Vasculitis Clinical Research Consortium (VCRC) - Vasculitis Foundation (VF) Fellowship is a mentored training program of up to two years for physician-investigators who have a strong interest in vasculitis and wish to pursue a period of specialized training with an emphasis on clinical and/or translational patient-oriented clinical investigation.

The VCRC-VF Fellowship Program is funded through the proceeds of the Chicagoland Golf Open, an annual event organized by VF Board member, Dr. Jeff Fishbein, and his extended family. Over the past four years, the Golf Open has raised over $500,000 for the Vasculitis Foundation.
Mindfulness and Vasculitis: A Conversation with James Sosebee

One of the most popular sessions at the 2017 International Symposium in Chicago was about the role of mindfulness in the management of a serious disease like vasculitis. The presentation was led by James Sosebee. James Sosebee is Assistant Professor of Human Anatomy & Physiology at Sinclair College, Dayton, Ohio. Sosebee is also a Certified Mindfulness Facilitator (CMF) trained through the UCLA Mindful Awareness Research Center (MARC).

In this interview, Sosebee talks about the terminology in describing an autoimmune illness and how it can impact one's response over vasculitis.

VF: Vasculitis patients in particular often feel they have lost all control over their bodies with this disease. In fact, the nature of autoimmunity is the body is attacking itself. How can mindfulness give the patient a greater sense of control?

JS: Yes, it is true, that in the case of an autoimmune disorder such as vasculitis, the body fails to recognize some aspects of itself as “self,” and as such, launches an offense. But, I would offer a slightly different perspective, as it relates to mindfulness and the statement of “having lost all control over their disease.”

What we know, from a number of overlapping fields of inquiry, is that there is evidence in support of bidirectional communication underscoring the activities of mind, brain, and the various physiological systems of the body, in which some degree of volitional control is afforded the individual patient.

VF: How important is the language or terminology that we use to describe an autoimmune illness. Can the words we use play a role?

JS: Language is very important. From a mindfulness perspective, the language of “attacking the body,” sets up an emotional tone, that ensures a high level of vigilance, sympathetic activation of the autonomic nervous system, and increased emotional arouse. This is where compassion/self-compassion practices come into being. Mindfulness as such, invites a more genteel and cooperative relationship with the body.

VF: Finally, what is the most important factor in becoming practiced in the art of mindfulness?

JS: The mindfulness research suggests that the degree of daily practice, either formal or informal, correlates with the degree to which these changes are introduced into the nervous system. Likewise, given the influence of inflammation in contributing to dysregulation of the immune system, many studies have provided evidence that pro-inflammatory markers are decreased with regular mindfulness practice.

New Mindfulness Study to Launch: Healthy Mind, Healthy You

The Vasculitis Patient-Powered Research Network (V-PPRN) is pleased to introduce a new mindfulness study to launch in the fall of 2017, Healthy Mind, Healthy You. This is a new study about how mindfulness can help people cope with stress. Funded by the Patient Centered Outcome Research Institute (PCORI) and involving 21 Patient Powered Research Networks (PPRNs) just like the V-PPRN, Healthy Mind Healthy You will be able to study the effects of mindfulness on a wide variety of populations and conditions.

What is the purpose of the study?

Healthy Mind, Healthy You aims to compare two kinds of mindfulness programs to see which is most effective in reducing stress and increasing well-being. One is an online, standard, eight-week mindfulness training; the other is an online, three-session mindfulness “light” training. The study may also tell us what groups of people do better with one or the other program.

How does the study work?

8,500 participants will be recruited from the 21 PPRNs including patients living with vasculitis, and will be randomly assigned to either the standard, eight-week program, or the three-session mindfulness “light” program. Participants can be children, teenagers, and adults, caregivers and people living with an illness or condition.

All participants will fill out standard well-being assessments every other week to see how they are doing. All sessions and assessments will be done online.

Stay Tuned for the Launch!

The V-PPRN will keep you informed about the status of the study. Please stay tuned for information about the launch and how to participate!

www.vpprn.org | kyoung@vasculitisfoundation.org •
By appreciating some of the differences in susceptibility, imaging findings, and increasing awareness of the entity of late onset-TAK, we hope to decrease the time to diagnosis for patients who have these diseases. This will make us better equipped to differentiate them so they can be studied closer in clinical trials.

Dr. Carol Langford, director of the Cleveland Clinic Vasculitis Clinic, discussed some of the therapeutic regimens that are in use for management of GCA and TAK. Treatment of both diseases has heavily relied on high doses and prolonged courses of steroids, which have many known detrimental side effects.

Methotrexate has been of modest benefit in both diseases. While TNF inhibitors looked promising in case reports, randomized clinical trials did not show any benefit. This highlights the importance of doing more randomized trials in vasculitis, so we can get clear answers about which treatments are beneficial. A randomized clinical trial looking at abatacept showed that it was better than placebo at 12 months in preventing relapses in GCA, but this benefit was not seen in terms of relapse free survival in Takayasu.

As we have learned more about the pathophysiology of these diseases, there has been greater understanding of the role of IL-6, a cytokine (small protein) that is found in higher levels in the serum and blood vessels of patients with vasculitis. IL-6 is secreted by T-cells and macrophages and drives inflammation and fever. Tocilizumab is a drug that binds to the receptor of IL-6 and blocks its downstream actions. It has been approved for use in patients with rheumatoid arthritis and Dr. John Stone, director, Clinical Rheumatology, Massachusetts General Hospital, discussed the landmark trial “GIACTA” which evaluated the role of tocilizumab in patients with GCA.

The GIACTA trial enrolled 250 patients from 14 countries with new or relapsing GCA. Patients treated with tocilizumab did better than the steroid only arm with more sustained remission, no increase in adverse events, and better quality of life measures. There have been no new therapies for GCA in more than 50 years, and tocilizumab was just approved by the FDA. The landscape is truly changing and we hope to improve the lives of our patients based on these trials with the goal of less or even possibly no steroids in the future. While this represents a major advance in our armamentarium for treating GCA, many questions still remain: which patients to treat, what types of patients would benefit most, how long to treat for, and of course the high cost of treatment cannot be ignored.

Eosinophilic Granulomatosis with Polyangiitis (EGPA)

EGPA/Churg Strauss Syndrome is the rarest of the AAVs and is associated with late onset asthma, pulmonary infiltrates, neuropathy and peripheral blood eosinophilia. About a third of patients have a positive p-ANCA, and those with the positive antibody classically have vasculitic manifestations (neuropathy, skin). ANCA negative patients more frequently have cardiac manifestations, including cardiomyopathy or myocarditis.

The disease features and response to therapies is different in EGPA, and these patients have often been excluded from larger clinical trials evaluating MPA and GPA. We have tried using many immunosuppressive agents including cyclophosphamide, azathioprine, and methotrexate to control the disease, but manifestations such as chronic asthma or rhinosinusitis frequently require long-term high dose steroids.

Steroids are used like an umbrella to shut down inflammation in a broad sense in EGPA and vasculitis in general. What we want to do is find a targeted therapy that shuts down what is driving the disease specifically. This will lead to less long-term toxicities and side effects.

We have learned that environmental exposures in both asthma and EGPA trigger the immune system though cells in the airway secreting inflammatory cytokines. This response also occurs in the cells lining the nasal cavity and can cause polyps or other ear, nose and throat involvement. The immune system activation results in T cells producing inflammatory cytokines such as IL-4, IL-13, and IL-5.

IL-5 is a cytokine that regulates growth, activation and survival of eosinophils. Levels of IL-5 are increased in patients with EGPA and are associated with disease activity. Therefore, reducing eosinophils and preventing their activation by inhibiting IL-5 is a rational approach to treatment. Mepolizumab, a monoclonal antibody specific for IL-5, has been studied in two pilot studies in EGPA with promising results, achieving a steroid sparing effect and remission maintenance, with a favorable safety profile. This has led to the MIRRA trial, the first ever double-blinded, placebo controlled trial in EGPA patients, to evaluate the efficacy and safety of mepolizumab in relapsing and refractory EGPA. 130 patients were enrolled in this trial which is now completed, and results will be available in late 2017. This means a possible medication outside of steroids, that is tailored to, and targets the mechanisms that drive disease in EGPA.

This is a brief summary of some of the exciting research that was highlighted at the 2017 ANCA Vasculitis Workshop. New insights into disease mechanisms, genetic variability and targeted therapies were presented and discussed. Sharing of ideas and research between different countries and subspecialists is key to moving forward in our understanding of vasculitis.

We have been steadily gaining ground in clinical trials and applying our knowledge to make real-life decisions in clinic. The science presented sheds new insights and raises many important questions that remain to be answered about how we can improve the lives of people with vasculitis.
Spotlight: Vasculitis in Iceland

Living with Vasculitis in Iceland: The Challenges of Care and Communication

Having a rare disease such as vasculitis in a large, populated country like the United States can be challenging enough, but what if you are a patient with vasculitis in a small country the size of Indiana, and with a population of just over 332,000?

This is the reality for Drifa Alfreosdottir and Maria Bjork Vioarsdottir who live in Reykjavik, Iceland. Born and raised in Iceland, they both have a deep love for their country, but also acknowledge some of the challenges that face a patient with a rare disease in their homeland.

Drifa was diagnosed in 2002 with Polyarteritis nodosa (PAN) after experiencing severe fatigue, dizziness and other symptoms that were originally attributed to household allergies. Maria’s diagnosis of GPA/Wegener’s followed a traumatic car accident in early 1997. Symptoms originally thought to be caused by post-accident surgeries were finally determined to be from vasculitis.

Drifa says that she had never met anyone else in Iceland with vasculitis. However, she knew there was at least one patient with the disease.

“After I was diagnosed with PAN in 2002, I asked my nurse if there was anyone else with the same disease,” recalls Drifa. “She said there was one other patient with vasculitis, but she couldn’t give me her name because of privacy rules. She only would say the patient’s first name began with the letter M. That was it.”

Over the next 15 years Drifa would occasionally wonder about this mystery patient known only by a single letter. “At least I knew I wasn’t the only person in Iceland with vasculitis,” Drifa said. “But I also knew I would probably never meet this person.”

However, something amazing happened on August 13, 2017 when Drifa joined Maria at the Icelandic Botanical Garden for a joint interview with Ed Becker, director of marketing for the VF.

When Drifa related the story about the nurse saying there was one other patient whose name started with M, Maria confirmed that she also knew that nurse and they soon realized that Maria herself was quite likely the other mystery patient.

Their amazing story underscores the compounded isolation patients with a rare disease may experience in a country as remote as Iceland. “We know there are some -- not many of course -- other vasculitis patients here. The problem is that we don’t have a way to meet each other because the doctors can’t share that private information. In a country like ours you really feel like you’re on your own,” said Drifa.

Maria agrees about the isolation, but she and Drifa have both found the Internet to be a bridge to at least communicate with other patients, and to stay educated about the disease. “I’m able to connect with other patients on Facebook if I feel that need,” says Maria. “Also, the VF has resources so I can learn the latest information I need to know.”

A video interview with Drifa and Maria will be available on the VF website in October.
Treating Patients with Vasculitis in Iceland: A Profile of Dr. Björn Ludviksson

By Ed Becker

Imagine you are a rheumatologist who is given the opportunity to work in an office that is approximately 168 miles from the Arctic Circle. You will be surrounded by active volcanos, and massive glaciers. You’ll also endure sub-zero temps during a good portion of the year. Do you take the job?

For Dr. Björn R Lúðviksson it was exactly what he wanted---to work in his native country of Iceland. After a decade working in the United States, he decided to return to his country where he currently serves as the Professor and Head of the Department of Immunology at the University Hospital in Reykjavik, Iceland.

After graduating from medical school in Iceland, Ludviksson received his specialty in internal medicine at the University of Wisconsin. That was followed by working at the National Institutes of Health (NIH) in Bethesda, Maryland. It was at the NIH that he decided specialize in autoimmune diseases. “At the NIH, I was in an environment that had a heavy focus on autoimmunity,” said Ludviksson. “I knew this was the area I wanted to concentrate. After a few years at the NIH I was offered the position here at the University of Reykjavik. My roots and family are here so I was happy to make the move.”

Established in 1981, the Department of Immunology is the central service and research laboratory for rheumatologic, allergic and immunologic diseases in Iceland. The department offers a clinical treatment center for individuals suffering from autoimmunity, allergy, asthma, immune deficiency and other immunologic diseases.

According to Ludviksson, approximately 800 to 900 patients are treated for autoimmune conditions at their center. How many of those patients have vasculitis? It’s not a figure that is easily determined, but there’s no question it’s an extremely small number.

“I’ve seen maybe six to eight patients with vasculitis here in Iceland,” said Ludviksson. “But I can’t say an exact number of how many are here because there are so many factors. I have a very mixed bag of patients. Many patients don’t have a known diagnosis, and maybe half of my patients have a primary immune deficiency along with vascular problems.”

Understanding the prevalence and impact of all autoimmune diseases in Iceland is a key part of his research. He was instrumental in developing a web-based application currently in use at the hospital to provide greater statistical analysis for doctors and researchers on the patients being treated for autoimmune based diseases.

A video interview with Dr. Luviksson will be available on the VF website in October.

Iceland Study Provides Insights into Disease, Paves Way for Large-scale Genomic Studies

By Yekaterina Vaydylevich
Scientific Program Analyst, NHGRI
National Human Genome Research Institute

For some, Iceland conjures thoughts of geothermal spas like the Blue Lagoon, moonlike landscapes and literary sagas peopled with Huldufólk, elfin creatures. Most people do not, however, think of large-scale genomic studies.

But maybe they should. Last month, Kári Stefánsson, M.D., Daniela Fanners Guðbjartsson, Ph.D., and their research team at deCode genetics announced findings based on the whole genome sequence information of 2,636 Icelanders and the genotypic information of 104,220 other Icelanders.

Iceland is well-suited for genomics research for a few reasons. The island’s relative isolation has resulted in a population of approximately 320,000 that is almost entirely descended from a single family tree. Data about the population’s genealogy has been extensively recorded since 740 AD, and sits in an accessible database called Íslendingabók or book of Icelanders.

In population genomics, this is called the founder effect, in which the lack of diversity limits the number of genomic variants (differences between people), and allows usually rare variants to become common enough in the population to be more easily noticed and studied. (To avoid awkward situations like accidentally dating your cousin, Íslendingabók was recently connected to an application that quickly identifies the degree of relatedness between any two people.)

Read the entire article: http://tinyurl.com/y9y4ns95
Genomes of Icelanders
Nature Genetics, Published online: March 25, 2015
Multidisciplinary Team Delivers Rapid Care for Patients with Giant Cell Arteritis to Prevent Irreversible Vision Loss and Other Serious Complications

Recently established to expedite care for patients with giant cell arteritis, the new Fast Track Clinic for Giant Cell Arteritis comprises a multidisciplinary team of rheumatologists, vascular medicine specialists, vascular surgeons, and pathologists from the Division of Rheumatology, Immunology and Allergy, Division of Cardiovascular Medicine, Division of Vascular and Endovascular Surgery, and Department of Pathology at Brigham and Women's Hospital in Boston.

“While giant cell arteritis is the most common of the systemic vasculitides, it is associated with serious complications,” said William P. Docken, MD, Co-Director of the Fast Track Clinic for Giant Cell Arteritis. “Currently, permanent vision loss occurs in 10-20 percent of reported case series, but this is preventable with prompt identification and timely initiation of treatment.”

Rapid Evaluation for Suspected Giant Cell Arteritis

To prevent these complications, patients are quickly evaluated within one day of referral by a rheumatologist and by vascular ultrasound examination of the temporal and axillary arteries to diagnose giant cell arteritis. If warranted, urgent temporal artery biopsy also is arranged.

Specialized Noninvasive Imaging for Definitive Diagnosis

With a resolution of 0.1mm, vascular ultrasound can visualize the temporal arteries and their branches. In the presence of active arteritis, a dark area appears in the wall of the temporal artery, which indicates inflammation.

The technique is noninvasive and provides immediate data; additionally, it can visualize larger arteries that branch off the aorta, such as the axillary and subclavian arteries. More than 400 vascular ultrasound examinations have been conducted in the Vascular Lab at Brigham and Women’s Hospital over the past three years.

Giant Cell Arteritis Advanced Treatment and Follow-up

We provide immediate diagnosis, treatment, and if desired, close follow-up for patients diagnosed with giant cell arteritis. Our team also manages conditions that can coexist with giant cell arteritis, such as polymyalgia rheumatica.

Multiple Locations

Our team sees patients at multiple locations throughout eastern Massachusetts, including:

- Brigham and Women’s Hospital Main Campus
- Brigham and Women’s Faulkner Hospital in Jamaica Plain
- Brigham Orthopaedic and Arthritis Center in Chestnut Hill
- Brigham and Women’s/Mass General Health Care Center in Foxborough
- Women’s Brigham and Women’s Orthopaedic and Arthritis Center in Chestnut Hill

Referral Information and Appointments

For appointments at the Fast Track Clinic for Giant Cell Arteritis, please call the dedicated line at 617.732.9562 or email fasttrackgca@partners.org. They will provide patients with evaluation by a rheumatologist on their team within one business day of referral.

Source: BWH Rheumatology Advances, Volume 1, No. 1, 2016

Giant Cell Arteritis Fund: Copayment and Premium Assistance Now Available

The HealthWell Foundation®, an independent non-profit that provides a financial lifeline for inadequately insured Americans, has opened a Giant Cell Arteritis Fund to provide copayment and premium assistance to eligible Medicare patients. Through the fund, HealthWell will provide up to $6,000 in copayment or premium assistance to individuals who have annual household incomes up to 400 percent of the federal poverty level. The new fund will assist these patients in accessing critical medications for treatment of their disease.

Joyce Kullman, Executive Director, Vasculitis Foundation, said, “Giant cell arteritis most often strikes people over the age of 50. Treating GCA often requires multiple doctors’ appointments, ongoing lab tests, and numerous medications. Treatment can quickly create a financial burden for older patients with limited incomes. The establishment of the HealthWell Foundation GCA fund is wonderful news and will provide a much-needed resource for many patients living with GCA.”

“The launch of the GCA fund represents our commitment to expanding our programs to reach as many patients in as many disease areas as possible,” said Krista Zodet, HealthWell Foundation President. “People living with giant cell arteritis, or temporal arteritis, can require treatment for years. Out-of-pocket costs associated with treating their condition often present a financial challenge and can be an added source of anxiety. Thanks to our dedicated donors, we are now able to offer GCA patients financial relief in the cost of their treatment.”

To determine eligibility and apply for financial assistance, visit HealthWell’s Giant Cell Arteritis (Temporal Arteritis) Fund page. To learn how you can support this or other HealthWell programs, visit www.HealthWellFoundation.org or 800.675.8416.
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 •
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

The Definition of Chronic Pain
While acute pain is a normal sensation triggered in the nervous system to alert you to possible injury and the need to take care of yourself, chronic pain is different. Chronic pain persists. Pain signals keep firing in the nervous system for weeks, months, even years.

Common chronic pain complaints include headache, low back pain, cancer pain, arthritis pain, neurogenic pain (pain resulting from damage to the peripheral nerves or to the central nervous system itself), psychogenic pain (pain not due to past disease or injury or any visible sign of damage inside or outside the nervous system). A person may have two or more co-existing chronic pain conditions. Such conditions can include chronic fatigue syndrome, endometriosis, fibromyalgia, inflammatory bowel disease, interstitial cystitis, temporomandibular joint dysfunction, and vulvodynia. It is not known whether these disorders share a common cause.

Treatments
Medications, acupuncture, local electrical stimulation, and brain stimulation, as well as surgery, are some treatments for chronic pain. Some physicians use placebos, which in some cases has resulted in a lessening or elimination of pain. Psychotherapy, relaxation and medication therapies, biofeedback, and behavior modification may also be employed to treat chronic pain.
**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](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.
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/ •

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
5524: PEXIVAS: Plasma exchange and glucocorticoid dosing in the treatment of anti-neutrophil cytoplasm antibody associated vasculitis: an international randomized controlled trial
5525: RITAZAREM: An international, open label, randomized controlled trial comparing rituximab with azathioprine as maintenance therapy in relapsing ANCA-associated vasculitis
5526: The Assessment of Prednisone in Remission (TAPIR) Trial
5527: Abatacept (CTLA4-Ig) for the Treatment of Relapsing, Non-Severe, GPA/Wegener’s (ABROGATE)
5535: VCRC Validation of Patient-Reported Diagnostic Data
5563: Clinical Transcriptomics in Systemic Vasculitis (CUTIS)

IGA VASCULITIS (HEINCH-SHOENLEIN PURPURA)
5562: A randomized multicenter study for isolated skin vasculitis (ARAMIS)
5563: Clinical Transcriptomics in Systemic Vasculitis (CUTIS)

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)

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)
5563: Clinical Transcriptomics in Systemic Vasculitis (CUTIS)

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

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

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VF Bob, our New Vasculitis Mascot

In April of this year, we lost our dear friend, Bob Sahs. Bob was a VF advocate and community cheerleader, traveling the world to increase awareness about vasculitis. To honor his warm spirit and commitment to community building, the foundation will be launching VF Bob, an exciting and socially-savvy campaign. We don’t want to say too much, just yet, but we know you’ll love it!

Look out for VF Bob in your November/December VF Newsletter, as well as all our social media platforms - Facebook, Twitter and Instagram. We can’t wait to see where VF Bob’s warm smile and positive attitude takes the vasculitis community. To learn more keep checking www.VasculitisFoundation.org/VFBob.

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New Book Tells Story of Going the Distance with Vasculitis
| By Ben Wilson

I recently sat down with fellow VF Ambassador Brandon Hudgins to talk about life after the Vasculitis Symposium, and more importantly, to talk about his new book “Going the Distance” — now available for purchase on Amazon for Kindle and in paperback.

**Ben:** So, it’s been awhile since we hung out back in June at the Vasculitis Symposium in Chicago. At that time, you were working on an exciting project—a book about your journey with vasculitis.

**Brandon:** Yes, I finally finished my book! It’s been incredibly exciting and humbling to go through the process; I’m a little nervous about what people think of it since I put so much time and effort in, but more than anything I’m excited to have the book finally available.

**Ben:** I’m very curious about the final product and the whole process. What was it like for you to collect all your experiences battling through vasculitis and organize them in a book?

**Brandon:** It was a little overwhelming at first, but I sat down with [co-author] John Fries, and hashed out some of the main themes I wanted to cover in the book. Once we established a path, it was clear that we should focus on everything traumatic I’ve dealt with in life, whether it was getting diagnosed with vasculitis or losing loved ones. I wanted to show how I’ve come out on the other side and that I’m still on my own two feet. In a roundabout way, it’s a self-help book, there are a lot of lessons I talk about and connect with through my own stories.

**Ben:** How is your health right now? I know you were suffering from a relapse earlier this year. Was it cathartic to write an inspirational and motivational book about past experiences you’ve had while fighting a new battle against vasculitis?

**Brandon:** The relapse actually made writing the book easier and going back over the challenges has given me even more motivation to fight back this time. In 2016 I made the decision to put myself out there and in the limelight to raise awareness about the disease and to make a difference in our community. Even if I don’t feel well, I know I must keep sharing my story because this is the platform I’ve chosen and it’s the best way to inspire others.


Order Brandon’s book through AmazonSmiles and you will be helping to support the VF!

**VF Library: Showcasing our Authors and their Books about Vasculitis**

In August, the VF unveiled one of its newest web pages intended to be a source of information, inspiration, and education for patients with vasculitis, or other autoimmune diseases.

The VF Library provides a showcase for authors whose stories can be a roadmap for others with the illness. Many of the books are first person accounts that detail the challenges and solutions to managing vasculitis daily. Some of the other titles are topics dealing with specific clinical and biological issues related to vasculitis.

Each title has a short description, and it’s linked to Amazon for easy ordering.

Note: Don’t forget, if you order one of these books on Amazon be sure to purchase through the Amazon Smiles program.

Visit [http://www.vasculitisfoundation.org/vf-library/](http://www.vasculitisfoundation.org/vf-library/) to see the list of books and authors.

Currently there are 13 books featured in the new VF Library. New titles continue to be added.
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