



Researcher Studying Potential Trigger of Inflammation Through VF-Funded Grant

By Ed Becker
Director of Marketing and
Communications

Vasculitis is a disease in which blood vessels are damaged due to inflammation. However, the source of the inflammation is often unclear, making the disease difficult to treat. Dr. Sonia Sharma is hoping her VF-funded study will yield valuable insight into the possible triggers and origins of an autoimmune response in vasculitis.



Sonia Sharma, PhD

Dr. Sharma received a one-year, \$50,000 research grant for her study, Metabolic dysregulation of pro-inflammatory responses in DADA2 vasculitis. She is the lead investigator, along with co-investigators: Rekha Dhanwani, PhD, Mariko Takahashi, PhD and Ian Mathews, PhD, who are all based at the La Jolla Institute for Immunology, California and Mohit Jain, MD, PhD, who is based at UC San Diego, California.

Finding the Trigger to the Smoking Gun

Although autoimmunity is complex, a high-level understanding begins with a basic understanding of the body's immune system. Working properly, the immune system protects us from bacteria, viruses, and even cancer. However, in vasculitis, and other autoimmune illnesses, our biological firewall becomes the "invader" itself wreaking havoc on the body's systems.

A key question for researchers like Dr. Sharma, is how to find the "trigger" that initiates an autoimmune response at a cellular level. Adenosine deaminase 2 deficiency (DADA2) is an inherited disorder which can cause vasculitis of medium-sized blood vessels. The disease is caused by mutations in the CECR1 gene, which encodes a key metabolic enzyme in the purine pathway. DADA2 was first discovered in 2014. DADA2 can present similarly to polyarteritis nodosa.

It is not clear how DADA2 leads to vasculitis, and there are currently limited treatment options. Dr. Sharma and colleagues have found that loss of adenosine deaminase 2 enzymatic activity can cause changes in cellular purine metabolism. This loss can also cause the accumulation

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Stay Up-To-Date with VF Disease Brochures and New VF Website

The VF begins the year with two of its most popular patient resources getting a make over, which includes a new look and updates to important medical information about vasculitis.

VF Disease Brochures

Possibly the most requested item by patients and medical professionals are the VF disease brochures.

Over the last eight months the VF has completed an overhaul of the brochures that were first introduced in 2006.

Each of the 18 disease-specific pamphlets were re-written by a vasculitis medical specialist to include the most relevant symptom, diagnostic, and treatment information.



VF disease brochures

The brochures are available in two formats. Printed hardcopies can be ordered from the VF Office. Brochures can be viewed or downloaded from the individual disease pages on the VF website.

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Dear Friends,

Thank you to all who donated in support of our 2018 Annual Appeal "Join Our Journey". With your support, we will focus on the critical first step of the journey, which is to help physicians recognize vasculitis as early as possible.

As part of our ongoing Recognizing Excellence in Diagnosis (V-RED) campaign, we are accepting applications for our 2019 awards program. Since its inception in 2014, patients worldwide have been able to nominate a medical professional they wanted to recognize for making a critical, early diagnosis of vasculitis. We are always interested in how health care professionals learn about vasculitis and utilize that knowledge to quickly recognize the signs and symptoms in their patients. Learn more on page 6.

We were also pleased to offer our first-ever VF educational conference in the Pacific Northwest. On January 12, 2019, over 100 patients, family members, physicians, and researchers from 11 states and numerous provinces in Canada, joined us for a one-day regional conference in Seattle, Washington.

Rare Disease Day February 28, 2019: Show Your Stripes!

Each year on the last day of February, the rare disease community comes together for Rare Disease Day to raise awareness of the challenges faced by the millions of people throughout the world who are impacted by rare diseases. This year, to honor the zebra--which is the official symbol of rare diseases in the United States--we encourage you to join the call to action "Show us YOUR Stripes". Please share your stripes by posting your photos to social media using the hashtags: [#showyourstripes](#) [#rarediseaseday](#).

This year we continue our partnership with the National Organization for Rare Disorders (NORD) to advocate for increased funding for research at the National Institutes of Health, ensuring access to affordable treatment, telemedicine, Medicare protection, and patient assistance programs. Through this partnership, we hope to encourage passage of these policies and the development of additional ones designed to improve patient experiences, outcomes, and ultimately, quality of life.

Join Us at Our Programs

We have one more regional conference at Mayo Clinic in Phoenix on March 9, and then our 2019 International Vasculitis Symposium July 19-21 in Bloomington-Minneapolis, Minnesota. We hope you will join us for one of these amazing conferences.

Sincerely,

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Mission Statement

Building upon the collective strength of the vasculitis community, the Foundation supports, inspires, and empowers individuals with vasculitis and their families through a wide range of education, research, clinical, and awareness initiatives.

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.

Paul Monach in New Role at Brigham and Women's Hospital

By Ed Becker

In September 2018, Paul Monach, MD, PhD, joined Brigham and Women's Hospital (BWH) in Boston, Massachusetts. He is the director of their new Vasculitis Center in the Department of Rheumatology, Immunology, and Allergy.



Paul Monach, MD, PhD

It's a circular career move taking Monach back to the roots of his training as a rheumatologist. He completed his residency and rheumatology fellowship at BWH.

Monach's specialization in vasculitis began in 2007 in the Section of Rheumatology at the Boston University School of Medicine and Boston Medical Center. He became the director of that vasculitis center in 2011. Since 2014, he has also been chief of the Rheumatology Section of the VA Boston Healthcare System.

According to Monach, he made the move for two reasons. "The move in large part was personal. I trained at BWH and have stayed in touch and already knew almost everyone there. Even 11 years later, it was the only place I would consider moving to, since moving would mean I would have to leave the great community of people who I have worked with at BU. The second reason was that I am able to do the same types of things I have been doing—taking care of patients with vasculitis and doing collaborative research—but I expect it will be easier to do so, for a few reasons."

According to Monach, BWH has a particularly strong research enterprise in laboratory-based immunology, which he expects will take his research in new directions.

"BWH has a larger population of patients with giant cell arteritis and more use of advanced imaging (ultrasound and PET scanning) to evaluate them." BWH is historically a prominent and successful institution in rheumatology (it started as a separate hospital for arthritis diseases), including clinical care, clinical research, and lab research, but it has never had anyone focus on vasculitis. I'm looking forward to adding that new area of expertise."

Trigger of Inflammation, *cont.*

of purine metabolites, which are bio-active molecules that modulate inflammatory responses at the cellular level. Excessive purines can lead to an over-exaggerated inflammatory response in both vascular endothelial cells and immune cells.

The hope is that by studying DADA2, it will lead to understanding of what triggers an immune response in vasculitis.

"When we started out on this project we were initially focused on the role of the immune system, particularly in the innate or early arm of the immune response," explains Dr. Sharma. "We very quickly zeroed in on the vascular endothelial cell, which is directly damaged in autoimmune vasculitis, as kind of a potentially new cellular mediator or driver of immune responses."

She says that when studying the origins of inflammatory signals, she and her team want to focus on vascular endothelial cells in particular, because they might not only be damaged in autoimmune diseases like vasculitis, but, they may also be participating in the harm.

"Perhaps with several vasculitis syndromes, we need to not only look at immune cells as the source of the problem, but perhaps also the vascular endothelium as a potential driver or origin of pathological inflammation, or alternatively as an amplifier of the inflammatory reaction," explains Dr. Sharma.

Blocking the Inflammatory Response

Ultimately, Dr. Sharma says, the goal would be to develop and design a specific treatment to alleviate, or re-normalize, abnormal purine metabolism in the vascular endothelium.

"So at the very early stages of our study, we are looking at several FDA-approved drugs that directly modulate the purine pathway. The hope would be that by correcting the metabolic dysregulation in vascular endothelial cells, as well as in the other immune cells, we can alleviate the source of the pathogenic inflammation," says Dr. Sharma.



Dr. Sharma's research team at La Jolla Institute for Immunology (LJI) (l-r) Kay Foos, Yulia Kushnareva, Sonia Sharma, Ian Mathews, Rekha Dhanwani, Mariko Takahashi, Quinn Bui

Continuing Our Journey in the New Year

By Beth Westbrook
VF Director of Development

Welcome 2019!

It's hard to believe we're this far into the new year.

Before we get too far into 2019, I want to thank you for your generous support of the VF during 2018. It isn't about the size of the gift, but the spirit in which it is given. Your generous support helped us launch numerous programs, including the 2018 launch of the "Join Our Journey" program.



Beth Westbrook

We have lofty goals for 2019 and beyond. You have put your trust in us to lead the community to meet these goals.

During the first year of Join of Journey, we focused on early diagnosis with the Pathways to Diagnosis initiative. At the Los Angeles Regional Conference, one of the speakers said, "The average length of time to achieve a vasculitis diagnosis is three years." That is unacceptable! In 2019, we will continue to reach out and support evidence-based projects that lead to an earlier diagnosis. Thanks to you – your gifts will continue our steps on this critical part of the journey.

The challenge we face going forward will be to keep up the momentum, and continue to generate critical funds and ongoing support.

One of my goals for this year is to build a sustainable volunteer program. Whether you like to write, fundraise, organize, or work at an event, we know the growth of the VF can be enhanced by volunteers. In the coming months, we will establish volunteer opportunities on our website. You may consider being a one-time volunteer or an ongoing volunteer.

Thank you. Simple words full of gratitude from all of us here at the Vasculitis Foundation. Be assured, your support makes all the difference in what we can achieve. I am grateful for all that was done in 2018, however, I'm restless to achieve the goal of early diagnosis, more effective treatments, and finding a cure for vasculitis.

May peace, joy, happiness, and good health follow you throughout 2019.

Seattle Patient Conference a Success

On Saturday, January 12, over 100 patients with vasculitis, their family members, and other guests attended the Vasculitis Foundation Patient Conference at the Crowne Plaza Seattle Airport Hotel in Seattle, Washington. The event, the first ever in this region, was held in partnership with the University of Washington Medical Center. The conference was made possible through grants from Celgene, Genentech and GSK.



Guest speaker, Phillip Seo, MD, Director of the The Johns Hopkins Vasculitis Center, gave his famous "Minions Vasculitis Talk".

The conference kicked off with the presentation, Vasculitis Update: What's New for Patients, led by Phillip Seo, MD, Associate Professor of Medicine Director, The Johns Hopkins Vasculitis Center. Five additional presentations rounded out the day: Lung Involvement in Vasculitis, Fast Track Clinics for Giant Cell Arteritis at University of Washington, Staying Healthy in Spite of Having Vasculitis, and Rarer Forms of Vasculitis.

Following a panel Q&A session, professional violinist, and VF Board of Director's member, Allison Lint, ended the day with a musical performance.

To view more photos from the Seattle Conference, visit VasculitisFoundation.org



VF Board Member and professional violinist, Allison Lint, performs for the guests at the Seattle Conference.

*Photos courtesy of Andy Starnes/
Vasculitis Foundation*

Join Us For Our Vasculitis Foundation Patient Conference **PHOENIX, AZ** Saturday, March 9, 2019



**Vasculitis Foundation and Mayo Clinic Arizona Present:
2019 Vasculitis Foundation Phoenix Patient Conference**

Mayo Clinic Education Center - Waugh Auditorium

5777 East Mayo Boulevard, Phoenix, AZ 85054



\$40 registration fee; \$25 VF member registration fee | DEADLINE March 4, 2019
Call to Register: 816-436-8211 Ext:1 or go to: <https://bit.ly/2DgOk6P>

Preliminary Schedule

| | | | |
|--------------|--|--------------|--|
| 8:30 a.m. - | Check-In/Registration | 11:45 a.m. - | Vasculitis Patient-Powered Research Network (V-PPRN) |
| 9:15 a.m. | Light Continental Breakfast | 12:00 p.m. | Kalen Young, MA V-PPRN Network Manager |
| 9:15 a.m. - | Welcome and Introduction | 12:00 p.m. - | Lunch: Patient Experience Story |
| 9:30 a.m. | Rodrigo Cartin-Ceba, MD Pulmonary and Critical Care Medicine Mayo Clinic Arizona | 1:00 p.m. | Suzanne DePaolis VF Board of Directors, President-Elect |
| 9:30 a.m. - | Large Vessel Vasculitis | 1:00 p.m. - | Kidney Involvement in Vasculitis |
| 10:00 a.m. | Kenneth J. Warrington, MD Chair, Division of Rheumatology, Mayo Clinic, Rochester, Minnesota | 1:30 p.m. | Alicia Rodriguez-Pla, MD, PhD Arthritis Center, University of Arizona |
| 10:00 a.m. - | Lung Involvement in Vasculitis | 1:30 p.m. - | New Biologicals for Asthma Management |
| 10:30 a.m. | Rodrigo Cartin-Ceba, MD Pulmonary and Critical Care Medicine Mayo Clinic Arizona | 2:00 p.m. | Matthew A. Rank, MD Chair, Division of Allergy and Immunology Mayo Clinic Arizona |
| 10:30 a.m. - | Morning Break | 2:00 p.m. - | Managing Long-Term Corticosteroid Therapy |
| 10:45 a.m. | | 2:30 p.m. | Speaker to be announced |
| 10:45 a.m. - | Advances in Treatment of ANCA-Associated Vasculitis | 2:30 p.m. - | Wrap-Up and Thank You |
| 11:15 a.m. | Ulrich Specks, MD Chair, Division of Pulmonary and Critical Care Mayo Clinic, Rochester, Minnesota | 2:45 p.m. | Rodrigo Cartin-Ceba, MD Joyce A. Kullman, Executive Director Vasculitis Foundation |
| 11:15 a.m. - | Upper Airway Involvement in Vasculitis | 2:45 p.m. - | Dessert Reception |
| 11:45 a.m. | David G. Lott, MD Division of Otolaryngology Mayo Clinic Arizona | 3:30 p.m. | |

The Phoenix Patient Education Regional Conference is made possible by grants from Celgene and Genentech.

Call to Register: 816-436-8211, Ext. 1

Pre-Symposium Vasculitis: Multidisciplinary Care for Multisystem Diseases Symposium

May 15, 2019 ~ Global Center for Health Innovation, Cleveland, Ohio

Editor Note: This event is for health care professionals.

Overview

Health Care providers are invited to attend the Pre-Symposium Event, Vasculitis: Multidisciplinary Care for Multisystem Diseases Symposium. Attend for an update on the multisystem nature of vasculitic diseases and the role of multidisciplinary collaboration in patient care. Experts from diverse medical specialties will discuss how specific disease features can impact the approach to the diagnosis and management in vasculitis.

Learning Objectives

Health care providers will learn about recent advances in the treatment of granulomatosis with polyangiitis and the impact of lung and kidney involvement on management.

A discussion will be held on therapeutic approaches used for asthma and other features of eosinophilic

granulomatosis with polyangiitis and how to differentiate this disease from other causes of hypereosinophilia.

Identify the immunosuppressive treatment options in giant cell arteritis, the role of imaging in its diagnosis and follow-up, and the spectrum of nonvasculitic disease that can affect the large vasculitic vessels.

Discuss the presentation, differential diagnosis, and treatment of cutaneous vasculitis.

Who Should Attend

This symposium is directed towards rheumatologists, nephrologists, pulmonologists, dermatologists, neurologists, and associated allied health practitioners interested in vasculitis.

For more information go to: <https://bit.ly/2SyoyTW>



V-RED Campaign Begins Its Sixth Year

By Ed Becker

Once again, the VF is accepting applications for its 2019 Recognizing Excellence in Diagnosis (V-RED) awards program. Since its inception in 2014, hundreds of patients worldwide have nominated a medical professional for making a critical, early diagnosis of vasculitis.

V-RED and Improving Awareness about Earlier Diagnosis

This unique recognition program is a perfect fit with the VF's goal of helping to improve the rate of early diagnosis that's part of the Join Our Journey program. By recognizing medical professionals who made a critical, often life-saving diagnosis of vasculitis, it helps raise awareness within the medical community, or among a doctor's peers.

Last year, a record number of patients nominated their medical professionals. One winning doctor was chosen,

and three others were awarded Honorable Mention status. All of the physicians nominated received a special certificate from the VF.

The VF also elevated awareness of the V-RED award through local, regional, and national media coverage.

How the V-RED Award Originated

The idea for the V-RED Award originated with VF Board Member, Karen Hirsch, whose son, Michael, was diagnosed with GPA/Wegener's in 2011 by Juanita Mora, MD, an allergist/immunologist at the Chicago Allergy Center.

"I followed my gut and ordered further testing," says Dr. Mora. "The labs and CT of his chest confirmed the diagnosis of GPA/Wegener's. Michael received prompt treatment. The early diagnosis was critical and lifesaving in the preservation of his healthy organs and getting him in to remission."

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Note: These two events are for medical professionals only.



Date & Location

- April 7 - 10, 2019
- Philadelphia, Pennsylvania

Plan on Attending Vasculitis 2019

The 19th International Vasculitis and ANCA Workshop. The Workshop is the premier academic meeting in the field of vasculitis. Investigators from around the

world share data and discuss approaches to clinical, translational, and basic science research in all forms of vasculitis. There are also sessions on state-of-the-art clinical care. The Workshop is designed to address the interests of experienced clinicians and investigators, as well as those new to the field.

For more information go to: <https://bit.ly/2TREMok>



Date & Location

- Saturday, April 6, 2019
- 7:00 a.m. - 4:00 p.m.
- Loews Philadelphia Hotel, Philadelphia, Pennsylvania

Course Overview

Designed by experts in the field, this one-day program will profile and discuss the recent advances made in the diagnosis and management of various forms of vasculitis, including giant cell arteritis, Takayasu's arteritis, ANCA-associated vasculitis (granulomatosis polyangiitis and microscopic polyangiitis), eosinophilic granulomatosis with polyangiitis syndrome, Behçet's disease, central nervous system vasculitis, and others. Each presentation will highlight the latest research

advances and provide attendees with a clear understanding of the current standard of care for treatment of these challenging diseases.

Target Audience

- Dermatology
- Internal Medicine - Nephrology
- Internal Medicine - Rheumatology

Credits

- Ama Pra Category 1 Credits™ (6.75 Hours)
- Non-Physician Attendance / Participation (6.75 Hours)
- Abim Moc Part 2 (6.75 Hours)

For more information go to: <https://bit.ly/2SJGX18>

New Resources in 2019, cont.

The New VF Website - Coming Soon

If you visit the VF website expecting to see something familiar—you may be in for a surprise.

The site has a completely new look that's designed to be more user-friendly, and easier to navigate.

Many of the most popular features from the old site, such as disease-specific information, locating medical

specialists, or video archives, are still accessible, but they're presented in a new way.

Enhancements include:

- The latest clinical information for all 18 vasculitic diseases.
- Updated listing of vasculitis specialists and centers throughout the world.

Glucocorticoid Elimination Works For 2/3 Of RA Patients On Tocilizumab

By Mitchel L. Zoler, Rheumatology News

CHICAGO – Nearly two-thirds of rheumatoid arthritis patients who achieved remission or low disease activity on tocilizumab plus low-dose prednisone were able to taper off prednisone treatment while remaining in at least low disease activity in a multicenter, randomized trial with 259 patients.



The results also showed that rheumatoid arthritis (RA) patients randomized to maintain prednisone treatment at 5 mg/day along with tocilizumab fared even better. After 24 weeks of the glucocorticoid-tapering regimen, by which time patients in the tapered arm had their prednisone dosage down to 0 mg, the average change from baseline in their disease activity score 28 with erythrocyte sedimentation rate (DAS28-ESR) was an increase of 0.538, compared with an average drop of 0.075 among untapered patients, a statistically significant difference for the study's primary endpoint, Gerd R. Burmester, MD, said at the annual meeting of the American College of Rheumatology.

But while the results definitively showed that RA patients treated with the anti-interleukin 6 agent tocilizumab (Actemra) as their primary drug benefited from continued, additional treatment with low-dose prednisone, the results also showed that many patients could come off prednisone without immediate downside.

These findings “have potential to inform clinical practice and aid in conversations with patients. RA patients who achieve at least low disease activity while receiving tocilizumab and long-term glucocorticoid treatment at 5 mg/day should be considered for tapering of their glucocorticoid dosage, ideally targeting discontinuation,” Dr. Burmester said.

Read the full article at: <https://bit.ly/2CkLJYZ>

IgA Vasculitis Linked To Higher Risk For Hypertension, Chronic Kidney Disease

By Jason Laday, Healio.com

Patients with IgA vasculitis, also known as Henoch-Schönlein purpura, are at an increased risk for hypertension and chronic kidney disease compared to those without the condition, according to recent findings in the *Annals of the Rheumatic Diseases*.

“IgA may be complicated by glomerulonephritis and it is thought that adult-onset IgA is associated with increased risk and severity of renal involvement compared with childhood disease,” Lorraine Harper, PhD, MRCP, of the University of Birmingham, in the United Kingdom, and her colleagues wrote. “However, long-term health outcomes of adult-onset IgA are not well characterized.”

Harper and her colleagues included 2,828 patients with adult-onset IgA vasculitis in their study, and matched them based on age and sex with 5,655 control participants. A total of 10,405 patients with childhood-onset IgA vasculitis were also included, and matched to 20,810 control participants.

“These findings emphasize the importance of blood pressure and renal function monitoring in patients with IgA [vasculitis],” they wrote. “Our data also suggest that IgA [vasculitis] should not be considered a ‘single hit’ disease, but that clinicians should monitor for long-term sequelae.”

Further research is required to clarify the cause of hypertension in patients with IgA [vasculitis], and to investigate whether such patients suffer from additional long-term sequelae than that are currently unrecognized.”

“Our data also suggest that IgA [vasculitis] should not be considered a ‘single hit’ disease, but that clinicians should monitor for long-term sequelae.”

Evaluation of Efficacy and Safety of Sarilumab in Patients With Giant Cell Arteritis

Now Enrolling Patients

Primary Objective:

To evaluate the efficacy of sarilumab in patients with giant cell arteritis (GCA) as assessed by the proportion of patients with sustained remission for sarilumab compared to placebo, in combination with a corticosteroid (CS) tapering course.

- › **Ages Eligible for Study:** 50 Years and Older
- › **Sexes Eligible for Study:** All

Inclusion criteria:

- › Diagnosis of giant cell arteritis (GCA) according to European League Against Rheumatism/American College of Rheumatology classification criteria.
- › New onset active disease or refractory active disease.
- › At least one of the symptoms of GCA within 6 weeks of baseline.
- › Either erythrocyte sedimentation rate ≥ 30 mm/hour or C-reactive protein ≥ 10 mg/L within 6 weeks of baseline.
- › Receiving or able to receive prednisone 20-60 mg/day for the treatment of active GCA.

For the full study description, design, full inclusion and exclusion criteria, and enrolling sites around the United States, please visit:

<https://clinicaltrials.gov/ct2/show/NCT03600805>

If you do not have Internet access, please contact the VF office for a study flyer: **800.277.9474**

ALLISON LINT AND
VIOLIN FOR VASCULITIS:
MUSIC & MEDICINE
AT PRITZKER

March 5, 2019
5:00 - 6:30 p.m.
Pritzker School of Medicine
924 E 57th Street Suite, Room 109
Chicago, Illinois

Evaluation of the Efficacy and Safety of Sarilumab in Patients With Polymyalgia Rheumatica

Now Enrolling Patients

Primary Objective:

To evaluate the efficacy of KEVZARA (sarilumab) in patients with polymyalgia rheumatica (PMR) as assessed by the proportion of subjects with sustained remission for sarilumab with a shorter corticosteroid (CS) tapering regimen as compared to placebo with a longer CS tapering regimen.

- › **Ages Eligible for Study:** 50 Years and Older
- › **Sexes Eligible for Study:** All

Inclusion criteria:

- › Diagnosis of polymyalgia rheumatica (PMR) according to European League Against Rheumatism/American College of Rheumatology classification criteria.
- › Patients must be on prednisone of at least 7.5 mg/day (or equivalent) and not exceeding 20 mg/day at screening and during the screening period.
- › Patient is willing and able to take prednisone of 15 mg/day at randomization.
- › Patients must have a history of being treated for at least 8 weeks with prednisone (≥ 10 mg/day or equivalent).
- › Patient must have had at least one episode of unequivocal PMR flare while attempting to taper prednisone at a dose that is ≥ 7.5 mg/day (or equivalent) within the past 12 Weeks prior to screening.
- › Unequivocal symptoms of PMR flare include shoulder and/or hip girdle pain associated with inflammatory stiffness.
- › Patients must have erythrocyte sedimentation rate ≥ 30 mm/hr and/or C-reactive protein ≥ 10 mg/L associated with PMR disease activity within 12 weeks prior to screening.

For the full study description, design, full inclusion and exclusion criteria, and enrolling sites around the United States, please visit:

<https://clinicaltrials.gov/ct2/show/NCT03600818>

If you do not have Internet access, please contact the VF office for a study flyer: **800.277.9474**

VF-Funded Study Publishes Results

By Dario A. Leone, PhD

The group of Professor Renate Kain, MD, PhD, head of the Department of Pathology of the Medical University of Vienna (<https://www.meduniwien.ac.at/hp/pathologie/>) and Principal Investigator of an international research group working on renal pathology and immunology published a manuscript on the potential role of LAMP-2 (Lysosomal Associated Membrane Protein -2) in immunity and autoimmunity in The Journal of Immunology.

The study explored the role of LAMP-2 in the presentation of antigens, a mechanism by which highly specialized immune cells termed antigen presenting cells (APC) display on their surface portion of molecules that are sampled during their constant patrolling of all tissues.

The antigens derived from pathogens are recognized by T and B lymphocytes that can react to them and initiate an immune response, while antigens derived from tissue recognized as “self” are tolerated and should not induce an inflammatory event. Alterations of this fine-tuned system are the main cause of autoimmune disease, a group of illness in which – as one cause of diseases - T and B lymphocytes miss-interpret the signals from the APC and react against healthy cells inducing cell death and generating auto-antibody.

The research group of Professor Kain and Professor Andrew J. Rees initially reported the presence of autoantibodies directed against LAMP-2 in a high

proportion of patients affected by renal vasculitis and that the generation of these autoantibodies may due to molecular mimicry with a bacterial protein, called FimH.

However the mechanisms leading to autoimmunity remained to be determined and consequently Dario A. Leone, MD, investigated whether the circulating anti-LAMP-2 antibodies influence the immune system. He analyzed their effect on human APC and found that antibodies specific for LAMP-2 are efficiently internalized by the APC and traffic to the antigen processing compartment.

Antigens from different sources were then chemically cross-linked to the anti-LAMP-2 abs to quantify their processing rate and to monitor the response of T lymphocytes. Surprisingly, antigen internalized by the LAMP-2 pathways were not “conventionally” processed and displayed on the surface of APC but were maintained in a more native condition and sorted into vesicles that were secreted extracellularly.

These extracellular vesicles termed “exosomes” are thought to serve as “long distance communication” they are equipped with proteins and specific molecules that are able to shape the immune system and they can travel in the blood stream to through the body. Therefore, exosomes currently constitute a “hot” research topic because of their potential application in drug delivery, vaccine strategy and cancer immunotherapy and up to date LAMP-2, is the first immune receptor that was shown to specifically divert antigens into exosomes, thus modulating T lymphocyte response.

Dolly's Story: Quick Diagnosis Gives 20+ Years

Editor's note: This story is adapted from an essay that Dolly Espinoza wrote about being diagnosed with Wegener's. Dolly's husband shared it with us after her death.



Dolly Espinoza

My name is Pete M. Espinoza. My wife, Dolly, was a Wegener's patient who, sadly, passed away on April 29, 2018.

Dolly was diagnosed in 1996 and lived with the disease for 22 years. We were living in Idaho when she became ill with flu-like symptoms - feverish and weak, with body aches. Dolly made an appointment with Dr. Margo Saunders and she prescribed medications. But, after no improvement, she hospitalized Dolly for tests, including one for her kidneys.

After the test results came back, Dr. Saunders told us that she believed Dolly had Wegener's granulomatosis (now GPA) and prescribed Cytoxan and prednisone. A rheumatologist at the University of Utah Medical Department agreed with the Wegener's diagnosis and added Methotrexate to her drug regime. She always considered herself fortunate that she was diagnosed in a short amount of time.

Over the next 20+ years Dolly suffered kidney failure, dialysis, a kidney transplant, and other health issues. Ultimately, she contracted leukemia and passed away.

Learning about vasculitis was frightening, especially since Dolly had never been sick. When she was first diagnosed, we weren't sure how to learn about vasculitis. Help came, after we were introduced to the Vasculitis Foundation's newsletter, which was a helpful resource and one for which we were grateful.

Dr. Alicia Rodriguez-Pla Joins Newly-Created University Of Arizona Vasculitis Center

By John Fries

Alicia Rodriguez-Pla, MD, PhD, MPH, a board-certified internist and board-eligible rheumatologist, has been appointed clinical assistant professor of medicine in the Rheumatology Division of the University of Arizona College of Medicine – Tucson.



Alicia Rodriguez-Pla, MD, PhD, MPH

In her new role, Dr. Rodriguez-Pla is part of a newly-created Vasculitis Center, a multidisciplinary medical team of specialists, all of whom have vasculitis-related experience and expertise. “We can communicate quickly with each other,” she says, “and we will try to coordinate the care of the patients in the most efficient and optimal way to assure that the best possible care is offered.”

Dr. Rodriguez-Pla earned her medical degree at the Universidad de Navarra in Pamplona, Spain. She also holds a PhD in immunology/rheumatology from the Universitat Autònoma de Barcelona, where she worked in translational and epidemiological research on giant cell arteritis.

Her career took her to the U.S. where she served four years as a visiting research, post-doctoral fellow at The Johns Hopkins University. At Hopkins she continued her research in giant cell arteritis and observed patients at their Vasculitis Center while earning a Master’s degree in

Public Health. Her final two years at Hopkins were funded through a Vasculitis Clinical Research Consortium (VCRC)/Vasculitis Foundation (VF) fellowship. After spending a short time practicing medicine in Spain and a stint at Baylor University in Texas working on lupus research, Dr. Rodriguez-Pla moved northeast to serve as a clinical fellow in rheumatology under Paul Monach, MD, then director of Boston University’s Vasculitis Center.

At BU, she and Dr. Monach began a research project to look for biomarkers of disease activity in different types of vasculitis, including giant cell arteritis, eosinophilic granulomatosis with polyangiitis, Takayasu’s arteritis, and polyarteritis nodosa. She also gained clinical experience in scleroderma—another rare autoimmune disease, though not vasculitic.

Dr. Rodriguez-Pla has been interested in vasculitic disorders for many years. “The first patient I saw during clinical rounds in medical school was a woman with Takayasu’s arteritis, and I didn’t know at the time that blood vessels could become inflamed,” she says. “It was then that I decided to become a rheumatologist,” she says.

Dr. Rodriguez-Pla is excited about her new role at the University of Arizona.

“I believe there has been a clear need for a vasculitis center in the southwestern U.S.,” says Dr. Rodriguez-Pla. “Many people from other areas are now moving and retiring to Tucson, and many of them have or will develop vasculitis. They now truly benefit from having a team of doctors interested in—and specializing in—their conditions.”

V-RED 2019, *cont.*

V-RED 2019 Yields Record Amount of Nominations

In 2018, a total of 42 patients nominated their medical professionals. This year the VF has received more than 50 nominations, and several more weeks remain for submissions.

For Karen Hirsch this level of participation validates the original idea for the V-RED Award.

“We all know that diagnosing vasculitis early is a continuing challenge. There are so many unfortunate stories where patients suffer permanent damage from a late diagnosis or misdiagnosis,” says Hirsch. “Our idea was to turn that around and recognize those

who are intervening early and using the award to spread awareness among medical professionals.”

If you would like to nominate a medical professional for this award, visit the 2019 V-RED web page at <https://bit.ly/2CZEZ1V>.

Nominations will be accepted until March 15, 2019.



Maureen and Bruce Howard with Keith Goldstein, MD, at Hunterdon Medical Center, Flemington, New Jersey. Dr. Goldstein was nominated by Maureen for the V-RED 2018 Award.

Ashley Spencer Refuses to Give In

By Ben Wilson

I've said it before, but if you are ever feeling down and out, or are struggling to find daily inspiration (an admitted challenge during the endless winter months), I'd suggest looking no further than the collection of young adults fighting against vasculitis. While each of us have been on unique journeys against this disease, very few of us have gone through what Ashley Spencer, the subject of this edition's patient profile, has gone through over the past six years.

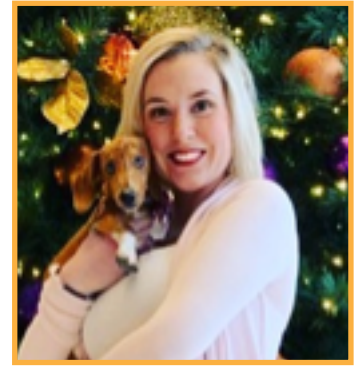
Ashley's story is quite possibly the best real-life example I've seen of the need for better education of vasculitis among our doctors and hospital systems.

Ashley, a standout student in physical therapy school with a bright future ahead of her, was 22 when she was diagnosed with EGPA. However, the aftermath of her diagnosis was anything but straightforward, and she nearly lost her life on multiple occasions as a result.

While living in the Philadelphia area and struggling to achieve remission, doctors repeatedly denied her requests for new therapies and treatments. This included Nucala, a groundbreaking treatment approved by the FDA in 2018, that has vastly improved the lives of many vasculitis patients (myself included). "They kept telling me I had an imaginary disease," Ashley says. "I remember the doctors talking outside of my room and actually calling me crazy in front of other people in the hospital."

After six years of struggles, Ashley had enough. She decided to uproot her life and move to Cleveland, Ohio, in the hopes that the Cleveland Clinic would provide better care.

However, she almost didn't make it there. On her flight to Cleveland, Ashley went into anaphylactic shock. Miraculously, two doctors happened to be on the flight, and helped save her life by administering EpiPens and Albuterol. While the story made national headlines, Ashley was still looking for long-term answers on how to control her disease. "You want the best treatment for yourself," she told reporters for The Washington Post at the time. "You don't want to be on chemo your entire life."



Ashley Spencer with her dog, Winston.

Fortunately, her conditions have started to improve. Doctors fought with her insurance company to get her approved for Nucala, which has helped her condition immensely and allowed her to begin weaning off methotrexate and steroid treatments. "It's a legit miracle drug," she says. "I feel like I have at least part of my life back now." Despite that, her vasculitis remains active and she has a wealth of side effects that have developed since her diagnosis in 2012, including a blood clot in her heart, that doctors found last summer.

Through it all, Ashley remains optimistic, and now wants to turn her attention towards educating physician groups about EGPA and prevent her experience from happening to anyone else. "I'm so passionate about it because you aren't crazy, you're fighting something that is real."

As a fellow EGPA patient, Ashley's resolve and determination is unbelievably inspiring. My hope is that we as a community, with Ashley leading the way, can coordinate efforts to better educate doctors and change the discussion (or lack thereof) about vasculitis in hospitals everywhere.

“I’m so passionate about raising awareness because you’re fighting for something that is real.”

Ashley Spencer

California Runner Finds Helpful Support Through VF and Brandon Hudgins

By John Fries

Art Diaz, a 49-year-old married father of two, embodies the southern California lifestyle of health and vitality. A native resident of Garden Grove in Orange County, Art works as a retail manager at Skechers, the lifestyle apparel brand headquartered in nearby Manhattan Beach. An avid runner, Art has spent many hours logging countless miles on local trails.

His running routine was interrupted in August 2017 when he suddenly developed a host of unexpected medical symptoms after a leg injury: blood clots in his legs, shoulder and chest pain, difficulty breathing, dramatic weight loss, and pronounced weakness. He went to Hoag Memorial Hospital Presbyterian in nearby Newport Beach, where, following blood tests that seemed to indicate vasculitis, Art's cardiologist immediately referred him to rheumatologist Kathy Karamlou, MD. A few more tests later, Dr. Karamlou diagnosed Art as having GPA.

"It happened so quickly," recalls Art. "Unlike many, I was fortunate to be diagnosed within three weeks. I'd never even heard of vasculitis, but thankfully my doctors were familiar with it. Dr. Karamlou put me on prednisone and Rituxan, and I was off work for three months."



Art Diaz and family

Since then, Art has been managing his illness and has resumed running. He continues to taper off his medications and recently completed his fourth course of Rituxan. He also found support via the Vasculitis Foundation and, not surprisingly, from elite runner Brandon Hudgins, who, coincidentally, is sponsored by Skechers, Art's employer.

"When I was first diagnosed, I started doing web searches to learn more," he says. "That's how I discovered the VF. I read Brandon's book, 'Going the Distance', which I found extremely inspirational. I'm looking forward to meeting him at the next VF Symposium."

"Support is critical," says Art when asked what advice he'd give to newly diagnosed patients. "It can make you feel alone, but you're not. Through the VF, you can interact with, not only doctors and other medical professionals, but also many individuals who share similar diagnoses and struggles. We're there for each other."

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The Vasculitis Clinical Research Consortium (VCRC) is the major clinical research infrastructure in North America dedicated to the study of vasculitis. The VCRC has grown to include 18 academic medical centers in the United States and Canada conducting investigator-initiated clinical and translational research. The VCRC also partners with 50 other centers worldwide for the conduct of clinical trials.

The VCRC conducts observational cohort studies, biomarker development, studies of genetics and genomics, clinical outcomes research, studies using an online patient registry, pilot clinical projects, and multicentered, randomized clinical trials. Core components of the VCRC include the VCRC Clinical Data Repository, the VCRC Biospecimen Repository, the RDCRN VCRC Patient Contact Registry, the VCRC-NIH Data and Safety Monitoring Board.

Join The VCRC Contact Registry!

Research offers no guarantees, but research cannot move forward without your help. Every active role a patient takes may possibly play a part in discovering new groundbreaking research and finding new treatments.

Participating Institutions:

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- Cedars-Sinai Medical Center United States
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Please visit the VCRC website to join the registry and to review the complete list of all current research studies available for patients to participate in. <https://www.rarediseasesnetwork.org/cms/vcrc/>

TAPIR Trial Recruiting Patients

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

What we are studying:

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

The study asks the question, is it more beneficial for patients with GPA to maintain low-dose prednisone intake during remission versus eliminating prednisone intake altogether?

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

You can participate in the TAPIR Trial if ...

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

**Other conditions may apply*

How to join the TAPIR trial:

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

Visit www.TAPIRTrial.org

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In Memoriam

IN MEMORIAM

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

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Save the date!

VF Calendar of Events • 2019

**Go to our online calendar with the latest information about
our upcoming events: Vasculitis Foundation**

www.vasculitisfoundation.org/events/

February 28, 2019

International Rare Disease Day

March 5, 2019

Allison Lint and Violin For Vasculitis: Music and Medicine

- ▶ Pritzker School of Medicine
924 E 57th Street Suite, Room 109, Chicago, Illinois
- ▶ 5:00 p.m. - 6:30 p.m.
- ▶ violinforvasculitis.org

March 9, 2019

VF - Mayo Clinic Arizona Patient Conference

- ▶ Waugh Auditorium
5777 East Mayo Boulevard, Phoenix, Arizona
- ▶ 8:30 a.m. - 3:30 p.m.

April 5, 2019

Violin For Vasculitis: Alabama

- ▶ violinforvasculitis.org

April 7-10, 2019

**The 19th International Vasculitis & ANCA Workshop
For Physicians and Researchers**

- ▶ Loews Hotel, Philadelphia, Pennsylvania
- ▶ vasculitis2019.org

April 13, 2019

**North Carolina/Raleigh Chapter Vasculitis
Support Group Meeting**

- ▶ UNC Wellness Center at Meadowmont in Chapel Hill 100
Sprunt Street Chapel Hill, North Carolina 27517
- ▶ 10:00 a.m. - 2:00 p.m.
- ▶ Contact: Jill Powell,
Administrator – Vasculitis Support Group
Jill_powell@med.unc.edu

April 13, 2019

Kansas City Chapter Meeting

- ▶ BEST Conference Center, Room 125
University of Kansas Edwards Campus
12600 Quivira Road, Overland Park, KS 66213

May 1-31, 2019

Vasculitis Awareness Month

May 18, 2019

Spaghetti Western Dinner

- ▶ 37811 176th Ave S.E., Auburn, WA 98092

July 19-21, 2019

International Vasculitis Symposium