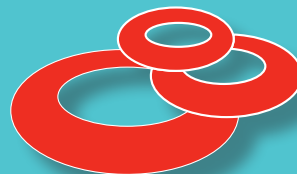


Vasculitis Foundation

SUPPORT AWARENESS RESEARCH



ANNUAL REPORT

2014 | 2015



A LETTER FROM THE EXECUTIVE DIRECTOR

Dear Friends,

As the Vasculitis Foundation closes the books on the 2014-2015 fiscal year, we are pleased to provide this Annual Report for your review. The report details our efforts to fulfill the VF's mission to raise awareness, educate patients and families about vasculitis, and encourage and fund research on vasculitis.

The Vasculitis Patient-Powered Research Network (V-PPRN) is a collaboration of the Vasculitis Foundation and the Vasculitis Clinical Research Consortium. The V-PPRN is a longitudinal cohort study (a study capturing patient data over a long period of time) that will give us the opportunity to follow patients with many forms of vasculitis over numerous years. By asking patients questions regularly about their health, disease flares, and other patient reported data, we can understand how people's health and lives change over time. Collecting patient data over time will help us better understand vasculitis and how to combat these diseases.

Over 1,000 patients have enrolled in the V-PPRN since its launch in November 2014. The V-PPRN has conducted two studies in addition to the longitudinal cohort data being collected and over half of the V-PPRN patient cohort participated in those studies. The VascWorks Study explored the impact that a vasculitis diagnosis may have on a patient's employment status, work productivity and income. The second study, AAV-PRO, explored quality of life issues for patients with ANCA-associated vasculitis. Investigators will use the reported data to develop better tools to more accurately assess and validate quality of life issues for patients with all forms of vasculitis.

The goal of the V-PPRN is to conduct high-quality studies that will improve the care and the health of patients with vasculitis by exploring research questions that matter most to patients and advance medical knowledge about vasculitis. During the first year, patients submitted over 305 questions for researchers to consider for more in-depth study.

The VF Research Program has been funding innovative research since 2002. This year, in addition to funding three new studies through our regular funding mechanism, we also funded two special studies for Eosinophilic granulomatosis with polyangiitis (EGPA/Churg Strauss Syndrome). The funding for the studies was provided by Mr. and Mrs. Ben and Kathy Johnson, in support of Kathy's ongoing battle with EGPA.

We were also pleased to name Dr. Medha Soowamber as the first fellow for the Vasculitis Clinical Research Consortium-Vasculitis Foundation (VCRC-VF) Fellow Program. Dr. Soowamber will complete her one-year fellowship (2015-2016) at the Toronto Western Hospital, University of Toronto, Canada under the mentorship of Dr. Simone Carette and Dr. Christian Pagnoux.

We are honored and privileged to provide patient support via phone, email, social media, educational webinars, regional conferences, chapter meetings, and symposia. We are continually humbled by our patients' strength, courage, and optimism in fighting their vasculitis.

Throughout this report we will also share information about our donors, our finances, our initiatives and successes. Your generosity and dedicated support makes our successes possible.

Thank you for your support.

Sincerely,
Joyce A. Kullman
Executive Director
Vasculitis Foundation

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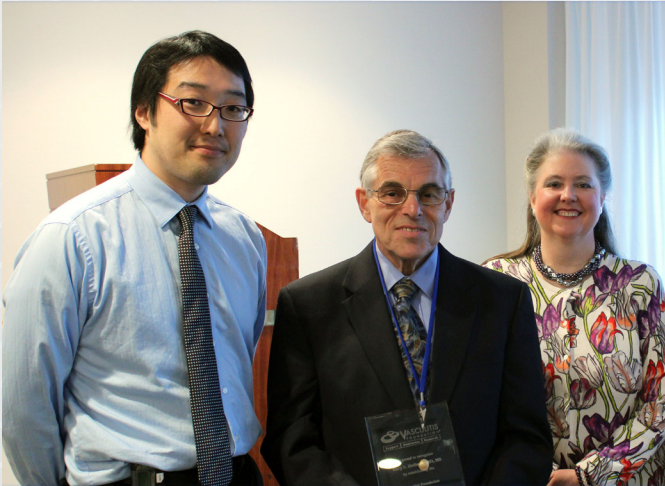
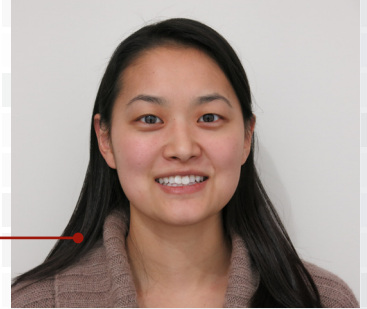
Awareness

Research



VCRC-VF VASCULITIS FELLOWSHIP

Dr. Rennie Rhee began the first year of her two-year VCRC-VF Vasculitis Fellowship at the University of Pennsylvania under the mentorship of Dr. Peter Merkel. Dr. Rhee shared, "The most rewarding part of my work is seeing patients get better—I think any physician would say the same. Whether I'm at the bedside or doing research, what drives me is knowing that I can make a positive impact on someone's life."



GARY S. HOFFMAN VASCULITIS FOUNDATION FELLOWSHIP

Upon the announcement of his retirement from patient care in 2014, the Vasculitis Foundation chose to recognize Dr. Gary S. Hoffman by partnering with the Cleveland Clinic to fund a yearlong fellowship at the Center for Vasculitis Care and Research in his honor. Dr. Hoffman has had a profound influence on the lives of people with vasculitis and is recognized as a world leader in vasculitis clinical care and research. Dr. Hiromichi "Hiro" Tamaki was introduced as the Hoffman fellow. He graduated from the University of Tokyo and completed an Internal Medicine Residency at the University of Hawaii followed by a rheumatology fellowship at the Cleveland Clinic. He will begin the second year of a two-year vasculitis fellowship in July 2015.

VF RECOGNIZING EXCELLENCE IN DIAGNOSIS AWARD (V-RED)

The Second Annual V-RED (Recognizing Excellence in Diagnosis) Award was presented to two worthy physicians. Dr. Sarah Durney of Powell Valley Healthcare in Powell, Wyoming, was nominated by Angie Kissner, who Dr. Durney diagnosed with GPA/Wegener's just 12 days after seeing her for the first time. In her nomination, Angie wrote, "Dr. Durney listens carefully and asks a lot of questions to find the answers. She described me one time as a puzzle and said she loved to solve puzzles. It made me sure that she would do whatever she could to help me feel better. I believe that she sees medicine as a calling and not a job."

The second recipient, Dr. Milan Shah, is an ophthalmologist at Midwest Eye Institute in Indianapolis, Indiana. He was nominated by Conney Freese-Posthuma, whose son, Jacob, had been dealing with a lot of health problems - nose bleeds, migraines, bloodshot eyes and more - for a long time with no real answers from many different doctors. As Conney shared, "Dr. Shah was the first doctor who put all of the symptoms together and diagnosed GPA/Wegener's before Jacob suffered serious complications from the disease."



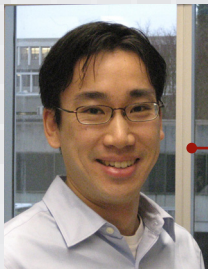


REGIONAL CONFERENCES

One-day regional conferences were held in Overland Park (Kansas City), Kansas, West Bloomfield, Michigan, New York City, Stanford, California and Cleveland, Ohio. For each conference, the Vasculitis Foundation partnered with vasculitis experts from nearby medical institutions to provide educational and informative sessions with special time for networking and socializing.

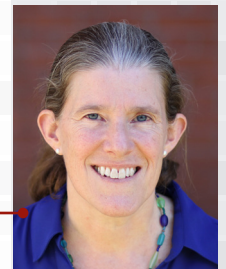
VF RESEARCH STUDIES

The Vasculitis Foundation selected five research studies for funding:



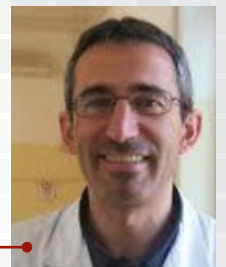
- **Jonathan Choy, PhD**
Simon Fraser University, Burnaby, British Columbia, Canada
Immune regulation by IL-6 in Giant cell arteritis
Award: \$50,000, one-year study

- **Susan Jick, DSc, Professor of Epidemiology**
Director, Boston Collaborative Drug Surveillance Program
Boston University School of Public Health, Boston, Massachusetts
Longitudinal study of morbidity and mortality in vasculitis patients
Award: \$98,641, two-year study



- **Renate Kain, MD, PhD**
Medical University of Vienna, Vienna, Austria
Role of LAMP-2 in tolerance to ANCA antigens
Award: \$50,000, one-year study

- **Davide Martorana, PhD**
Diagnostic Department, Medical Genetics Unit
University Hospital of Parma, Parma, Italy
Exome Sequencing in EGPA Patients
Award: \$48,000, two-year study



- **Parameswaran Nair MD, PhD, FRCP, FRCPC**
McMaster University in Ontario, Canada
(co- investigators Manali Mukjerhee MD and Nader Khaladi)
Investigating Autoimmune Mechanisms Underlying EGPA
Award: \$50,000, one-year study

VF EDUCATIONAL PROGRAMMING

Throughout the year, the Vasculitis Foundation hosted educational webinars featuring many of our vasculitis consultants and outside medical experts discussing different topics of importance for our community. Webinar topics ranged from updates on research efforts to managing medications, support for caregivers, the NIH's new Vasculitis Translational Research Program, nutrition, exercise, ophthalmology concerns and, most importantly, hope. We record all of the webinars and make them available on our website to reach the widest possible audience and expand access to our vasculitis educational programming.

2015
WEBINAR
SERIES

ROAD MAP TO WELLNESS

WATCH AND LEARN! EDUCATIONAL SESSIONS FOR PATIENTS AND FAMILIES TO **LEARN ABOUT VASCULITIS**

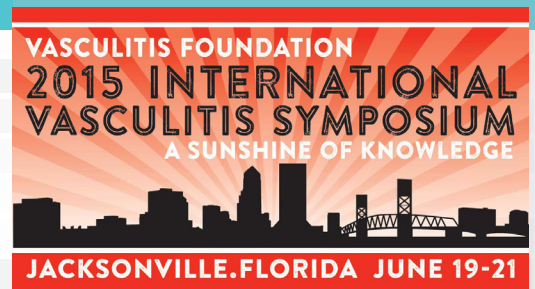


VASCULITIS SYMPOSIA

In April, the Vasculitis Foundation helped sponsor the 17th International Vasculitis and ANCA Workshop in London, England. The four-day meeting brought together over 500 vasculitis researchers from around the world to discuss current and future research studies, clinical trials, and ongoing collaborative efforts.

In conjunction with the Workshop, the Vasculitis Foundation partnered with the Vasculitis UK to host a one-day educational conference for over 100 patients and family members in London. The meeting featured many of our European vasculitis experts sharing their expertise and knowledge.

We were pleased to complete our year with our amazing and inspirational 2015 International Vasculitis Symposium in Jacksonville, Florida, June 19-21. Over 250 patients, family members, health care professionals and researchers gathered for the meeting. With the theme "A Sunshine of Knowledge", the weekend featured vasculitis experts discussing the most current diagnostic tools, promising new treatment options and exciting advances in research. Although it was hot and muggy in Florida, the attendees had an amazing time learning from the experts and networking with other patients and family members. As one of the attendees said, "When I think about my experience at the Symposium, I think about people sitting at a table talking and **CONNECTING AND LEARNING** from one another; I could not tell who was a patient, researcher, care provider - it was a community." ~ Ana



EXTRAORDINARY STORIES

The VF's Extraordinary Stories Project expanded and now includes over 150 videos on our YouTube Awareness Channel. The videos feature interviews with patients, family members, physicians and researchers, and provide hope and encouragement to those who are struggling with vasculitis. The Project enriches our goal of alleviating the isolation that patients and their families experience when these life-threatening diseases affect them.



VF AWARDS RECOGNIZING POSITIVE CHANGE

The Vasculitis Foundation works to support positive change in the lives of people who live with vasculitis and three special awards were presented during the Symposium:

• The 2015 Bruce Macdonald Volunteer Spirit Award recognized Elaine Holmes, the longtime leader of the Raleigh/North Carolina VF Chapter, for her dedication to helping patients find excellent medical care, raising awareness of vasculitis in the general public and promoting fundraising activities for the Vasculitis Foundation.

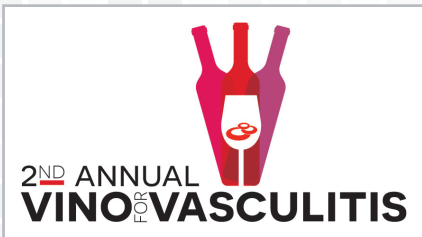


• The 2015 VF Online Patient Advocate Award, new this year, recognized Marianne Vennetti, co-founder and director of Alliance for Cryoglobulinemia, for her extensive work and dedication in advancing patient advocacy in the world of rare diseases.

• The 2015 Raising Vasculitis Awareness Star was awarded to Allison Lint, founder of the Violin-4-Vasculitis Awareness Campaign, which has taken her to more than 25 states as she shares her love of classical music and raises awareness of vasculitis and funds for the Vasculitis Foundation.



All of our programs and initiatives would not be possible without the support of our many supporters. Throughout the year members hosted golf tournaments, Rallies in the Alley Bowling Tournaments, walks, runs, music concerts, dinners, wine tastings, a piano recital and even a Taekwondo kick-counting contest!



VASCULITIS FOUNDATION
 STATEMENT OF ACTIVITIES
 FOR THE YEARS ENDED JUNE 30, 2015 AND 2014

	2015	2014
UNRESTRICTED NET ASSETS		
Revenues and other support		
General Donations	\$296,925	\$284,530
Dues	43,107	47,624
Memorials	29,209	34,882
In-kind Contributions	3,980	10,374
Honors	34,824	30,568
Other	2,259	3,457
Symposium Revenue	45,860	64,251
Interest and Dividends	4,230	4,008
Unrealized Gain (loss)	1,146	(7,819)
Realized Gain (loss)	650	30,103
	462,190	501,978
Net assets released from restrictions	703,556	501,978
	1,165,746	860,592
Expenses		
Patient Support, Awareness, and Research	908,411	713,377
Administrative	64,071	84,465
Fundraising	60,731	23,601
Total Expenses	1,033,213	821,443
	132,533	39,149
CHANGE IN UNRESTRICTED NET ASSETS		
TEMPORARY RESTRICTED NET ASSETS		
Revenues		
Restricted Donations	532,329	335,666
Interest and Dividends	12,109	12,630
Unrealized Gain (loss)	(436)	(6,227)
Realized Gain (loss)	1,833	45,523
Net assets released from restrictions	(703,556)	(358,614)
	(157,721)	28,978
	(25,188)	68,127
NET ASSETS, BEGINNING OF YEAR	\$1,179,624	\$1,111,497
NET ASSETS, END OF YEAR	\$1,154,436	\$1,179,624

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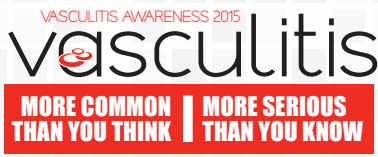
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