

Vasculitis Foundation

support awareness research



annual report 2013 | 2014

Dear Friends,

As the Vasculitis Foundation closes the books on the 2013-2014 fiscal year, we are pleased to provide this Annual Report for your review. The report details our efforts to fulfill the VF's mission of raising awareness, educating our patients and families, and encouraging and funding research on vasculitis.

With the theme "**Knowledge Bringing Freedom**" the July 2013 International Vasculitis Symposium in Philadelphia celebrated the VF's commitment to providing educational opportunities for our members. Celeste Lee, the symposium's keynote speaker and a 31-year survivor of vasculitis, encouraged attendees to have **HOPE**, her acronym for living with Humor and Optimism and the goal of finding joy each day. She also encouraged patients to establish solid Partnerships with their medical teams and to Educate themselves about their vasculitis so that they are fully engaged with their own care.

In October 2013, the Vasculitis Foundation awarded a two-year grant of \$99,920 to Dr. Carolyn T. Thorpe, the University of Pittsburgh, for her study, "**Impact of Healthcare Utilization and Informal Caregiving for Primary Systemic Vasculitis (SV)**". The study will determine the cost of treatment for patients and characterize costs and mortality by socio-demographic, clinical, and geographic factors. The study will also describe the nature and impacts of informal caregiving for SV and examine predictors of greater burden. This research will provide preliminary data for future federal grant applications, including further studies of variation in treatment for SV, comparative effectiveness of SV treatments, and development of psychosocial interventions to better support SV patients and their loved ones.

In January 2014, the Vasculitis Foundation, in partnership with investigators from the University of Pennsylvania and the Vasculitis Clinical Research Consortium, were awarded a PCORI grant of \$1,000,001 to establish the Vasculitis Patient-Powered Research Network (V-PPRN). The goal of the V-PPRN research program 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.

Throughout the report we also share information about our donors, our finances, our program initiatives and successes, and additional research grants funded during this year. The following email, received earlier this year, sums up the Vasculitis Foundation's mission to help members of our community to have hope and live better lives.

"Thank you for your support. You didn't even know us but when I emailed you about my brother's condition, you gave us help and hope for the future. Thank you for caring about us."

- Jodika

Sincerely,
Joyce A. Kullman
Executive Director

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During 2013-2014 the Vasculitis Foundation had many successes, thanks to countless donors, volunteers, and supporters. The VF's mission to empower the vasculitis community through education, awareness, and research, was reached in the following ways:

- In July 2013, the VF held the International Vasculitis Symposium: "Knowledge Bringing Freedom" in Philadelphia. The three-day educational event was attended by 278 people.
- The "Roadmap to Wellness Webinar Series" was kicked off in January 2014, allowing educational opportunities for the vasculitis community in the comfort of their own homes. The series featured vasculitis experts discussing in-depth topics including nutrition, medication, research efforts, and communication strategies.
- The VF's Extraordinary Stories video project expanded and now includes more than 100 videos on YouTube. The videos, which feature interviews with patients, family members, physicians and researchers, provide hope and support to those who are struggling with vasculitis.
- The Vasculitis Foundation's Rally in the Alley events were held in Chicago, Kansas City, Streator, IL, and Millstone Township, NJ. These, in addition to many other volunteer-run fundraising events, contributed to the VF's education, support, awareness, and research efforts.
- The Vasculitis Foundation's Facebook Page, Facebook Group, Twitter following, and Linked-In connections all grew. The VF ramped up social media communication efforts in order to reach this growing population of friends and followers.
- The Vasculitis Foundation awarded fellowship grants to Dr. Elizabeth Brant at the University of North Carolina, Chapel Hill, and to Dr. Rennie Rhee at the University of Pennsylvania, Philadelphia. The Vasculitis Foundation Fellowship provides the opportunity for one- or two-year tracks designed to support the training of physician scientists who wish to gain clinical expertise in vasculitis and who may also wish to pursue an investigational career in this field.
- The VF announced the creation of the Vasculitis Clinical Research Consortium (VCRC) Vasculitis Foundation (VF) Fellowship Program in Clinical Investigation. The VCRC-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 trainee will undertake the Fellowship between 2014-2019 at a VCRC-affiliated site in North America that has an established distinct clinical and research program in vasculitis and availability of senior faculty mentors.
- The Vasculitis Foundation is the largest private funder of research on vasculitis. Because of VF-funded research, new and improved treatments and greater understanding of vasculitis have increased the life expectancy for patients and improved their quality of life. The VF is currently funding 10 research studies including a two-year epidemiology study. In 2014, three Vasculitis Foundation Research Grants were awarded to the following researchers:
 - "Rho-kinase Activity in Large Vessel Vasculitis," Lindsay S. Lally, MD, and Robert F. Spiera, MD, Department of Medicine, Hospital for Special Surgery, New York City.
 - Microbubble Contrast-Enhanced Vascular Ultrasonography: A Novel Method of Detecting Large Vessel Vasculitis," Kimberly P. Liang, MD, Division of Rheumatology and Clinical Immunology, University of Pittsburgh.
 - "The Role of microRNA in a Novel Mouse Model of Vasculitis," Carola Vinuesa, MD, MSc, PhD, Department of Pathogens and Immunity, Australian National University, Acton, Australia.
- The Vasculitis Foundation announced that a team with representatives from the VF was awarded a grant to establish the Vasculitis Patient Powered Research Network (V-PPRN). The V-PPRN is comprised of the Vasculitis Foundation, the Vasculitis Clinical Research Consortium (VCRC), and experts in constructing federated databases including the electronic health record (EHR), disease-specific health data and patient-reported outcomes. Part of the \$1 million award will result in direct funding to the VF to support such activities and patient engagement and communication. The research team is led by Peter A. Merkel, MD, MPH at the University of Pennsylvania Vasculitis Center and Director of the VCRC and George Casey, MBA, VF Board Member. The team is also comprised of medical professionals, researchers, patients, and patient advocates.

vasculitis foundation
STATEMENT OF ACTIVITIES
FOR THE YEARS ENDED JUNE 30, 2014 AND 2013

	2014	2013
UNRESTRICTED NET ASSETS		
Revenues and other support		
General Donations	\$284,530	\$211,421
Dues	47,624	46,624
Memorials	34,882	21,195
In-kind Contributions	10,374	10,425
Honors	30,568	10,955
Other	3,457	1,889
Symposium Revenue	64,251	5,953
Interest and Dividends	4,008	3,424
Unrealized Gain (loss)	(7,819)	11,687
Realized Gain (loss)	30,103	3,159
	501,978	326,732
Net assets released from restrictions	358,614	301,997
	860,592	628,729
Expenses		
Patient Support, Awareness, and Research	713,377	498,523
Administrative	84,465	139,375
Fundraising	23,601	36,749
Total Expenses	821,443	674,647
	39,149	(45,918)
CHANGE IN UNRESTRICTED NET ASSETS		
TEMPORARY RESTRICTED NET ASSETS		
Revenues		
Restricted Donations	335,666	339,815
Interest and Dividends	12,630	13,436
Unrealized Gain	(6,227)	5,571
Realized Gain (loss)	45,523	12,284
Net assets released from restrictions	(358,614)	301,990
	28,978	69,109
	68,127	23,191
	\$1,111,497	\$1,088,306
	\$1,179,624	\$1,111,497

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