

Vasculitis Foundation

support awareness research



annual report 2012 | 2013

Dear Friends,

Vasculitis. More common than you think. More serious than you know.

The message of *Vasculitis Awareness Month 2013* speaks volumes as to why the Vasculitis Foundation is needed and important. We are here to serve the vasculitis community through education, support, awareness, and research. We are here to work TOGETHER to better serve those living with vasculitis.

And during fiscal year 2012-2013, we feel we have done that in many ways. This annual report reflects our work in summary, and provides you with a detailed report of our finances, our directors, our donors, and the projects that you helped make happen.

The fiscal year began in July 2012 when the VF hosted a one-day symposium at Emory University Hospital in Atlanta, Georgia. 160 people and 12 vasculitis experts attended the event. Several of the sessions were streamlined online for patients around the world to watch, illustrating our new focus of providing more online resources and communication through webinars, the new VF website, and stronger Facebook and Twitter messaging.

In December 2012, the new VF website was launched featuring extensive education, awareness, research and support sections. The site enables patients, families and health care professionals to find up-to-date information on the diagnosis and treatment of each of the vasculitic diseases, to connect with research opportunities, to find physicians and to learn about VF activities and programs.

The new site gave the VF a better way to promote new ventures, including the announcement to fund four new research studies. The studies included research on microparticles and their role in the treatment of GPA; the role of microRNA in GPA; the development of a uniform histology for the diagnosis of small vessel CNS vasculitis in adults and children; and the role of unique antibodies to proteins 14-3-3 in Giant cell arteritis. The VF is currently funding eight studies and to date has funded 29 studies since 2002 for a total of \$1.4 million.

In addition, Dr. Elizabeth Brant, University of North Carolina, was selected as the first fellow of the VF Fellowship Program. During her two-year fellowship Dr. Brant will develop diagnostic and therapeutic skills, provide care for patients and gain in-depth experience in the use of immunosuppressive therapy in patients with systemic vasculitis. Dr. Brant's research efforts will focus on venous thromboembolism (VTE), a condition that studies show is common in ANCA vasculitis.

The year concluded with an additional half-day educational conference at the Cleveland Clinic, and the unveiling of a new vasculitis awareness video. Partnered with the very successful *Helping Extraordinary People Live Extraordinary Lives* Project we hope we helped patients, family members, and friends. If you have not viewed the many stories available on the VF YouTube channel, please commit just 10 minutes to see first hand the stories that offer hope and insight into the challenges of living with a chronic illness and the impact it has on the lives of both patients and their families.

Because ultimately, that is why the Vasculitis Foundation exists.

Sincerely,
Joyce A. Kullman
Executive Director

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2012 - 2013 summary

The Vasculitis Foundation advocates for early diagnosis, leading edge treatment and ultimately a cure for all types of vasculitis.

The Vasculitis Foundation works to alleviate the isolation that patients and their families experience when these rare life-threatening diseases affect them. The VF helps build a strong positive outlook through our Support, Awareness, and Research Programs. During 2012-2013:

- The VF launched a new website. Since the launch one year ago, the website has seen 146,563 visitors.
- The VF launched a new pediatric section on the website, which offers specific information for our pediatric and young adult patients.
- The VF's *Extraordinary Stories* project was a huge hit, with more than 70 videos uploaded onto YouTube.
- As part of *Vasculitis Awareness Month 2013*, a new video was introduced.
- VF Chapters reorganized and began work on educational meetings planned around the U.S. for *Vasculitis Awareness Month 2014*.
- The VF welcomed new members to the Medical and Scientific Advisory Board: Susanne Benseler, MD, Patrice Cacoub, MD, Simon Carette, MD, Rodrigo Cartin-Ceba, MD, Peter Grayson, MD, PhD, Peter Heeringa, PhD, Tanaz Kermani, MD, Atul Khasnis, MD, MS, Alfred Mahr, MD, PhD, Kathleen Maksimowicz-McKinnon, DO, Mehrdad Maz, MD, Eamonn Molloy, MD, MS, FRCPI, Christian Pagnoux, MD, MSc, MPH, Amr Sawalha, MD, Francisco Silva, MD, Jason Springer, MD, Antoine Sreih, MD, Yusuf Yazici, MD, and Rae S. M. Yeung, MD, PhD, FRCPC.
- The Vasculitis Foundation awarded a fellowship grant in the amount of \$99,615 to Elizabeth Brant, MD, University of North Carolina, Chapel Hill. 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 awarded \$50,000 to support the vasculitis research study "**Development of a uniform histology scoring system for Small Vessel CNS vasculitis in Childhood and Adulthood,**" Susanne M. Benseler, MD, MSCE, PhD., Department of Pediatrics, Division of Rheumatology, The Hospital for Sick Children.
- The VF awarded \$99,206 to support the vasculitis research study "**Circulating microparticles as therapeutic targets of plasma exchange in antineutrophil cytoplasmic antibody (ANCA) associated vasculitis,**" Paul Brogan, BSc, MBChB, MRCPCH, MSc, PhD, FRCPCH, Paediatric Rheumatology/Infectious Disease and Microbiology Unit, Institute of Child Health.
- The VF awarded \$50,000 to support the vasculitis research study "**To Understand Role of 14-3-3- in Giant Cell Arteritis,**" Ritu Chakravarti, PhD, Department of Pathobiology, Lerner Research Institute, Cleveland Clinic Foundation.

vasculitis foundation
STATEMENT OF ACTIVITIES
FOR THE YEARS ENDED JUNE 30, 2012 AND 2013

	2013	2012
UNRESTRICTED NET ASSETS		
Revenues and other support		
General Donations	\$211,421	\$320,656
Dues	46,624	55,256
Memorials	21,195	88,564
In-kind Contributions	10,425	21,506
Honors	10,955	17,454
Other	1,889	3,786
Symposium Revenue	5,953	16,602
Interest and Dividends	3,424	3,535
Unrealized Gain (loss)	11,687	(476)
Realized Gain (loss)	3,159	(1,842)
	326,732	525,041
Net assets released from restrictions	301,997	281,065
	628,729	806,106
Expenses		
Patient Support, Awareness, and Research	498,523	509,031
Administrative	139,375	76,885
Fundraising	36,749	94,050
Total Expenses	674,647	679,966
	(45,918)	126,140
CHANGE IN UNRESTRICTED NET ASSETS		
TEMPORARY RESTRICTED NET ASSETS		
Revenues		
Restricted Donations	339,815	304,217
Interest and Dividends	13,436	12,588
Unrealized Gain	5,571	4,594
Realized Gain (loss)	12,284	(1,112)
Net assets released from restrictions	301,990	(281,065)
	69,109	39,222
	23,191	165,362
NET ASSETS, BEGINNING OF YEAR	\$1,088,306	\$922,944
NET ASSETS, END OF YEAR	\$1,111,497	\$1,088,306

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