

Vasculitis Foundation

support awareness research



annual report 2011 | 2012

Dear Friends,

The Vasculitis Foundation supports and empowers our community through education, awareness, and research. Throughout the year all of our initiatives work to reinforce this mission. We work diligently with the help of thousands of volunteers, advocates, and foot soldiers – helping spread the word about vasculitis and the Vasculitis Foundation.

In this annual report we reflect on the work of the 2011-2012 fiscal year, and provide you with a detailed report of our finances, our donors, and the projects that you helped make happen. There were many highlights, which are summarized throughout this report. A few of our larger projects are outlined below:

In January 2012, the VF Board of Directors selected three studies for research funding. The studies, receiving total funding of \$150,000, examine granulomatosis with polyangiitis (GPA, Wegener's), Churg-Strauss Syndrome and giant cell arteritis. Details of these research projects may be found under the Research Program description in this report.

On April 20, 2012, the VF hosted its Second International Research Consensus Conference to review the VF Research Program and to discuss the future of VF-funded research on vasculitis. The one-day meeting was held in Chicago, Illinois, and drew experts from Boston University, Centers for Disease Control and Prevention, Cleveland Clinic, Groningen University, Mayo Clinic, New York University, Rush University, The Johns Hopkins University, University of Lübeck/Germany, and the universities of California, North Carolina, Pennsylvania and Utah. Discussion centered on setting research priorities for the VF to consider for funding. Key areas discussed included: epidemiology, genetics, etiology, pathogenesis, therapeutics, fellowships, and outcomes.

The Chicago Vasculitis Symposium was held on April 21, 2012. Almost 200 patients, family members, friends, caregivers and health care professionals attended the daylong meeting at The Searle Conference Center at Rush University. In addition, 263 people from 10 countries participated in the meeting via an online webinar. The theme "Knowledge. Community. Power." was in full swing as vasculitis experts from around the United States and Germany shared their knowledge and expertise with the attendees.

We truly cannot say it enough – the work completed by the Vasculitis Foundation would not be successful without the commitment of the vasculitis community. We are nothing without our members, our volunteers, our medical community, and our friends. Thank you for your continued commitment to the Vasculitis Foundation. Please enjoy this summary of 2011-2012 happenings.

Sincerely,
Joyce A. Kullman
Executive Director

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vasculitis foundation programs

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.

support and awareness programs

Support for patients and their family members is the heart of the Vasculitis Foundation mission. Support is provided through direct communication with dedicated staff and expert medical consultants, regional symposia, web site and social media, bi-monthly newsletter, and chapters worldwide. And raising awareness about vasculitis – what it is, how it is treated, who is affected – is key to future early diagnosis, better treatment and prognosis.

During the 2011-2012 fiscal year volunteers from around the world helped in our efforts by passing out information, holding support meetings, and organizing events. A few of those activities include:

- In August 2011, more than 1,000 people participated in the Fourth Annual Mountain Top Baseball Tournament. The event, organized by Terry Tokach, raised more than \$10,000, bringing the four-year event total to over \$37,000.
- In September 2011, the Fourth Annual Western Massachusetts Golf Open raised over \$35,000 for the Vasculitis Foundation. The event was held at The Ranch Golf Club in Southwick, Massachusetts, and was organized by Kate Tierney and Carl Cieplinski.
- Also in September 2011, Helen Mayor participated in the Great North Run in United Kingdom.
- Jamie Alfieri McLean held her Dinner, Dance and Auction in October 2011.
- Jarrod Sheets organized Raising Awareness One Step at a Time, Des Moines to Kansas City, 7 Days, and 200 miles.
- Violin 4 Vasculitis: Raising Awareness Through Music gained success thanks to the work of Allison Lint.
- Karl Vonder Schmalz, a runner and Polyarteritis nodosa patient, completed the NY City Marathon in November 2011.
- The Vasculitis Foundation had a presence at the American College of Rheumatology Annual Scientific Meeting, Chicago, Illinois, in November 2011.
- Members of The Ricardo Lee Vasculitis Foundation participated in the PanCaribbean's Sigma Corporate Run on February 19, 2012, in Kingston, Jamaica.
- In March 2012, Ginny Smith held the 9th Annual Crop for a Cure.
- Reaching Beyond the Clouds published. The book tells the inspiring and uplifting story of Cindy Abbott, a Wegener's patient, who successfully summited Mount Everest in 2010.
- Andrea Pittini, an Italian pianist, composer and music producer, dedicated his song, "Life" to help support the 2012 Vasculitis Awareness Campaign.
- Robert S. Lebovics, MD, FACS, was interviewed by Laura DeAngelis for "Health and Home Report", a monthly syndicated cable TV program. The interview aired during the month of May in support of Vasculitis Awareness Month.

research program

The Vasculitis Foundation is the largest private funder of vasculitis research and has funded over \$1,000,000 in research worldwide. In January 2012, the Vasculitis Foundation funded the following research projects:

Grantee: Sharon Chung, MD, MAS, assistant adjunct professor, Division of Rheumatology, University of California, San Francisco

Award: \$50,000 for one year

Topic: Exome sequencing in granulomatosis with polyangiitis (GPA, Wegener's)

Her proposed project is an advancement over current genetic studies, since she will be focusing on rare genetic mutations instead of the common genetic mutations that are usually studied. The VF funding is crucial to the undertaking, but its patient network also is critical. Genetic research like this is completely dependent on patients who are willing to participate in genetic studies and provide DNA samples. "When more individuals participate, more powerful studies can be conducted, and thus, we are more likely to identify the genes involved in this disease," Dr. Chung explains. "Participation in genetic studies is an easy, low-risk way of helping move research forward for these diseases."

Grantee: Shadi Swaidani, research associate, immunology, Cleveland Clinic Lerner Research Institute

Award: \$50,000 for one year

Topic: Investigating the molecular mechanism for IL-25-driven Act1-dependent eosinophilic vasculitis

"This research project will help us understand the underlying causes and mechanisms that contribute to the development of eosinophilic vasculitis," Swaidani explains. Of particular interest is the role of one protein, IL-25, in promoting eosinophilic vasculitis and its potential use as a therapeutic target for Churg-Strauss Syndrome. "Such understanding will hopefully bring a future where we can better prevent, diagnose, and treat this disease."

Grantee: Cornelia Weyand, professor of medicine, Stanford University School of Medicine

Award: \$50,000 for one year

Topic: Small molecule therapeutics in giant cell arteritis

"In this study we will examine how the immune cells are activated in the first place; how they respond to activation and how immune activation translates into the injury in the blood vessel," Weyand explains. The study gives special attention to a new type of immuno-modulatory drugs, called the JAK inhibitors, which can suppress cellular activation. Experiments will explore the potential of such new inhibitors as a new treatment approach in giant cell arteritis (GCA).

vasculitis foundation

STATEMENT OF ACTIVITIES

FOR THE YEARS ENDED JUNE 30, 2012 AND 2011

	2012	2011
UNRESTRICTED NET ASSETS		
Revenues		
General Donations	\$342,162	\$247,050
Dues	55,256	51,264
Memorials	88,564	29,425
Honors	17,454	10,492
Other	3,786	6,403
Symposium Revenue	16,602	145,732
Interest and Dividends	3,535	3,463
Unrealized Gain (loss)	(476)	22,183
Realized Gain (loss)	(1,842)	1,942
	525,041	517,954
Net assets released from restrictions	281,065	210,026
	806,106	727,980
Expenses		
Patient Support, Awareness, and Research	\$509,031	\$639,221
Administrative	76,885	67,908
Fundraising	94,050	47,635
	679,966	754,764
CHANGE IN UNRESTRICTED NET ASSETS	\$126,140	\$(26,784)
TEMPORARY RESTRICTED NET ASSETS		
Revenues		
Restricted Donations	\$304,217	\$287,861
Interest and Dividends	12,588	11,868
Unrealized Gain	4,594	24,145
Realized Gain (loss)	(1,112)	12,177
Net assets released from restrictions	(281,065)	(210,026)
CHANGE IN TEMPORARY RESTRICTED NET ASSETS	39,222	126,025
CHANGE IN NET ASSETS	165,362	99,241
NET ASSETS, BEGINNING OF YEAR	\$922,944	\$823,703
NET ASSETS, END OF YEAR	\$1,088,306	\$922,944

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