

The Vasculitis Foundation: Our 30-Year Journey

1986

- Marilyn Sampson, a registered nurse and Wegener's patient, founds the Wegener's Granulomatosis Support Group, International (WGSGI), with Connie Barnett and Fern Thompson in Platte City, Missouri.



- VF Medical Consultants are established with Nabih I. Abdou, MD, PhD, (shown with Marilyn below), Thomas R. Cotton, MD, Thomas J. McDonald, MD, and Steven Weiner, MD.



1987

- Marilyn writes the first educational brochure; it's mailed to 194 members.
- Myrna and Carol Swart host the first meeting of the WGSG Los Angeles Chapter.

1994

- First Wegener's Granulomatosis Patient Seminar "Together in Adversity," brings 182 patients, family members and friends to Kansas City, Missouri.

1995

- Carol Swart (in center of photo), a Wegener's patient, builds the organization's first website.
- Michael Clay, a Wegener's patient, creates the Wegener's ListServe, enabling patients everywhere to share information and support via the World Wide Web.



1996

- The first, "Wegener's Granulomatosis Awareness Week" is launched to raise awareness of the disease
- Second Wegener's Patient Seminar "Together for a Brighter Future" includes international vasculitis medical experts for the first time.

1997

- Marilyn Sampson, RN, (below left) and founder of the Wegener's Granulomatosis Support Group, International, passes away after battling cancer.



- Iva N. Roe (above right), a Wegener's patient, becomes president and executive director of the WGSG.
- More than 1,000 patients complete the first Wegener's Patient Survey. Data compiled by Glennon Kullman, a Wegener's patient, and the results published in an article by Dr. Nabih I. Abdou, in the February 2002 Journal of Rheumatology.
- NC/Raleigh Support Group meets for the first time.

1998

- Third International Patient Symposium "Meeting the Challenge Together" is held in Kansas City, Missouri. Members vote to change the name of the organization to Wegener's Granulomatosis Association.
- VF Medical Consultants now number 16, with 13 different medical institutions represented.
- Over 600 patient packets are mailed to patients in 36 countries.

1999

- Nancy Olona (right) organizes the first Colorado Walk for Wegener's and raises \$22,840 for research.
- Shane Onufrock and John Cooksey create a 30-second public service announcement, which is aired on TV multiple times during Wegener's Awareness Week.
- Ed Becker launches the PAN Research and Support Network as an online resource for patients with Polyarteritis Nodosa.



2000

- WGA volunteers host booths at international meetings for ENTs, family physicians, nephrologists, and rheumatologists.
- Fourth International Patient Symposium "Challenging Wegener's in the New Millennium" is held in Kansas City.

2001

- WGA Small Grant Program is established to study the etiology, epidemiology, diagnosis, treatment, and patient relief from the complications of Wegener's. Maximum awards are \$35,000 for 12 months. Dr. Richard Erickson, a Wegener's patient and board member, chairs the Research Committee.

2002

- WGA receives a \$100,000 gift from the estate of Gabrielle and D. M. Sarkisian (a Wegener's patient); the board establishes the Marilyn Sampson and Iva N. Roe Endowment Fund to help ensure future financial stability of the organization.
- First research grant of \$35,000 is awarded to Dr. Gary S. Hoffman and Dr. Alexandra Villa-Forte, Cleveland Clinic Center for Vasculitis Care and Research, for their study "Short-term cyclophosphamide therapy in a cohort of more than 200 patients".



- Iva Roe retires as executive director and Joyce Kullman (above left) is named executive director. Shannon Morgan and Mary Ann Quick (above right) join the staff; Shannon, as Patient Support/Chapter and Support Group Coordinator, and Mary Ann, as Patient Support Coordinator.
- Fifth International Patient Symposium "Gaining Strength through Knowledge" is held in Kansas City.
- Lynn Ann Casey, a board member, organizes the "Kitchens Around the World" cookbook and raises almost \$10,000 from booksales.
- Dennis and Carmela Banfield host the first of many fundraising efforts over the next 10+ years, raising over \$12,000 for research on Wegener's.

2003

- We expand our research efforts, joining the NIH's Vasculitis Clinical Research Consortium (VCRC), an integrated group of medical centers, patient support organizations, and clinical research resources dedicated to conducting clinical research in different forms of vasculitis.
- VF Medical Consultants now number 21 and represent 14 different medical institutions.
- David and Mary Anne Nichols (right) host the First Jeffrey Nichols Memorial Golf Tournament. Over its 10+ year run, the event will raise almost \$50,000 for the organization.



2004

- The VF hosts the Sixth International Patient Symposium "Knowledge is the Key" in Cleveland, Ohio, the first symposium held outside of Kansas City, Missouri.



- Jane Dion (above) establishes the Churg Strauss Syndrome Association and partners with the WGA to provide patients with educational materials and information about research studies and to raise awareness.

2005

- We participate in AARDA's Second Annual Congressional Briefing (below) and members visit Capitol Hill to raise awareness of autoimmune diseases and the need for research funding.



- WGA membership approves the name change to Vasculitis Foundation, effective January 1, 2006.
- Dr. Don Gebhart, a retired ENT surgeon and Wegener's patient, becomes chair of the VF Research Committee.
- 600 patient information packets, 300 family packets and 290 medical packets are mailed to physicians and medical personnel.

2006

- WGA becomes the Vasculitis Foundation and the Support and Education Committee (below) is established to create educational and awareness materials for all the different forms of vasculitis.



2006 (continued)

- Diann Alford organizes the First Keesha Vessell Walk: Celebrating a Life (right). The annual walk has raised almost \$40,000 for research over the past 10 years.
- We launch a new website built by volunteers Michael Cherry, Michael Clay, Tim Costin, Bruce Macdonald, Carol Swart, and Bill Walters.



- First International Vasculitis Consensus Conference (below) is held in Chicago, Illinois to review the WGA Small Grant Program. Attendees include physicians, researchers and members of the NIH. Recommendations include renaming the program the VF Research Program, increasing grants to \$50,000 for one-year studies and focusing research on areas that can decrease the morbidity and mortality of vasculitic diseases. We have funded 13 studies.
- We partner with the Johns Hopkins Vasculitis Center to host the 6th International Patient Symposium, "Learn...Live...Thrive!!!" in Baltimore, Maryland.
- We award our first fellowship to Dr. Eammon Molloy at the Cleveland Clinic with financial support from PRISM Ltd. International, the VF's 2006 Corporate Citizen. PRISM employees around the world fundraise and volunteer at WGA symposiums in support of their boss, Steve Madincea, a board member and Wegener's patient.
- Jennifer Price joins the organization as our first Financial Coordinator.



2007

- First International Patient Symposium is held at Queen's College, Cambridge, England (below). More than 150 patients and family members attend, along with 23 vasculitis experts from Europe.



- VF provides sponsorship for the 13th International Vasculitis and ANCA Workshop in Cancun, Mexico.
- We partner with the VCRC and the Rare Diseases Clinical Research Network to sponsor a training for young and/or new investigators conducting clinical research in rare diseases.
- Jordan Crane is hired as VF Director of Development.

2008

- We host the 9th International Vasculitis Symposium "The Vasculitis Journey" at the Mayo Clinic, Rochester, Minnesota.

2009

- The VF name and 3-ring logo (right) are trademarked.
- VF helps sponsor the 14th International Vasculitis and ANCA Workshop in Copenhagen, Denmark.



2010

- We fund three new research studies and reach our goal of funding more than \$1,000,000 in research on vasculitis. We publish our first VF Research Funding Report detailing the accomplishments of the VF Research Program to date.
- Leslie Scott-Lysan creates the VF Facebook Discussion Group. In its six years, the group has attracted nearly 4,500 members.
- We host the 9th International "All Star Vasculitis Symposium" in Long Beach, California and, also, a CME-credit course, attended by more than 100 physicians.
- Cindy Abbott, a Wegener's patient (right), successfully summits Mount Everest, while raising awareness of Wegener's and rare diseases in general.



2011

- In celebration of the 25th Anniversary of the Vasculitis Foundation, we launch a new awareness slogan: Know Vasculitis. No Vasculitis.
- The FDA approves Rituxan® (rituximab) for the treatment of Granulomatosis with polyangiitis (GPA/Wegener's) and microscopic polyangiitis (MPA). This is the first drug ever approved by the FDA for the treatment of any form of vasculitis.
- Vasculitis Awareness Week expands to Vasculitis Awareness Month and is moved to May to avoid competing with Breast Cancer Awareness Month in October
- Allison Lint (below), a Wegener's patient, launches "Violin-4-Vasculitis," a 50-state awareness effort.



2012

- We launch a new slogan, Helping Extraordinary People Live Extraordinary Lives, and release our first VF Awareness Video featuring patients talking about the impact of vasculitis on their lives.



- The VF receives a grant from Genentech to launch a new online library of patient videos entitled, "Extraordinary Vasculitis Stories" produced and directed by Ed Becker. (above) More than 160 patients have recorded their stories.
- More than 300 patients attend one-day regional patient conferences in Atlanta, Georgia and Chicago, Illinois.



- The VF Medical and Scientific Board (above) grows to 60 members. The group is an integral part of the VF's mission, providing patient support and education and overseeing the Research Program.

2013

- We host the 10th International Vasculitis Symposium, "Knowledge Bringing Power," in Philadelphia, Pennsylvania (below). More than 300 patients and healthcare professionals attend the meeting.



2013 (continued)

- We introduce our new awareness slogan: Vasculitis. More Common Than You Think. More Serious Than You Know. The board votes to have the slogan trademarked.
- The first Rally in the Alley is held in Chicago, Illinois and raises more than \$16,000.
- We award the first VF Fellowship to Dr. Elizabeth Brant, who will train at the UNC Kidney Center.

2014

- Dr. Robert Torrano, San Jose, California, (right) is the VF's inaugural recipient of the Recognizing Excellence in Diagnostics (RED) Award.
- We partner with investigators at the University of Pennsylvania and PCORI to establish the Vasculitis Patient-Powered Research Network (V-PPRN). The goal is to conduct high-quality studies that will improve the care and the health of patients with vasculitis.
- The inaugural Chicago Vasculitis Golf Open raised more than \$75,000 in support of the VCRC-VF Fellowship Program and the establishment of a Chicago Vasculitis Center.
- We partner with the VCRC to fund the first of five VCRC-VF fellowships, which will take place at recognized VCRC centers of excellence. Dr. Rennie Rhee is our first recipient and will train at the University of Pennsylvania in Philadelphia.
- We launch a monthly educational webinar series to present topics of interest to our community.



2015

- We debut a new website, which averages 10,000 + visitors per month.
- We launch VF E-News, an electronic communication tool to keep in touch with members of the vasculitis community.
- Dr. Medha Soowamber is named as the second VCRC-VF Fellow and will train at the University of Toronto, Canada.
- We fund a record number of studies (five), including two projects on Eosinophilic granulomatosis with polyangiitis (EGPA/Churg Strauss syndrome).
- We announce the Gary S. Hoffman VF Vasculitis Fellowship. Dr. Hiro Tamaki (left) will train for one year at the Cleveland Clinic before returning home to Japan to join a vasculitis center.



2016

- We fund three new studies and break the \$2,000,000 mark in funding research on vasculitis.
- We launch Victory Over Vasculitis: VF Team Brandon, a partnership with Brandon Hudgins, a long-distance runner with GPA/Wegener's. Over 300 people have joined his virtual team to train with Brandon and cheer him on to his goal of making the 2016 US Summer Olympics Team.
- We celebrate our 30th anniversary, a time to celebrate our accomplishments and look forward to the next 30 years.



Because space is limited here, we are only able to list a few of our many achievements and mention a small number of the people whose time, dedication, leadership, and hard work over the past 30 years has brought us to where we are today. Please visit VasculitisFoundation.org to see a more detailed timeline.