



Vasculitis Awareness Week Handbook

May 3 - 9, 2009

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Thank you for your interest in participating in this important endeavor. This is your opportunity to make a positive difference in the lives of people living with a vasculitis illness.

Please help raise awareness of vasculitis, meet new people and make new friends, while raising money for an important cause.

This year, Vasculitis Awareness Week is May 3-9, 2009.

What is Vasculitis Awareness Week?

Vasculitis Awareness Week is an international effort organized by the Vasculitis Foundation (VF) to advance public awareness of this rare disease, as well as the progress in treatments and advances in research. **By uniting, we can create an international coalition, which speaks stronger and louder than as a single entity.**

We look forward to partnering with our patients and family members, other vasculitis disease support groups, patient advocacy groups, and medical and research groups in this effort.

We encourage all patients with vasculitis to share their personal stories, whether as a patient with Behcet's disease, Buerger's disease, Central Nervous System, Churg Strauss Syndrome, Cryoglobulinemia, Giant Cell Arteritis, Henoch-Schönlein Purpura, Hypersensitivity Vasculitis, Kawasaki disease, Microscopic polyangiitis, Polyarteritis nodosa, Polymyalgia rheumatica, Rheumatoid vasculitis, Takayasu's arteritis, and Wegener's granulomatosis.

How To Support Awareness Week?

Vasculitis Awareness Week is characterized by events and raising awareness all over the world. Some events include:

- Walk/Run Events
- Host a Dinner
- Hints to Raise \$100 in 10 Days!

To support Vasculitis Awareness Week, here are some strategies to consider:

- Distribute brochures to doctors' offices, dental offices, pharmacies, hospitals, schools, libraries and grocery stores.
- Write, call or email your friends and tell them about vasculitis and your individual disease (i.e. Wegener's).
- Contact your local media and ask to be interviewed about vasculitis. Explain how it is not so rare as rarely diagnosed, describe symptoms, and explain about the importance of research being conducted to discover the cause(s) of vasculitis.

- Contact your local civic clubs (Kiwanis, Rotary, and Lions), churches, synagogues or temples and offer to speak to their members about your experience with vasculitis.
- Coordinate a VF informational display at a health fair, festival, store, or school.
- Call or send letters/emails to Talk Shows/Investigative Shows asking them to spotlight vasculitis and/or offering to share your story with their audience.
- Ask your city to declare a Proclamation for Vasculitis Awareness Week.
- Visit with your Congressional representatives when s/he is back from Washington in the home office. What you're doing is starting a relationship. Tell your story. Explain why research is important. You're not asking them for anything, just getting to know them.

Background on Vasculitis

Vasculitis is an inflammation of the blood vessels, arteries, veins or capillaries. When such inflammation occurs, it causes changes in the walls of blood vessels, such as weakening or narrowing that can progress to the point of blood vessel blockage.

Members of the vasculitis family include: Behcet's disease, Buerger's disease, Central Nervous System, Churg Strauss Syndrome, Cryoglobulinemia, Giant Cell Arteritis, Henoch-Schönlein Purpura, Hypersensitivity Vasculitis, Kawasaki disease, Microscopic polyangiitis, Polyarteritis nodosa, Polymyalgia rheumatica, Rheumatoid vasculitis, Takayasu's arteritis, and Wegener's granulomatosis.

Because there are so many types of vasculitis, the group is sometimes referred to in the plural: *vasculitides* (pronounced "vas que lit' i deez", with the accent on the third syllable). Although the diseases are similar in some ways, they often differ with respect to which organs are affected.

A result of vasculitis is that the tissues and organs supplied by affected blood vessels do not get enough blood. This can result in organ and tissue damage, which can even lead to death.

Because vasculitis is caused in part by an overly active immune system, the treatment usually involves the use of medications that suppress parts of the immune system.

The Vasculitis Foundation

The Vasculitis Foundation (VF, formerly the Wegener's Granulomatosis Association) was founded in May 1986 with 3 patients; and our database now includes over **8,000** patients with vasculitis. The VF is a registered 501 (c) (3) non-profit organization and is a member of the National Organization for Rare Disorders, Inc. (NORD), American Autoimmune Related Diseases Association, Inc. (AARDA), and the BBB Wise Giving Alliance.

The volunteer VF Medical Consultants represent the finest medical institutes in the country and consult with primary care physicians and other medical specialists regarding treatment for patients.

The VF funds research for qualified institutions to determine the cause of vasculitis, to develop a cure for the disease and to improve treatment options for all patients with vasculitis.

The VF Newsletter is sent six times a year and has a circulation of over 4,000.

Our original Internet Web site was developed by Carol Swart, a Wegener's patient, in 1996. Our current Web site is www.vasculitisfoundation.org and receives **thousands** of hits each month.

The Vasculitis Foundation has been contacted by patients in Argentina, Australia, Bangladesh, Belgium, Bolivia, Brazil, Brunei, Canada, Chile, China, Columbia, Croatia, Cyprus, Denmark, El Salvador, England, Finland, France, French W. Indies, Germany, Greece, Iceland, India, Indonesia, Iran, Ireland, Israel, Italy, Japan, Kuwait, Latvia, Lithuania, Mexico, N. Ireland, Netherlands, New Zealand, Norway, Pakistan, Peru, Romania, Russia, S. Africa, Scotland, Sicily, S. Korea, Spain, Sweden, Switzerland, Syria, Turkey, Venezuela, W. Indies, and all the United States of America.

Awareness Week Event Suggestions

When considering an event, design the event to make friends first, then raise money. And most importantly, have FUN.

This section provides information about how to host events, raise awareness, and support our fundraising efforts as a way to participate in Awareness Week in your neighborhood!

Walk/Run Event

Hosting a walk/run event is easy to do. Invite your local chapter or support group, or do a smaller walk on your own with friends and family.

The Vasculitis Foundation office can provide:

- Step by Step Guidelines for an Event
- Balloons
- Certificates of Appreciation
- Raffle tickets
- Registration/Pledge master forms
- Tote/plastic bags
- T-shirts
- VF Brochures
- 501(c) (3) non-profit letter
- Event liability insurance
- VF membership list for your geographical area
- **Save-the-date postcards**

The VF office can also help:

- Assist/Design your event flyer/poster
- Assist/Write your news release
- Assist/Write Corporate sponsor letter
- Anything else!! Let us know what you may need to make your event a success!

Regardless of the amount of money you raise, a walk/run event is a valuable tool to raise awareness of Vasculitis and your specific disease

If you don't want to organize a walk/run event yourself, find a walk/run event that is close. You can walk in honor or in memory of someone special.

For information or to put your Walk/Run Event on the calendar, please contact the VF office.

Host a Dinner

Sharing information about vasculitis and the Vasculitis Foundation over a meal is an excellent opportunity for raising awareness and fundraising.

Host a dinner or weekend brunch at home

- Host a dinner and ask guests to make a tax deductible donation.
- Share your experience with vasculitis and the mission of the VF.
- Provide guests with grab bags filled with VF brochures, T-shirts, or bracelets.

Sponsor an event at a local restaurant

- Ask your favorite local restaurant to help host a benefit. (Many new restaurants are happy to host a benefit as an opportunity to train staff before the real opening.)
- Put up flyers and send blast emails to friends, family and co-workers 4 to 6 weeks in advance.
- Contact local media to advertise the occasion.
- Remind everyone 5 to 7 days before the event.
- Include a raffle or donation bucket at the restaurant that night and place informational brochures on the tables.
- Remind guests that the meal and any additional donations are tax deductible.

Raise \$100 in 10 Days!

Every contribution to raising awareness, supporting our organization, or raising funds help. Here are some ideas on how to raise \$100 with very little effort.

1. Put in your own \$20
2. Ask your best friend/spouse/roommate for \$20
3. Bake cookies for your co-workers for \$20
4. Ask your Mom and Dad to contribute \$20
5. Hold a yard sale! Turn that junk into \$20
6. Ask a neighbor for \$20
7. Ask two people from church/mosque/temple for \$10 each
8. Offer to walk your neighbor's dog for a \$10 donation – (two walks and you've just raised \$20)
9. Ask your boss or a businessperson you work with to contribute \$20
10. Ask two members of your fan club, (or family) for \$10 each

Donations are tax deductible!

Other ideas:

Bowling Tournament
 Pet Photo Contest
 Bake Sale
 Craft Sale
 Pet Walk or Parade
 Jewelry Party
 Scrapbooking Party
 Basketball Tournament
 Fishing Tournament
 Car Wash
 Garage Sale
 Dress Down Day (at the officer)
 Silent Auction
 Barbeque
 Book Sale

Bingo Party
Art Show
Fashion Show
Tribute Luncheon
Class/Workshop (i.e. quilting, photography)

Get the Word Out!

How to Write a Press Release

There are two kinds of releases that you should consider circulating: a calendar announcement and a press release.

Calendar Announcement – All newspapers and most other publications post listings of upcoming local events. If you call the publication, they will give you the name, address and email of the person in charge of the calendar of events. A calendar announcement is the who, what, when, where, and how. It lets the reporter know that something is coming up that needs to be on their radar.

If you would like your event to make the community calendars, you should consider sending the calendar announcement as soon as you have the date of your event (even 6-months ahead is okay!). If your event is only a few weeks away, then send the calendar announcement one-week prior to your event. And, it never hurts to follow up with a phone call.

Press Release – A press release gives more details about the event and should include quotes from organizers, or someone involved in the event. The actual press release can be used several ways: 1) You may send out the press release the day before, or morning of the event, to let the reporter know what is going to happen. 2) Another way to use a press release is after the fact. Some media outlets – particularly print – may not be able to come to the event, but will write a short article on what happened. If you utilize the press release in this way, write in past tense. Also, if you have digital photos of the event send them!

How to Circulate a Press Release to Your Local Media Outlets

Journalists are looking for true stories, events or people that present something new, important and interesting to the audience that reads, listens, or sees their story. When pitching a story idea (or circulating a press release) there are a few key things to remember:

1. **Are you pitching your story to the right person?** When pitching a story about Awareness Week there are several “right” people. You should first consider pitching your story to the assignment editor, as he/she is the keeper of all story ideas. Other appropriate people would be the health reporter, or if you are doing a special event, the features reporter. If you do go directly to the reporters, it doesn’t hurt to copy the assignment editor so that he/she can follow up. You can find names for these contacts by calling the publications or by going to www.newspaperlinks.com. which offer free links to ever newspaper by city.
2. **Don’t write them with your opinions - yet.** Though you have a personal connection with vasculitis, when writing a press release start with the facts. Let them know the date

and time of your event; where it will be held; who will be there (i.e. 150 vasculitis patients, their families and friends); and why you are holding the event.

3. **Send your press release in an email.** Most media Web sites include email contact information for their newsroom; this is the easiest and best way to make sure they have all the facts clear. When writing the email use the subject line to tell them about your event. For instance: 5th Annual Walk for Vasculitis Awareness – May 3-9, 2009.
4. **Send the text in the body of the email.** Some media outlets cannot open attachments due to security. It is okay to attach the press release to the email, but make sure you cut and paste it in the main message as well.
5. **Follow up with a phone call.** Once you send the email, wait a couple of days and then follow up. This is where you should tell your personal story. Call the person you sent the email to and ask if they received it. Explain why they should cover your event and how vasculitis has had an effect on you/your family. Once the person on the other line hears your story they will likely want to interview you in person.
6. **If you are unwilling to be interviewed, make sure you know of someone involved in your event that is willing.** Every reporter wants a personal story to go along with the facts. Not everyone likes to tell their story, just make sure you have a least one person who will! You will want to have their name and phone number to pass along to the reporter.
7. **Don't forget NPR (National Public Radio)!** Often forgotten, your local NPR affiliate is a great source for getting your story out there. They are always looking for the local spin on a national story and often will run your story package numerous times.

Other Ideas:

National Public Radio Commentaries: NPR is looking for commentaries or essays that tell a tale, reveal a personal reflection, or add an informed perspective to events in the news. They want pieces that express an original idea with clear, creative writing.

Every person involved in the VF has a story to tell about their experience with Vasculitis. Whether a patient, doctor, family member or friend, take a few moments and share your story with NPR during Awareness Week! Here is how to do it:

1. Send one or two written commentaries in the body of the email. Do not send attachments, as NPR is unable to open attachments due to security.
2. Each commentary should take about two-and-a-half minutes to read aloud (about 450 words in length).
3. Include your name, address, daytime telephone number, and e-mail address.
4. Send your commentary (with the words "Commentary Submission" in the subject line) to *Morning Edition*: mecommentary@npr.org and to *All Things Considered*: atcommentary@npr.org.
5. Go to www.npr.org for more information.

Forms and Samples

The following are forms for planning your event and samples of marketing materials.

Vasculitis Fact Sheet

- There are over 15 different types of vasculitis, all are considered rare
- Although the diseases are similar in some ways, they often differ with respect to which organs are affected
- Early diagnosis is key to preventing permanent organ damage and helping patients regain their health
- Because vasculitis is caused in part by an overly active immune system, the treatment usually involves the use of medications that suppress parts of the immune system
- Members of the vasculitis disease family include: Behcet's disease, Buerger's disease, Central Nervous System, Churg Strauss Syndrome, Cryoglobulinemia, Giant Cell Arteritis, Henoch-Schönlein Purpura, Hypersensitivity Vasculitis, Kawasaki disease, Microscopic polyangiitis, Polyarteritis nodosa, Polymyalgia rheumatica, Rheumatoid vasculitis, Takayasu's arteritis, and Wegener's granulomatosis.
- The Vasculitis Foundation (VF) was founded in May 1986 with 3 patients; and our database now includes over 8,000 patients with vasculitis diseases
- The VF is a registered 501(c)(3) non-profit organization and is a member of the National Organization for Rare Disorders, Inc. (NORD), American Autoimmune Related Diseases Association, Inc. (AARDA), and the BBB Wise Giving Alliance
- The volunteer VF Medical Consultants represent the finest medical institutes in the country and consult with primary care physicians and other medical specialists regarding treatment for patients
- The VF funds research for qualified institutions to determine the cause of vasculitis, to develop a cure for the disease and to improve treatment options for all patients with vasculitis
- The VF newsletter is sent six times a year and has a circulation of over 4,000
- Our original Internet Web site was developed by Carol Swart, a Wegener's patient, in 1996; our current Web site is www.vasculitisfoundation.org and receives thousands of hits each month
- The Vasculitis Foundation has been contacted by patients in Argentina, Australia, Bangladesh, Belgium, Bolivia, Brazil, Brunei, Canada, Chile, China, Columbia, Croatia, Cyprus, Denmark, El Salvador, England, Finland, France, French W. Indies, Germany, Greece, Iceland, India, Indonesia, Iran, Ireland, Israel, Italy, Japan, Kuwait, Latvia, Lithuania, Mexico, N. Ireland, Netherlands, New Zealand, Norway, Pakistan, Peru, Romania, Russia, S. Africa, Scotland, Sicily, S. Korea, Spain, Sweden, Switzerland, Syria, Turkey, Venezuela, W. Indies, and all the United States of America.

“Sample” Letter to the Editor

Most media outlets have websites and you can send emails directly to the editor/reporters. Many newspapers and television stations have designated health or science writers. Address the letter to someone specifically; this will help if/when you need to follow-up to see if they are going to do an interview. Names can be found on the websites or by calling the media outlets. Please contact the VF office if you need to know how many patients live in your area or need additional medical information.

The following sample letter can be sent to all local media outlets (newspapers, radio and television stations). Please request a **human interest article/segment** about your vasculitis disease.

Date
Editor's Name
Name of Newspaper/Radio Station/Television Station
Street Address
City, State, Zip Code

Dear Editor:

I was diagnosed with: fill in type of Vasculitis, a rare vasculitis disease, in fill in the year. Fill in disease is a chronic, autoimmune, vasculitis disease that affects people of all ages. There are over 20 different types of Vasculitis, all considered rare. Although the diseases are similar in some ways, they often differ with respect to which organs are affected.

Tell personal story here: How the disease has affected you, (i.e. lung involvement, kidney involvement etc.), how long it took to get diagnosed, how you cope with the disease, where you find your strength etc.

On (Date), we plan to hold a (Name of Event). Our goal is to raise awareness of the disease in the general public and medical community. Early diagnosis and effective treatment is key to preventing permanent organ damage, chronic conditions and loss of life.

The Vasculitis Foundation (VF) is an international organization for patients with Vasculitis, family members, caregivers, and medical professionals. This non-profit group has over 4,000 members in 58 countries and offers support through: education, awareness and research.

For more information please call the VF at 1.800.277.9474 or visit the group's website: www.vasculitisfoundation.org.

Sincerely,
Your name, address, phone number, email

“Sample” Calendar Announcement

FOR IMMEDIATE RELEASE
Date

Contact: Joyce Kullman, Executive Director
Vasculitis Foundation
800.277.9474

VASCULITIS AWARENESS WEEK TO BE CELEBRATED May 3-9, 2009

WHAT: Vasculitis Awareness Week is an international effort organized by the Vasculitis Foundation to advance public awareness of this rare disease, as well as the progress in treatments and advances in research.

Vasculitic diseases include: Behcet’s disease, Buerger’s disease, Central Nervous System, Churg Strauss Syndrome, Cryoglobulinemia, Giant Cell Arteritis, Henoch-Schönlein Purpura, Hypersensitivity Vasculitis, Kawasaki disease, Microscopic polyangiitis, Polyarteritis nodosa, Polymyalgia rheumatica, Rheumatoid vasculitis, Takayasu’s arteritis, and Wegener’s granulomatosis.

WHEN: May 3-9, 2009

WHERE: Awareness events to take place throughout the world.

WHO: The Vasculitis Foundation is an international non-profit organization with over 4,000 members in 58 countries. The group provides educational materials for patients with vasculitis, their caregivers, family members and medical professionals. The VF also encourages and supports research into the cause, cure and treatment of vasculitis. For more information, please call 1.800.277.9474 or visit the organization’s website: www.vasculitisfoundation.org.

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“Sample” Press Release

FOR IMMEDIATE RELEASE

Date

Contact: Joyce Kullman, Executive Director
Vasculitis Foundation
800.277.9474

(KANSAS CITY, MISSOURI): A name of event for the Vasculitis Foundation will be held: fill in the date & time. Registration starts at: fill in time. The name of event is being held to raise awareness of: fill in your disease, an uncommon autoimmune vasculitis disease. Donations will benefit the Vasculitis Foundation, which offers support to patients with vasculitis as well as funds research.

(If you are holding the event in honor or memory of someone, please provide a brief description – i.e. The event is in honor of Sara Doe, who was diagnosed with Wegener’s in 1999.)

Additional information, registration and pledge forms are available by contacting:
(give your name, email and phone number).

Vasculitis diseases are chronic, autoimmune diseases. There are approximately 15 different disorders that are classified as “vasculitis”. Although the diseases are similar in some ways, they often differ with respect to which organs are affected, which medications are used to treat them, and other characteristics.

The symptoms of vasculitis depend on the particular blood vessels that are involved by the inflammatory process. Different types of vasculitis involve blood vessels in characteristic locations throughout the body.

Because vasculitis is caused in part by an overly active immune system, the treatment usually involves the use of medications that suppress parts of the immune system. All of the medications have a long list of possible side effects.

The Vasculitis Foundation is an international non-profit organization with over 4,000 members in 58 countries. The group provides educational materials for patients with vasculitis, their caregivers, family members and medical professionals. The VF also encourages and supports research into the cause, cure and treatment of vasculitis. For more information, please call 1.800.277.9474 or visit the organization’s website: www.vasculitisfoundation.org.

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“Sample” Proclamation

Please contact your city mayor or state governor and ask them to issue a proclamation to honor the 2009 Vasculitis Awareness Week.

(Office of the Name of the government entity)

Proclamation

WHEREAS, Vasculitis is an uncommon, chronic, autoimmune illness; and

WHEREAS, the early, correct diagnosis of Vasculitis is very important for successful disease treatment; and

WHEREAS, Vasculitis Disease drastically affects the lives of its victims each year; and

WHEREAS, raising awareness in the general public and medical community will highlight the need for better treatments and research into the cause and cure of all Vasculitis Diseases including:

Behcet's Disease
Central Nervous System Vasculitis
Cryoglobulinemia
Henoch-Schönlein Purpura
Kawasaki Disease
Polyarteritis Nodosa
Rheumatoid Vasculitis
Wegener's Granulomatosis

Buerger's Disease
Churg–Strauss Syndrome
Giant Cell Arteritis
Hypersensitivity Vasculitis
Microscopic Polyangiitis
Polymyalgia Rheumatica
Takayasu's Arteritis

WHEREAS, the Vasculitis Foundation, a worldwide, health support organization, has headquarters in Kansas City, Missouri:

NOW, THEREFORE, I name of official, title of official, name of government, do hereby proclaim May 3-9, 2009 as

Vasculitis Awareness Week

IN TESTIMONY WHEREOF, I have hereunto set my hand and caused to be affixed the Great Seal of the name of government entity, location of entity and the date.

Signature of Official: _____ Date: _____

Awareness Week Poster



Vasculitis Awareness Week May 3 - 9, 2009

Vasculitis is an inflammation of the blood vessels, arteries, veins or capillaries. When such inflammation occurs, it causes changes in the walls of blood vessels, such as weakening or narrowing that can progress to the point of blood vessel blockage.

Members of the vasculitis family include:

Behcet's disease	Buerger's disease	Central Nervous System
Churg Strauss Syndrome	Cryoglobulinemia	Giant Cell Arteritis
Henoch-Schönlein Purpura	Hypersensitivity Vasculitis	Kawasaki disease
Microscopic polyangiitis	Polyarteritis nodosa	Polymyalgia rheumatica
Rheumatoid vasculitis	Takayasu's arteritis	Wegener's granulomatosis

Symptoms include:

Abdominal pain/Gastrointestinal bleeding; Asthma; Atypical severe headaches; Chronic sinusitis/Nasal allergies; Cough/Shortness of breath; Fatigue/Weakness; Fever; Joint pain/Facial soreness; Kidney problems (bloody urine, dark urine); Lung inflammation; Nerve problems (numbness, weakness, pain); Skin lesions/Rashes; Vision changes

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