



Fundraising and Awareness Event Planning Handbook

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Handbook Overview

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.

The Vasculitis Foundation relies heavily on our volunteers to organize and participate in chapter events, act as local area contacts, and organize events. We encourage our members to host events to:

- raise awareness of vasculitis in your local community
- raise funds for our education, awareness and research programs
- **educate the public about the Foundation's mission**
- honor or memorialize a family member or friend

This handbook provides some history of the VF's fundraising events. More importantly, you will receive tips on how to plan and organize your event, and will know how the VF office can support you. We are here to assist in your efforts!

History of Our Fundraising Events

In 1999, Nancy Olona organized the VF's first fundraiser, the *Colorado Fun Run*, in honor of her niece, Jessica, who was diagnosed with a form of vasculitis at the age of six that year. The goal of the Run was to raise awareness of vasculitis and to raise funds for the VF.

Nancy invited her family, friends and co-workers to join her for a Fun Walk/Run at a local city park that has a trail circling a beautiful lake. Participants gathered pledges ahead of time. Local businesses donated door prizes and local restaurants donated all the food and drinks. A clown even donated her services.

The group gathered on a Saturday morning wearing event t-shirts and sporting helium-filled yellow balloons. They set out on the trail, some walking, some running, and others pushing strollers. After the walk, attendees enjoyed food and drinks, the clown performed and the kids had the opportunity to have their faces painted. Everyone had a great time and the event raised more than \$12,000.

Since this inaugural event, members have hosted many events and raised thousands of dollars for the VF.

VF Event Guidelines and Application

This information is designed to help you plan and carry out a fundraising event or promotion to benefit the VF. Please note that all fundraising activities that involve the use of the VF's name MUST BE REVIEWED AND APPROVED IN ADVANCE.

1. **A Fundraising and Awareness Event Application and the Preliminary Budget Form must be completed and submitted to the Vasculitis Foundation no less than four weeks prior to the proposed fundraising activity. Applicants must reapply annually for approval. Please submit to: Vasculitis Foundation, P.O. Box 28660, Kansas City, Missouri 64188, or via email at: vf@vasculitisfoundation.org or jblankenship@vasculitisfoundation.org**
2. **All publicity must be approved by the Vasculitis Foundation prior to distribution. Publicity that includes the VF's logo, must adhere to the style guide for usage of the logo.** Copies of publicity may be submitted to: Vasculitis Foundation, P.O. Box 28660, Kansas City, Missouri 64188, or via email at: vf@vasculitisfoundation.org or jblankenship@vasculitisfoundation.org
3. The public should be informed how the VF will benefit from the event or promotion. If the Foundation will not receive all of the proceeds, then the percentage that benefits the Foundation should be clearly stated on all materials.
4. If entering into contracts or service agreements, please submit to the VF for review. The VF's legal counsel reserves the right to review all related agreements prior to signing on behalf of the Foundation.
5. Vasculitis Foundation and all related individuals and entities are not liable for any injuries sustained by event volunteers or participants related to an event benefiting the Foundation. **Please see Page 23 for the Waiver and Release of Liability Form that all participants should sign.**
6. **Proceeds should be remitted to the Foundation within 1 week of the date of the event and final remittance should be within 30 days of the event.** Please do not send cash in the mail. Provide a complete record of all donations including name/address and pledge amounts for thank you notes and tax deductions.
7. **If you are hosting an event to support a patient's medical expenses, please refer to Page 15 for the VF Patient Proceed Event Policy.**

The VF Can Help You With Your Event

- Provide a letter of authorization to validate the authenticity of the event and its organizers
- Provide tax receipts to donors who make checks payable to the Vasculitis Foundation or who make online donations
- Offer event planning training to organizers
- Help with the design and mail your event invitation/flyer
- Assist/write your news release and assist with contacting your local media
- Assist/write a corporate sponsorship proposal
- Set up your event page on the VF Web site, which provides an opportunity for you to blog about your event
- We can assist you by providing the following, should you need them.
 - Pledge/registration forms
 - Balloons
 - Tote/plastic bags
 - T-shirts
 - Vasculitis Foundation brochures
 - 501(c)(3) non-profit letter and tax-exempt form
 - Event liability insurance
 - Membership list for your geographical area
 - Thank-you letters to donors and volunteers
 - Save-the-date postcards
 - Waiver and Release of Liability Forms

Planning and Organizing an Event

This section gives you useful and practical tips to better organize your event and have a great time hosting it.

Best practices and suggestions for planning and organizing include:

- Consider an activity that you would enjoy planning.
- Plan ahead to make sure it goes smoothly.
- Set up a committee and create a master task list.
- Work with the VF office to set and follow an event budget.
- Set and follow an event planning timeline.
- Ask friends and family to help implement the event.
- Work with the VF office to coordinate flyers, mailings, etc.
- Increase your revenues by soliciting sponsorships from local businesses.
- Announce the event in local publications.
- Promote the Foundation's mission at every opportunity.
- Have FUN !

In the planning process, it is critical to plan ahead when organizing an event. Here are the essential steps to a well-organized, successful event:

Six Months to a Year Prior to Event

Establish your objectives -- What do you want your event to accomplish?

- Raise awareness of vasculitis in your local community
- Raise funds for the VF's education/awareness/research programs
- Bring together your local support group, family, and friends for an activity
- Honor or memorialize a family member or friend

Decide on the type of event you want to hold and how you want to raise awareness and funds.

There are a lot of great ideas for events that are interesting and fun. Not only do you raise funds for the VF but you also raise awareness in your community.

Things to consider when selecting the type of event:

- How much time can you invest in organizing the event?
- Who is your target audience?
- What type of event will attract a lot of interest in your area?

Examples of events to consider:

Bowling Tournament	Dinner Party
Spaghetti Dinner	Jewelry Party
Golf Tournament	Online Golf Tournament
Motorcycle Group Ride	Scrap Booking Event/Party
Recycling Project	Swim-A-Thon
Walk/Run	Basketball Tournament
Tennis Tournament	Individual Walk
Restaurant Sponsor Day	Vegas Night
Scratch Cards	Department Store Promotion
Pet Photo Contest	Car Wash
Bake Sale	Garage Sale
Lemonade Stand	Read-A-Thon
Craft Sale	Dress Down Day (at the office)
Pet Walk or Parade	Silent Auction
House Party	Barbeque
Book Sale	Workshop/Class
Bingo Party	Art Show
Tribute Luncheon/Dinner	Fashion Show

Pick your location, date and time. Check your local school and community calendars for other events. If you plan to invite the public, pick a weekend when there are not a lot of other events. (Don't forget to list your event on these calendars.) Choose a location that is easy to find (well-known city, county or state park, walking trail, school track, etc.); make sure there are bathroom facilities.

- Check to see if reservations and/or permits are required at the location (most places require reservations). Keep copies of all your paperwork.
- Ask if deposits are required. If a deposit is required, contact the VF office to coordinate payment. Do not sign any contracts prior to contacting the VF office. After speaking with the office, complete the appropriate paperwork and send a copy to the VF office. The office will write the check to the facility and mail it directly with the paperwork. The office will send a copy to the event organizer.
- **Ask if sales tax is exempt since the Foundation is a non-profit 501(c)(3) organization.**
- Ask if liability insurance is required. If a certificate of insurance is required, please contact the VF office immediately and ask to have one ordered. The certificate can only be issued within 30 days of the event but takes a minimum of 14-working days to process.
- Contact our office and provide the details of the event so we can help you prepare and publish the event on our website.
- Make sure you have a **rain date or a bad-weather plan** just in case. Make sure you have an easy way for people to find out if the event is cancelled for the day, such as a call-in number.

One to Six Months Prior to Event

Determine the format of the event including a detailed schedule of activities. **For example**, for Walk/Run events decide how long the course will be (keep the trail between 1 – 3 miles), or decide on a timeframe, (i.e., 9:00 a.m. to 12:00 noon). Have a clear start and clear end time. Some things to consider for any type of event are:

- Do you need to arrive early to set up for the event?
- Do people need to arrive early to register?
- What are all of the things you need to bring (signs, nametags, etc.)?
- Will you have an awards ceremony? Do you need prizes? Who will judge the awards?
- **City permits needed for use of streets?**
- **Decorations?**
- **Audio Visual?**
- **Entertainment?**
- **Flowers?**
- **Refreshments?**
- **Meals?**
- **Security?**
- **Power/heat/lights/air conditioning needed:**

Plan out a detailed timeline to make sure you have enough time for all of the events.

Make a list of sponsorship opportunities available.

Invite the participants and generate publicity. Some ideas include:

- Contact local members of the Vasculitis Foundation
- Invite your friends and family members
- Tell your co-workers about your efforts
- Ask the VF office if a Board, or staff, member is available
- Notify the general public
- Contact local media, (TV, radio and newspaper) and ask them to attend
- Ask the local media to interview you prior to the event for added publicity

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 – 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 his/her 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. **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.**

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

1. 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: **You can find names for these contacts by calling the publications or by going to www.newspaperlinks.com, which offer free links to every newspaper by city.**
2. **Are you pitching your story to the right person?** When pitching a story about your event 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.
3. **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.
4. **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 – May 3, 2009.
5. **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.
6. **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.
7. **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.

Assemble your event team and make sure you have enough help to set-up, run the event, and clean-up.

- Recruit your family, friends and co-workers to help with the event.
- Contact college and high school service clubs and groups to provide volunteers; their help may be considered a community service credit.
- Create committees that could include:
 - publicity/advertising: ask local media to put you on their calendars of events (this coverage is usually free for non-profit events)
 - set-up
 - registration (This often takes a lot of planning. It is also the first impression of the event for participants.)
 - refreshments
 - entertainment
 - clean-up
- **Have regular committee meetings**

Find sponsors and solicit donations of goods, services, and funds. Organizers are encouraged to solicit as many donations as possible to help defray the cost of the event. Donations include funds to underwrite the event, food and drink for the event, door prizes, or services such as music or entertainment.

Some ideas to help:

- Consider what amount of underwriting it would take to name the event for the sponsor, i.e., Bank XYZ presents the Vasculitis Walk for Health. The VF office can help you put together a proposal package with appropriate benefits for the sponsor.
- Consider other levels of sponsorship; have a presentation package ready with levels when you meet with potential funders; include photos from past events and publicity if you have it.
- Keep a scrapbook of each event to use for promotional purposes so sponsors can see what they will get (if it's possible to include children and/or dogs in the event such as a walk, consider it; children and dogs are great attention getters).

Things that could be donated to the event include:

- refreshments and food
- entertainment (bands, disc jockeys, clowns, face-painting artists, etc.)
- printing (flyers, nametags, posters, etc.)
- venue
- door prizes/drawing prizes
- auction items

Places to contact include:

- Check with grocery stores, bagel and pizza shops, bakeries, etc. to see if they will donate water, ice, and/or juice, fruit, bagels, cookies and chips. McDonalds is a good source for cold drinks in large coolers. People like to be fed!!!
- Wal-Mart, Kmart, Target and other retail stores will sometimes provide gift cards to buy supplies (paper goods, plastic ware, certificates, nametags, etc.). Go to the customer service desk and ask to speak to a manager, and then explain what you are doing.
- Visit local merchants, stores and businesses that you and your event team members frequent and ask them to donate to the event.
 - One member asked the convenience store where she stops every morning for coffee to donate the ice for her event; they said yes.
- Contact a local printer and ask if they will print your event flyers free of charge or at a discounted rate. Offer to add their logo to the bottom of the flyer.
- Local movie theaters will usually donate movie tickets for you to give away as door prizes, or in a drawing.
- Restaurants will often donate gift certificates.
- Don't forget to ask your smaller, local retail stores. They are usually very community-minded – and you won't have to go through some big corporate office.
- Ask your company to donate. And remember, company matching gifts can double your fundraising dollars!

IMPORTANT NOTES:

1. Most stores and businesses require proof of the VF's non-profit status. Please contact the VF office (800.277.9474) to receive a copy of our non-profit 501 (c)(3) tax-exempt letter mailed to you.

2. Please keep a detailed list of ALL sponsors and donors. The office can send thank you notes to all sponsors and donors. You may want to personally thank supporters and/or send notes as well.

Register participants and continue to generate publicity:

- Make a list of people (w/addresses and/or emails) you want to invite.
- Make sure you have registration and pledge forms (the office can provide these).
- Consider making **save the date** cards, or send a save the date email.
- Mail and hand-deliver event flyers to family, friends and co-workers. The VF office can help with mailing the flyers to area members.
- If the event is open to the public, place an announcement in the local newspaper and on the local cable television community calendar. Post on the running club website calendars. (Drop off event flyers at other running events prior to your event. There is usually a table where flyers can be displayed.) Send flyers to local running shoe stores; they usually have bulletin boards where they post upcoming races.
- Send out registration and pledge forms one month prior to the event (not too soon, so people forget about it – but enough time for them to get pledges). Encourage people to register by mail. Ask the VF to send you a list of members in your area.
- Post event flyers in local stores.
- Make sure ALL your doctors know about the event.
 - Invite them and their staff to participate AND donate.
 - If appropriate, ask them to give a short talk on vasculitis.

One Month Prior to Event

- Get supplies from VF office. VF will provide brochures, t-shirts, water bottles, tote bags, drawing tickets and balloons for most events (order in advance; items ordered less than three weeks prior to event cannot be guaranteed).

One Week Prior to Event

- Call the event location and reconfirm reservations and review details with the coordinator.
- Contact event team members and review game plan.
- Contact local media (TV, radio and newspaper) and ask again for them to cover the event.
- Send out a group email to all registered participants and others to remind them of event.

One Day Prior to Event

- Organize supplies:
 - water, ice, bagels, juice, bananas (or other items)
 - coolers for water, ice, juice
 - trays for bagels, bananas (or other food)
 - picnic tablecloths
 - trash bags
 - cash box
- Send out a group email to all participants to remind them of the event.
- Rally your event team – does everyone have an assignment and KNOW their assignment?

Day of the Event

- Arrive at the location **at least** two hours early.
- Put up VF event signs where needed (balloons attached); make sure that people can easily find you from any direction.
- Set up check-in/registration tables.
- Set up music or entertainment.
- Prepare registrant bags (with t-shirts, water bottles and brochures).
- Blow up balloons/decorate.
- Collect pledge sheets and donations.
- Ask each registrant to sign **Waiver and Release of Liability Form** (Form may be found in the back of this book).
- Check each pledge sheet and confirm money amounts (checks must be made payable to the Vasculitis Foundation). Track cash donations carefully!
- Sell drawing tickets.

Don't forget to bring office supplies such as: tape, scissors, pens, pencils, calculator, paper, and notepads, **receipt book. etc.

Running Your Event

Finally, **run the event with energy and enthusiasm and have fun!**

Registration – think this through carefully so it is very organized. This is the participants' first and lasting impression!

- Everyone should be welcomed with a smile.
- If there is a parking area, station volunteers to greet and direct participants as they arrive.
- Use large signs (or balloons) to indicate where different activities take place.
- Train the volunteers and make sure they know their jobs. Be sure volunteers know what to do and that someone is available if there are questions.

Then, start the event!

- **HAVE FUN!**
- Take pictures.
- Give out door prizes and award prizes for event participants.
- Announce drawing winners.

Clean up – and pat yourself and your volunteers on the back – **GREAT JOB!!**

Within One Week After Your Event

- Remit all donations to VF (let VF know of any late pledges to be sent).
- Remit all cash donations via check or money order. Do NOT send cash.
- Provide complete record of all donations including name/addresses and pledge amounts.
- Provide list of sponsors who need to receive a thank you letter from VF. The VF office will mail thank you notes for all donations (must have complete name and mailing address). If you prefer to mail your own, please let us know. It is essential to thank the participants and let them know how much we appreciate their support.
- Provide list of event team members who need special thank you from VF.
- Thank your sponsors and let them know how the event went.
- Write a letter to your community newspaper thanking everyone for participating and thanking your sponsors and include a few sentences about vasculitis.
- Contact the VF office to let us know how you did. After your event, please send us information about how the event went so that we can include information in our newsletter and on our website. You can send along pictures too!

Be sure to **evaluate the event**. After your event, VF will send you an evaluation form to fill out concerning your fundraiser. This gives us much needed information as to what works in various locations. Please be sure to return it in the envelope provided.

- What worked?
- What didn't?
- Was your planning time sufficient?
- How can we improve upon the event next year?

Shortly after the event, for your own purposes, make a list of lessons that you learned.

Financial Guidelines

It is important that you track your donations according to our policy for fundraising events.

1. **TRACK ALL EXPENSES:** This will help when determining the tax- deductible amount of the donation. Please submit a complete list of expenses to the VF office.
2. **REASONABLE EXPENSES:** Only reasonable expenses will be reimbursed. A detailed expense record and all receipts must be submitted. Please contact the VF office if you have a question on whether an expense will be reimbursed **BEFORE** you buy it. Receipts are needed. Prior to making purchases please obtain a copy of the VF's tax-exempt form, so that you are not charged tax when making your purchases. Acceptable expenses include:
 - rental fee for location
 - postage
 - printing
 - envelopes
 - food/drink
3. **REMITTANCE OF MONIES:** Monies must be remitted to the VF within one week of the date of the event. A final remittance should be within 30 days of the event. Please provide as complete a list of donors, addresses, and amount of donations as possible.

Please don't hesitate to ask any questions about these financial guidelines.

PATIENT PROCEED EVENT POLICY

The Vasculitis Foundation understands that patients with vasculitis and their families often face medical bills and other expenses due to their diagnosis. Many family members and friends are interested in holding a fundraising event to benefit the patient. The VF encourages those interested in holding a patient proceed event to do so and suggests that prior to planning those involved consult an accountant to receive advice on setting up finances for the event.

As part of the VF's mission is to raise awareness about vasculitis, the organization is more than happy to provide VF brochures and disease information for attendees. Due to nonprofit tax law and the many requests for financial support or sponsorship, the VF is only able to provide support in the manner of print information. While we appreciate that some planners are interested in donating a portion of the proceeds to the VF, we believe it is in the best interest of the patient to retain 100% of the proceeds for medical bills and living expenses.

In addition, due to VF policies and nonprofit tax law, we are unable to accept a donation on behalf of a patient, as we do not currently have a grants program for patients.

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Forms and Samples Index

Fundraising and Event Application Form - *to be completed and returned to VF*

Preliminary Budget - *to be completed and returned to VF*

Checklist for Event Organizers

Vasculitis Fact Sheet

“Sample” Letter to the Editor

“Sample” Calendar Announcement

“Sample” Press Release

Waiver & Release of Liability Form

Event Evaluation Form - *to be completed and returned to VF*

FUNDRAISING AND EVENT APPLICATION

Please complete and return to VF

Contact Information and Assurance:

Contact Name: _____

Street Address: _____

City: _____ State: _____ Zip: _____

Phone: _____ Email: _____

Fax: _____

I have read, understand, and agree to abide by the preceding guidelines for fundraising events to benefit the Vasculitis Foundation.

Signature

Date

Event Information:

Date and Time of Proposed Event: _____

Name of Proposed Event: _____

Name of Location: _____

Address of Location: _____

Projected Attendance: _____

Briefly explain how funds will be raised (ticket sales, pledges, sponsorship, auction, etc.):

Does the event require insurance? Yes No (circle one)

If yes, name of contact person to receive proof of insurance: _____

Contact's fax number or mailing address: _____

Are there any other beneficiaries of this event? Yes No (circle one)

If yes, please list the other organization(s)/individual(s):

Proceeds are to be split as follows (insert percentage):

_____ awareness/patient support _____ research

(Please note that in order for the Foundation to accomplish its mission in supporting and empowering patients through education, awareness and research, at the very least, a portion of the event proceeds for awareness and patient support is crucial).

Basic Checklist for Event Organizers

- Submit the Fundraising and Event Application to the VF
- Submit the Preliminary Budget Proposal to the VF
- Recruit volunteers and assign tasks
- Keep VF informed regarding any changes for any updates that are needed for web page
- Create timeline to accomplish all tasks
- Secure facility and any contractors needed
- Submit contracts to VF for approval
- Generate publicity
- Solicit sponsorships
- Order supplies needed from VF
- Gather items needed
- Showtime -- Have FUN
- Have each participant sign a Waiver and Release of Liability Form
- Send all monies and financial information to VF
- Complete Event Evaluation Form and return to VF

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 Wegener's and other 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 hundreds 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.

The week of May 3-9, 2009, has been designated as Vasculitis Awareness Week. 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

(Event) to be held (Date)

WHAT: (Describe the event) Donations will benefit the Vasculitis Foundation, which offers support to patients with vasculitis as well as funds research.

WHEN: (Date and time)

WHERE: (Location)

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

(Name of City): A (name of event) for the Vasculitis Foundation will be held: (date & time). Registration starts at: (time). The 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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WAIVER AND RELEASE OF LIABILITY

I, _____, am a willing participant in a fundraising and awareness event in honor of the Vasculitis Foundation and the patients, family members, and the medical community it supports.

As part of this event I agree to assume all risks and to release and hold harmless the Vasculitis Foundation, its officers, employees, agents, sponsors, officials and volunteers, including walk leaders.

I intend by this Waiver and Release to release, in advance, and to waive my rights and discharge all of the persons and entities mentioned above, from any and all claims for damages for death, personal injury or property damage which I may have, or which may hereafter occur to me as a result of my participation in the event. I understand and agree that this Waiver and Release is binding on my heirs and legal representatives.

I understand that I am solely responsible for my health and safety, and I acknowledge that I am physically capable of participating in and completing this event.

I agree to allow the Vasculitis Foundation the use of my name and likeness (event photos) for any purpose related to advertising or promotion of the event worldwide and in perpetuity.

I have carefully read this Waiver and Release and fully understand its contents. If I am under the age of 18 years of age at the time of registration, my parent or legal guardian has completely reviewed this Waiver and Release, understand and consents to its terms, and authorizes my participation by his/her signature below. I am aware that this is a RELEASE OF LIABILITY and a contract between me and the persons and entities mentioned above and I sign of my own free will.

Signature: _____ Date: _____

Printed Name: _____

Signature of parent or guardian if participant is under 18 years of age.

Parent Signature: _____ Date: _____

Printed Name: _____

Publicity/Marketing:

Did the VF office produce a flyer/invitation for you? Yes _____ No _____

Did the VF office mail flyers/invitations for you? Yes _____ No _____

Did you mail event flyers/invitations yourself? Yes _____ No _____ How many? _____

If not, how did you spread the word about the event?

Did you submit a News Release to local media? Yes _____ No _____

Did you submit photos to the media? Yes _____ No _____

What other advertising did you do?

Please list any media that covered the event:

If possible, please mail a copy of any print media related to your event to the VF office.

Financial/Budget:

Did you collect registration fees? Amount: \$ _____

Did you collect pledges? Amount: \$ _____

Did you collect drawing/auction money? Amount: \$ _____

Other money collected? Amount: \$ _____

Total amount raised: \$ _____