

Community Fundraising Kit

Making it easy to support the IPPF

5/1/2012

International Pemphigus Pemphigoid Foundation

Introduction

Thank you for your interest in raising funds to support the International Pemphigus Pemphigoid Foundation (IPPF). As a patient-driven organization, our success depends on the initiative of supporters like you. Each dollar that you raise will help the IPPF increase patient support programs, accelerate research, and provide vital information to pemphigus/pemphigoid patients and their families. We are grateful for your desire to help, and look forward to working with you to bring closer the day when people will no longer suffer from these brutal diseases.

Whether you've hosted fundraising events in the past or are new to fundraising, this **Community Fundraising Kit** is designed to help you effectively raise money and awareness for the IPPF. **We ask that you carefully review this document as it contains important legal and accounting guidelines that are necessary to follow when raising money on behalf of the IPPF.**

The IPPF has the extraordinary privilege of being recognized by the Internal Revenue Service (IRS) as a tax-exempt charitable organization; this tax exempt status is crucial for our ability to carry out our mission. In order to preserve this status, it is essential that you comply with the various IRS regulations described in this document regarding nonprofit fundraising activities.

We are here to help make your event as easy and successful as possible. If you have any questions, or if there is anything we can do to support your efforts, please don't hesitate to contact us.

Fundraiser Contact:

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Planning Your Event

Step 1: Contact the IPPF

The sooner you get in touch with us, the better we will be able to assist you as you begin planning your event! We can answer questions, provide materials, connect you with someone who has organized an event before and help publicize your event. Also, it helps for us to know if you are collaborating, or co-hosting this event with another organization, as they may require additional documentation from the IPPF.

Please contact us to notify us about your event.

Step 2: Plan Your Event

- 1) **Choose your event.** Decide which type is best for you based on your resources, time frame and fundraising goals. Look through the suggestions offered in the appendix or come up with an idea of your own.
- 2) **We strongly encourage you to organize an event committee.** Choose your committee members wisely. You may need:
 - a) **Bookkeeper** to document all income and expenses
 - b) **Volunteer chairperson** to recruit and organize volunteers for the day of your event
 - c) **Publicity chairperson** who will contact radio and TV stations
 - d) **Printing chairperson** to have brochures, signs, T-shirts, etc. printed
 - e) **Sponsorship chairperson** to recruit corporate sponsors, to get auction items donated, to follow up with confirmation letters, etc. You'll need someone in this position who can network and who isn't afraid to ASK

Why form an event committee? Events can take a lot of effort. By forming a committee, or team, you can share the work of planning, coordinating and executing your event. By making these decisions early, you help give everyone involved an idea of what you expect from their participation.

Who should you ask to join the event committee? We suggest gathering a group of family and friends whom you can trust and depend on. Ideally you should try and organize your committee with real “go-getters.” This is also a great opportunity to involve those family members and friends who always ask, “What can I do to help?”

- 3) **Create a timeline.** Once you have determined who will be on your event committee, organize a kick-off meeting to set a date, create a timeline and delegate tasks. Try to think of everything that needs to be done to make this event happen. You may need as long as 10-12 months to plan your event.
- 4) **Reserve a location.** Consider the space you will need, activities that will be held, the weather and anything else that could restrict the venue of your event. Begin buying supplies and reserving any vendors you need as well.
- 5) **Obtain necessary and appropriate licenses, permits, and insurance.** For your protection and peace of mind, we encourage you to obtain event insurance appropriate for the size and nature of the event. Event insurance can protect you against loss due to cancellation or postponement, and against financial liability that could arise from your event. Event insurance is required by many venues. Here are some resources to assist with obtaining event insurance:
 - www.nasep.org/insurance-apply-now.jsp
 - www.privateeventinsurance.com
 - www.insureaparty.com
 - www.csicoverage.com

We recommend that alcohol not be served unless it is believed to be necessary to the success of the event. If alcohol will be served, you are responsible for obtaining insurance, permits and licenses that may be required by your state. Check with the venue about policies for hosting events where alcoholic beverages will be served.

Depending on your state, if you are selling products or conducting certain types of events, such as a raffle, bingo, or games of chance, you might need to obtain an appropriate permit or sales tax license. The National Association of State Charity Officials provides a directory of state agencies responsible for regulating such activities: www.nasconet.org/agencies

It is important to know that bingo, raffles, sweepstakes and other gaming activities are not considered charitable activities under federal, and most state, laws. Therefore, fees paid to participate in gaming fundraisers are not tax deductible. There are also federal reporting requirements concerning gaming fundraisers. See IRS Publication 3079: www.irs.gov/pub/irs-pdf/p3079.pdf.

- 6) **Recruit sponsors.** Ask corporations, restaurants, local vendors, individuals and anyone else you can think of. Ask for in-kind (goods and services) as well as monetary donations.
- 7) **Enlist volunteers** for the day of the event from local high schools, your neighborhood, area youth groups, churches, etc.

Step 3: Gather Materials

Materials from the Foundation: The IPPF is happy to provide you with materials for your event to help teach people about our work as well as provide participants with more information about pemphigus and pemphigoid. Here is a list of some of the materials that can be made available to you. Please call us to discuss specific needs that you have for your event.

- Brochures
- Fact Sheets
- Banners or signs
- “Support” Bracelets

Step 4: Publicize Your Event

When you organize a fundraising event, you have a unique opportunity to garner media attention. The effective use of free media opportunities gives you the chance to raise awareness about pemphigus and pemphigoid within your community and to call attention to the importance of raising funds for research.

For information about how to contact various media outlets and tips for talking about pemphigus and pemphigoid and the IPPF, please refer to the **Media Relations** section of this document

The IPPF logo may be used on marketing and event materials only with permission from the IPPF. In order to use the logo, please fill out the **Third-Party Fundraiser Agreement** found in the appendix and return it to us. Once we receive this document, electronic copies of the logo will be e-mailed to you.

Please refer to the **Fundraising Policies** section to insure compliance with the IPPF policies on promotion and publicity.

Step 5: Collect Donations

Event organizers have three options for accepting donations. Before selecting the option that's right for your event, please carefully consider the implications of each option on you and your donors.

Option 1

- Each event participant pays a registration fee (i.e. meal tickets or golf fees) directly to the event organizer to cover expenses, AND makes a second payment via check or credit card to the International Pemphigus Pemphigoid Foundation or IPPF as a tax-deductible donation.
- Event participants receive a letter from the IPPF indicating the tax-deductible portion of their donation, which is equal to the amount of their payment to the IPPF.
- Event organizer pays for event expenses with registration fees that they have collected from event participants and/or sponsors.

Option 2

- Each event participant writes a single check payable to the International Pemphigus Pemphigoid Foundation (IPPF) or donates online at www.pemphigus.org/donate.
- The event organizer records the value of any goods and/or services received by each participant, and sends this information, along with all collected checks, to the IPPF.
- Each participant receives a tax receipt from the **IPPF only for the tax-deductible portion of their payment**, which is the amount of the payment above and beyond the value of any goods or services received in exchange for the donation. *(For example: a gala participant writes a check for \$100 to the IPPF and the value of the dinner is \$40; then the donor receives a letter acknowledging their \$60 tax deductible contribution.)*
- Event organizer pays for all expenses through sponsorships and in-kind donations that they have collected.

If you choose Option 1 or 2, please have donors put the name of your event in the memo line of their checks, so that we know these payments are linked to your event.

Option 3

- Event participants make a cash, check or credit card payment directly to the event organizer.
- Event participants do not receive a tax receipt from the IPPF.
- Event organizer pays for event expenses with event revenue and sends net proceeds (revenue minus expenses) to the IPPF.

If you choose Option 3, it may be helpful for you to set up a separate bank account, or a subaccount within your personal account, in order to keep money that you raise segregated from your personal funds. Please send one check with net proceeds from this account to the International Pemphigus Pemphigoid Foundation (IPPF). Note: this payment is not tax deductible. Also submit a detailed report of expenses.

PLEASE NOTE

In order for donors to receive a tax receipt from the International Pemphigus Pemphigoid Foundation they must make a payment by check or credit card directly to the International Pemphigus Pemphigoid Foundation or IPPF. The IPPF CANNOT issue a tax receipt for payments made to the event organizer or any other organization. That means that if you decide to accept payments directly from event participants (Option 3) they will not receive a tax receipt from the IPPF. ***This must be clearly communicated to event participants.***

All bills and expenses are the responsibility of the event organizer. The IPPF CANNOT, under any circumstances, reimburse event organizers for any expenses.

What to do with cash donations. If you receive cash donations, please go to your local bank and get a bank check (issued to International Pemphigus Pemphigoid Foundation), or a money order for the total cash amount. Then, mail it to the IPPF offices.

Please refer to the **Fundraising Policies** section of this document in order to insure that all funds are handled in compliance with the IRS and International Pemphigus Pemphigoid Foundation policies.

Step 6: Submit Donations and Reports

Within 15 days after your event:

- 1) Send all checks via certified US Postal mail (with tracking) to:

The International Pemphigus Pemphigoid Foundation (or IPPF)
1331 Garden Highway #100
Sacramento CA 95833

- 2) Email the following to events@pemphigus.org:

- a) An spreadsheet (Excel, Google Docs, Open Office, etc.) containing the following information:
(NOTE: An example **Template for Third Party Fundraiser Donations** found in the appendix and available for download)

- (1) Contact information of event attendees, donors, and sponsors, including any individual or corporations who made in-kind (i.e., non-cash) contributions.
- (2) The type and amount of all donations or sponsorships, whether cash or in-kind
- (3) A description and estimated fair market value of any goods and/or services received by each donor. *(e.g. if you are conducting an auction we must know the fair-market value and auctioned price of each item purchased, so that we can provide accurate tax receipts)*

- 3) At your earliest convenience, please email or mail us the following:

- a) A brief summary of your event, including anything notable that happened, and any lessons learned so that we can share this knowledge with future event organizers.
- b) A final sample of marketing materials, tickets, invitations, checklists, programs, or anything else we can use as a model to help future fundraisers.
- c) Pictures! We'd love to showcase your successful fundraiser in our newsletter, website, at the IPPF Annual Meeting, and beyond, so please send any pictures you'd like to share, especially group pictures.

Step 7: Send Thank You Notes

We believe it is important to acknowledge the generosity of all donors in a timely manner. We will send a tax receipt to all donors who make payments directly to the IPPF. Donors should receive their tax receipt within 2 to 4 weeks of the date that the IPPF receives the donation depending on the time of year and the volume of donors.

In addition, we encourage you to send a personal “thank you” note to all donors, event participants, sponsors and volunteers, as your note will have more personal meaning... In your note you may want to include a sentence that states, “Keep an eye out for your official tax receipt in the mail from the IPPF.”

Fundraising Policies

A “Third-Party Event” is defined as any fundraising activity conducted by a group or individual that is not employed by the International Pemphigus Pemphigoid Foundation and where the IPPF has no fiduciary responsibility and little or no staff involvement in its execution. These policies pertain to all events or activities benefiting the IPPF that are organized and executed by third parties.

Organizer Responsibilities

- 1) All expenses are the responsibility of the event organizer. The IPPF is not responsible for any expenses incurred for a third-party fundraising activity, and will not advance funds or reimburse expenses. We recommend finding event sponsors or charging a registration fee to help cover expenses. You may not purchase goods or services under the IPPF’s name, and the IPPF sales tax-exemption (on purchases) cannot be extended to any third-party event or fundraising effort.
- 2) The event organizer is responsible for the planning and execution of the event including safety precautions and adherence to applicable laws. As the beneficiary of a fundraising event, the IPPF does not accept or assume any liability associated with the event including but not limited to any injuries sustained by event volunteers or participants during the event. The event organizer will indemnify, defend, and hold harmless the IPPF, its directors, officers, and employees from any and all claims that may arise out of or relate to such event.
- 3) The event organizer is responsible for obtaining all applicable permits or licenses, including but not limited to alcohol, solicitation, and sales tax licenses.

Promotion & Publicity

- All third party events must be publicized and conducted in a manner that makes it clear that the IPPF is the beneficiary, not the sponsor or host of the event.
- Promotional materials must clearly state that the event is raising funds that will benefit the IPPF (e.g. “proceeds benefit the IPPF”).
- Event names may not incorporate the name of the IPPF, as in “The IPPF Walk-a-thon.” The IPPF’s name may be used in a second clause identifying the relationship of the event with the Foundation, such as “John Doe Walk-a-thon, benefitting the IPPF.”
- All event materials that include the IPPF’s logo, including, but not limited to, advertising, press releases, posters, flyers, tee-shirts and public service announcements, must be reviewed and approved prior to distribution.

Financial Policies

- The event organizer may not keep any portion of the proceeds (beyond real expenses) as profit or compensation for organizing the event.

- The event organizer may not set up a temporary bank account in the IPPF's name as this is illegal.
- Donors must be informed that the tax deductible amount of a donation is only the amount that is over and above the value of any goods or services received in exchange for the donation. For example, if a participant pays \$200 to participate in a golf outing and the value of the outing is \$50, the donation amount is \$150. If a donor pays less than the value of an item then they will not receive a tax deduction.
- If goods are sold to raise money as part of a fundraising event it must be made clear to the event participants what percentage of the sale price benefits the IPPF.

Media Relations

You don't have to be a seasoned public relations professional or publicist to capture the attention of editors and reporters. However, you have a better chance of getting your event "covered" with some proven methods of generating media interest. It often takes lots of friendly follow-up and persistence to break through the clutter in a newsroom. Your biggest strength is your passion and enthusiasm for – and accurate knowledge of – the importance of raising pemphigus and pemphigoid research dollars.

Research: Know your Local Reporters and their Beats

As with any form of communications, know your audience. Before you send a pitch letter, press release, or pick up the phone, compile an accurate media list. Find the names of editors and reporters who report on related topics, such as community, health, or science-related topics. In other words, find out their beat. You can often find their contact information (phone, fax, email) and instructions for submitting a story idea to the publication as well.

Here are some reporters most likely to cover your story:

- Daily newspapers – Features Editor, Calendar Editor, Health Reporter, Metro Desk
- Weekly newspapers - Features Editor, Calendar Editor, Health Reporter, Metro Desk
- Television stations – Assignment Desk, News Desk or Health Reporter
- Radio news station – News Desk

Pitch: Tell your Story

A "pitch" is used to make an editor or a reporter take interest in your story. It can take the form of a one-page letter or a phone call. The two most important things to remember: keep it brief (it's a teaser) and give them a compelling reason why they should cover your story. For instance, why would your event or your personal story be of interest to their readers or viewers? Why are you hosting a fundraising event? At the end of the letter or conversation, offer to send them more information in the form of a press release. We have included a **Sample Pitch Letter** in the appendix to help you get started.

Talking Points

About the IPPF

The IPPF provides direct access to innovative and effective support that promotes the very best health care, improves quality of life, stimulates community resources, advocates for favorable government policies, accelerates the pace of scientific discovery and is the world's best source of information on pemphigus and pemphigoid. We are compassionate in understanding, tireless in service, and relentless in advocating. One person at a time, we make a difference, building a community of care and hope.

What the IPPF Does

- offers a physician referral service to help patients find the best medical care possible;
- provides a number of valuable and popular patient support services;
- publishes informational brochures, pamphlets and a quarterly newsletter with news, useful information, medical updates, personal stories and more;
- runs an annual Patient/Doctor meeting;
- collaborates with pharmaceutical companies on the leading edge of treating these diseases;
- provides up-to-date information about current clinical trials and research on the disease in which patients may be able to participate;
- maintains relationships with Congressional representatives and others who may be able to encourage or provide research funding.

About Pemphigus and Pemphigoid

Pemphigus is a group of rare autoimmune blistering diseases of the skin and/or mucous membranes. Pemphigus is chronic and progressive and characterized by blisters and ulcers on the skin and mucous membranes. The oral mucosa is often the first site of involvement. Typically patients will have had multiple oral ulcers (broken blisters) that persist for weeks to months. Pemphigoid is a group of sub-epidermal, blistering autoimmune diseases that primarily affect the skin, especially the lower abdomen, groin, and flexor surfaces of the extremities. Here, autoantibodies (anti-BPA-2 and anti-BPA-1) are directed against the basal layer of the epidermis and mucosa. The condition tends to persist for months or years with periods of exacerbation and remission. Scar formation in mucous membrane pemphigoid can lead to major disability.

Pemphigus & Pemphigoid Fast Facts:

- **Location:** pemphigus occurs on the skin, in the mouth, eyes, and throat with more than 80% of cases affect the oral mucosa; pemphigoid affects few people with 10-40% having mucous membrane involvement
- **Incidence:** 1 per million per year: about 300 new cases per year in the US
- **Age range:** all ages
- **Gender distribution:** affects women more frequently than men
- **Treatment options:** primarily immunosuppressants, topical steroids, and intravenous drugs
- **Approved drugs:** none

Things to Keep in Mind When Talking to the Media

Be prepared.

- Know the five “Ws” of your event: who, what, when, where, why (and how)
- Be familiar with a publication and its audience
- Have the IPPF’s mission statement and key messages with you for reference.

Be truthful and direct.

- Make your key points as simply and as often as possible.
- Have engaging examples or anecdotes to back up your key points. Tell your personal story.
- If you do not have the answer to a reporter’s question, admit it and offer to get the information for the reporter as soon as possible. (Be sure to follow up!)

Be confident and relaxed.

- You know your story and what you are doing .
- A successful interview is often a conversation, not an inquisition.

Be sure you understand the question before you answer.

- If you’re not sure what the reporter is asking, say so.
- It’s OK to ask a reporter to rephrase a question.

Be aware of saying things “off the record”

- It does not exist; what you say can be quoted.

Never say “no comment.”

- Give a reason for why you can’t discuss certain topics or issues.
- There are many ways to give a “non-answer.” You can redirect the conversation by saying, “I can’t discuss that, but what I can tell you is this program is successful because...”

Don’t be afraid to show emotion.

- This is a very emotional topic for you and your family...and for many other families out there who may really connect with your message and be inspired by your story.

Silence, or long pauses, is OK.

- When you’ve made your point, stop speaking. Don’t feel like you have to keep talking. People often speak nervously to fill the silence, which may dilute their original, well-articulated point.

Remember, you have control over what you say in an interview.

- The editor has ultimate control over what finally appears in print or on the air.

Press Release:

The IPPF has written a **Sample Press Release** (see appendix). It contains key points and messages and leaves “holes” for you to fill in and distribute to the media. It’s suitable for all types and sizes of events – from letter writing campaigns, to bake sales, to dinners. Any and every event counts and we want as many people as possible to know about it.

After you’ve personalized your press release, you’re ready to send it via fax or email to the contacts on your media list. Be mindful of publications’ deadlines. In some instances, they need to be notified six weeks before the event in order to be included in the calendar listing.

Follow up: be friendly, yet persistent

After you distribute your press release to your media list, be sure to follow up. Editors and reporters are typically under deadline and have a lot going on, so give them a few days to get to it. Then pursue your first-round of follow up with a call or email. We suggest that you ask if they received the release, gauge their interest in covering the story and stress that you are available to help.

Don’t be discouraged if it takes you several attempts to reach an editor or reporter. Follow up, whether it’s the first round or third round, is a great opportunity to stay in a reporter’s mind and build a relationship. Sometimes just a friendly, informative 30-second conversation can go a long way.

Press Placement

The IPPF would appreciate receiving a copy of all press releases and placements you receive, so we can monitor what is being written about the Foundation.

Final Outcome

Please do not be discouraged if your press release and story ideas do not get placed. For whatever reason, many press releases slip by the wayside and never make it to print. Your efforts are still worth it, and we appreciate all the time you've spent.

Appendix

Ideas for Fundraising Events

Dinner & Party Events

Bar-b-que
Birthday party
Black & white ball
Casual at-home approach
Celebrities
Children's party
Dessert
Gourmet food & wine
Halloween party
Masked ball
Restaurant tasting menu
Seasonal parties
Spaghetti supper
Themed parties
Unique locations
Valentine dance
Wine & cheese reception

Sporting Events

Bike-a-thon
Bowl-a-thon
Bowling
Golf
Golf tournament
Monopoly
Motorcycles
Pet parades
Poker
Rides
Runs & walks
Stroll-a-thons
Swim-a-thon
Tennis tournament

Other Ideas

Art exhibit
Auction
Bagel or donut sales
Benefit concert
Bingo
Block party
Book sale
Candy bar sale
Car wash
Carnival
Chocolate festival
Craft fair
Dance-a-thon
Disco night
Fashion show
Flower arranging
Garage sale
Garden tour
Holiday bazaar
Ice cream social
Loose change collections
Movie night
Pay to dress down at work
Pizza sale
Prize drawing
Raffle
Services for sale
Sidewalk sale
Soup sale
Sporting events parties
Talent competition
Teen dance
Toy fair
Treasure hunt
Wine tasting
Yard sale

Third Party Agreement

Third Party Fundraising Agreement

This Agreement is entered into between the International Pemphigus Pemphigoid Foundation (“IPPF”) and the event organizer “Organizer”).

Clearly Print First and Last Name

Organizer plans to conduct a fund-raising event for the purpose of generating money to support the mission and work of the IPPF. The IPPF gratefully acknowledges Organizer' efforts and agrees to use the donation in its charitable work.

Organizer agrees that it has read and will comply with the IPPF’s policies related to third-party fundraising, incorporated herein by reference. Organizer acknowledges that it is not an agent of the IPPF and the IPPF has played no part in the organization, promotion, or execution of its fundraising event and has no control over it. Consequently, Organizer agrees that it will fully indemnify, defend and hold harmless IPPF, its directors and employees from any and all claims that may arise out of or relate to such event, regardless of who might make such a claim.

Event organizer - printed name

Event organizer’s signature

Date

NOTE: The areas in RED are to help you fill in the blanks and create your own appeal letter. If you need help, please contact us and we will be glad to assist.

Sample Letter for Letter Writing Campaign

Date

Name

Address

City, State/Province, Zip/Postal Code

Dear _____,

I'm writing to let you know about an issue that is important to me. _____ [person's name and relation, such as "John, my 8-year-old son," or "Lee, my friend,"] was diagnosed with a rare disease called pemphigus, pemphigoid, pemphigus vulgaris, cicatricial pemphigoid, etc.. Pemphigus/Pemphigoid is a rare, autoimmune skin disease that can also affect mucous membranes such as the eyes and mouth.

For _____ this has meant [insert a bit of information about your personal situation, or that of your friend/family member – multiple surgeries, relapses, or we've been lucky. Tell your story here.]

While the course of this disease can be unpredictable, one thing is for sure: more effective treatments are needed. The International Pemphigus Pemphigoid Foundation (IPPF) is the only organization dedicated to finding a cure for these devastating diseases. Since its inception in 1994, the Foundation has increased awareness, created a patient registry to help advanced research, and helped reduced diagnosis time from over a year to less than 10 months.

Scientists are making great progress each day, but there is still more that needs to be done. Won't you please help by making a gift of \$_____ to the International Pemphigus Pemphigoid Foundation today? [It is always more effective to ask for a specific dollar amount. Remember not to ask for too little. People can always give less, but might not think to give more.] A check can be sent to: IPPF, 2701 Cottage Way #16, Sacramento CA 95825 OR visit www.pemphigus.org to make a donation and to learn more about the Foundation.

I know that, with your help, we can find a cure! Thank you for supporting me and for supporting!

With appreciation,

(Personally Sign)

NOTE: The areas in RED are to help you fill in the blanks and create your own appeal letter. If you need help, please contact us and we will be glad to assist.

Pitch Letter to Reporter

Date

Editor or Reporter's Name
Newspaper or other publication
Address (City, State, Zip)

Dear [Editor or Reporter's Name]:

I am writing to suggest a story idea to raise awareness about a family of devastating skin diseases that, until recently, have been virtually ignored by the research community. Pemphigus and pemphigoid are rare, autoimmune blistering skin diseases that affect people of all races, ages, and genders. In some cases, these disease can lead to secondary infections and health complications that can lead to death.

To date, there are no drugs approved to treat pemphigus or pemphigoid. [Person's name and relation, such as "John, my 8-year-old son," or "Jane, my friend,"+, was diagnosed with [pemphigus vulgaris, pemphigus foliaceous, bullous pemphigoid, mucous membrane pemphigoid, etc] in [year], and [his/her] life may depend on research to find new treatments. The International Pemphigus Pemphigoid Foundation (IPPF) is the only organization dedicated to finding a cure for these devastating diseases. Since its inception in 1994, the Foundation has increased awareness, created a patient registry to help advanced research, and helped reduced diagnosis time from over a year to less than 10 months.

On [date of event], I am hosting a [type of event] to raise awareness about pemphigus and pemphigoid and to raise funds for the IPPF. We ask that you consider covering our event. You could help your readers gain invaluable information about pemphigus and pemphigoid, which can affect people of any age and background. You'd also be giving your readers a great way to support our efforts on behalf of the IPPF. Please help us in our fight against these diseases!

Sincerely,

]Your name]
[Your phone number]
[Your email]

P.S. A press release is available upon request.

NOTE: The areas in RED are to help you fill in the blanks and create your own appeal letter. If you need help, please contact us and we will be glad to assist.

Sample Press Release

For Immediate Release: [Date]
Contact: [Your name, Phone, Email]

LOCAL [WOMAN, MAN, FAMILY] FIGHTS FOR A CURE FOR RARE SKIN DISEASE

[Woman, Man, Family] from [Your Hometown] Hosts A [Type of Event] to Raise Awareness and Funds for the International Pemphigus Pemphigoid Foundation

(HOMETOWN, STATE) – [Your Name] is making a difference in the fight to find a cure for pemphigus and pemphigoid. [He,She] first learned about these rare, autoimmune skin diseases when **“her sister was diagnosed in 2004”, “his friend told him he had been diagnosed in 2009”, tell your story here, limit it to one to two sentences*. [Your name] knew that [he/she] could help find a cure and decided to take action to make sure others do not have to suffer with this devastating disease.

On [event date], [your name] will host a [type of event] at [event location] to raise awareness about pemphigus and pemphigoid, two rare, autoimmune blistering skin diseases, and to raise funds on behalf of the International Pemphigus Pemphigoid Foundation (IPPF).

The IPPF is a nonprofit organization that, since 1994, has helped increase patient’s quality of life, raise awareness, and advocate for pemphigus and pemphoid research. [Your name] is actively involved with the IPPF and hopes to inspire the [your city/town’s name] community to come out, have fun and make a generous contribution in support of [patient’s name (use with permission)] to benefit the International Pemphigus Pemphigoid Foundation.

(Use this or draft a similar quote) “I want everyone to know more about pemphigus and pemphigoid, and how they affect people all over the world,” said [your full name]. “Our [type of event] is a fun way to raise awareness; however, the purpose of the event is very serious because much more research is needed to find a cure for these devastating skin diseases.”

Pemphigus and pemphigoid are rare, autoimmune, blistering, skin diseases. Pemphigus is chronic and progressive and characterized by blisters and ulcers on the skin and mucous membranes. Pemphigoid is a group of sub-epidermal, blistering autoimmune diseases that primarily affect the skin, especially the lower abdomen, groin, and flexor surfaces of the extremities. Before the advent of corticosteroids, pemphigus had a high fatality rate, with approximately 70+% of patients dying within a year.

About the International Pemphigus Pemphigoid Foundation

The International Pemphigus Pemphigoid Foundation (IPPF) is a registered 501(c)(3) non-for-profit organization. The IPPF is the pre-eminent global organization dedicated to improving the quality of life of all people diagnosed with, or affected by, pemphigus or pemphigoid. The IPPF provides direct access to innovative and effective support that promotes the very best health care, improves quality of life, stimulates community resources, advocates for favorable government policies, accelerates the pace of scientific discovery and is the world’s best source of information on pemphigus and pemphigoid. We are compassionate in understanding, tireless in service, and relentless in advocating. One person at a time, we make a difference, building a community of care and hope.

Interviews Available

[Your name], and IPPF staff, are available for interviews.

Event listing details:

Who: [your name and any other community partners]

What: [name of event]

Where: [address, intersection, location and directions, if needed]

When: [day, month, date, year, time frame]

Why: To raise awareness and money for pemphigus and pemphigoid on behalf of the International Pemphigus Pemphigoid Foundation

Additional info:

[Anything not covered in the Press Release or that you feel is important to help your event be successful]

NOTE: The areas in RED are to help you fill in the blanks and create your own appeal letter. If you need help, please contact us and we will be glad to assist.

Sample Donation Collection Form

LAST NAME	FIRST NAME	AMOUNT	STREET ADDRESS	CITY	STATE	ZIP	HOME PHONE	CELL PHONE	EMAIL	TY NOTE SENT