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event leader guide

fundraising to benefit the Pulmonary Fibrosis Foundation

The mission of the Pulmonary Fibrosis Foundation (PFF)

is to help find a cure for idiopathic pulmonary fibrosis, advocate for the pulmonary fibrosis community, promote disease awareness, and provide a compassionate environment for patients and their families.

This *Event Leader Guide* is provided by the Pulmonary Fibrosis Foundation as a public service to our patient community.

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Pulmonary Fibrosis
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thank you!

THE PULMONARY FIBROSIS FOUNDATION (PFF) IS THANKFUL that you have chosen us as the beneficiary of your third party fundraising effort. Third party fundraising events are defined as events held by individuals, businesses, groups, service clubs, schools, and similar organizations on behalf of the Pulmonary Fibrosis Foundation. The third party Event Leader is responsible for the event and sending the net proceeds to the PFF as a single amount.

Thank you for your time, effort, and dedication! Your commitment enables us to further our mission to serve as the trusted resource for the pulmonary fibrosis (PF) community by raising awareness, providing disease education, and funding research.

In this *Guide* you will find helpful information and guidelines for making your event a great success. Please also download the *Team PFF eToolkit* for additional tools and templates from www.pulmonaryfibrosis.org/get-involved/fundraise-for-team-pff.

Please feel free to contact Jennifer Bulandr, Director of Community Events and Social Media, at jennifer@pulmonaryfibrosis.org with any questions you may have as you review this *Guide*. We appreciate you taking on this vital role to benefit the pulmonary fibrosis community!

Sincerely,

THE PULMONARY FIBROSIS FOUNDATION

five easy ways to raise \$1,000

- 1 Ask 4 family members to pitch in \$250 each.
- 2 Ask 10 friends to contribute \$100 each.
- 3 Ask 20 neighbors to give \$50 each.
- 4 Raise \$500 and ask your company to match your donation.
- 5 Ask 50 people from your social circle to pitch in \$20 each.

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Steps for a Successful Fundraiser

CHOOSE AN EVENT TYPE

- The most successful events combine something that is fun and meaningful to you and your family, as well as interesting to your community.

CHOOSE YOUR DATE AND LOCATION

- Once you have an event type, choose your desired date and potential locations. Event Leaders are responsible to obtain any required permits or insurance.

ASSEMBLE YOUR EVENT TEAM

- Recruit your family, friends, and co-workers to help you with your event.

ESTABLISH YOUR GOALS

- Determine your fundraising goals and create a work plan for you and your Event Team. Give Event Team members specific tasks to complete.

SET UP YOUR ONLINE DONATION PAGE

- Visit www.firstgiving.com/pulmonaryfibrosisfoundation and click on the “Start Fundraising” button. Then follow the simple steps to create your page.

COMPLETE YOUR EVENT SUMMARY

- Once you have your event details set, please fill out the *Team PFF* third party Event Registration and Fundraising Agreement Form at www.bit.ly/TeamPFFevent.

Welcome to Team PFF!

SPREAD THE WORD

- Congratulations—now it’s time to invite everyone you know! Post to your Facebook page, send an email invitation, Tweet about your event, etc. Your event will also be added to the *Team PFF* event calendar on our website and announced on our Facebook and Twitter.

ENJOY

- You have put together an incredible plan and now is the day to enjoy your guests and your event!

Event Leader Basics

Team PFF is an inclusive fundraising program at the Pulmonary Fibrosis Foundation. As an Event Leader we look to you to actively fundraise, promote, and host a successful third party event. We created this *Guide* to help answer your questions and provide you with resources and tools to make planning and hosting your third party event a positive experience. Below is an overview of your responsibilities and the benefits of being a *Team PFF* Event Leader.

YOU ARE RESPONSIBLE FOR

- **Costs** – All costs and expenses including permits, liability insurance, licenses—especially those for raffles/games of chance.
- **Complying with the Law** – Ensuring your event complies with all federal, state, and local laws governing charitable fundraising and gift reporting.
- **Media Coverage** – Your local newspaper, radio, and TV station would love to hear from you!
- **Volunteers** – Recruiting volunteers to help at your event.
- **Marketing** – Advertising your event by creating and posting flyers, posting on social media, etc.

AFTER REGISTERING YOUR EVENT WITH THE PFF YOU WILL RECEIVE OUR EVENT LEADER “WELCOME KIT” INCLUDING

- **Fact Sheets** – Informational fact sheets about pulmonary fibrosis and the PFF to help educate your guests
- **Breathe Bracelets** – 10 PFF Breathe Bracelets
- **Discount** – Discount code for Shop PFF items for your event
- ***Breathe Bulletin*** – A copy of the latest edition of the PFF’s magazine, the *Breathe Bulletin*
- **PFF T-shirt** – A Pulmonary Fibrosis Foundation T-shirt to wear the day of your event.

OTHER CONSIDERATIONS

- **Documentation** – Event Leaders must fill out the *Team PFF* Third Party Event Registration and Fundraising Agreement Form at www.bit.ly/TeamPFFevent.
- **Taxes** – Event Leaders are not permitted to use the Pulmonary Fibrosis Foundation’s tax exempt status in conjunction with an event.
- **Fundraising** – All fundraising for a third party event is to be conducted for the exclusive benefit of the Pulmonary Fibrosis Foundation.

- **Contributions** – Please note, contributions made to a Team PFF event are not considered a tax donation.
- **Event Proceeds** – We request that you provide your final net proceeds in one check made payable to the Pulmonary Fibrosis Foundation, as well as a completed *Team PFF* Event Closing Form within 15 days of your event. The Pulmonary Fibrosis Foundation will provide a single acknowledgement to the third party Event Leader for the event proceeds.

Please mail your check and closing form to:

Pulmonary Fibrosis Foundation
Team PFF/YOUR EVENT NAME
230 East Ohio Street, Suite 304
Chicago, IL 60611

Fundraising FAQs

I want to host an event to benefit the Pulmonary Fibrosis Foundation. What are some examples of events I can organize?

First, thank you for hosting a third party event to benefit the Pulmonary Fibrosis Foundation! Some examples of successful events have included:

- Organizing a bake sale
- Conducting a Dress Down Day/Jeans Day at work
- Holding a spare change drive
- Selling PFF Breathe Bracelets at work, school, or in your neighborhood
- Hosting a Dine Out for PFF Fundraiser at your local restaurant
- Organizing a silent auction
- Hosting a direct sales party (i.e., PartyLite®, Tealightful®, Origami Owl®, etc.) to benefit the PFF
- Organizing a silent auction
- Participating in personal fundraisers using our online fundraising platform, FirstGiving. For example, running in a local 5K or participating in other events.
- Donations in lieu of wedding favors, baby shower favors, anniversary gifts, etc.
- Bowling to benefit the PFF

A local company wants to give their services for an in-kind contribution. Will they receive a tax receipt?

The Pulmonary Fibrosis Foundation does not issue tax receipts for in-kind contributions.

I would like to have sponsors for my third party event help me cover expenses. Will the Pulmonary Fibrosis Foundation be able to issue tax receipts for their support?

Per IRS regulations, the Pulmonary Fibrosis Foundation does not issue tax receipts for sponsors. The Pulmonary Fibrosis Foundation is not permitted to share any of its licenses, permits, or tax exemption benefits with third party Event Leaders or their sponsors.

Will a staff member from the Pulmonary Fibrosis Foundation be able to come to my event?

Thank you for inviting us! Please contact Jennifer Bulandr, Director of Community Events, at jennifer@pulmonaryfibrosis.org with the date of your event and we will see if we are able to attend.

The venue where I want to host my event requires that I have liability insurance. Can I use the Pulmonary Fibrosis Foundation's insurance?

The Pulmonary Fibrosis Foundation is unable to insure your event. The Pulmonary Fibrosis Foundation is not permitted to share any of its licenses, permits, or tax exemption benefits with third party Event Leaders.

I have some awesome photos from my third party event. What can I do with them?

We would love to see your photos and share them with our online PF community. Please send them to Jennifer Bulandr at jennifer@pulmonaryfibrosis.org.

Will the PFF send acknowledgement letters to each of my event attendees?

The Pulmonary Fibrosis Foundation provides a single acknowledgement to the third party Event Leader for the event net proceeds. Please personalize the thank you letter in the eToolkit to send to your guests.

I've hosted my event but would like to do more. Any ideas of what I can do now?

We love your enthusiasm and offer to help! Please contact Jennifer Bulandr at jennifer@pulmonaryfibrosis.org for ideas about how to volunteer, be an advocate, and help us by planning an event for Global Pulmonary Fibrosis Awareness Month this September.

May I use the Pulmonary Fibrosis Foundation's tax exempt status to purchase items for my event?

The Pulmonary Fibrosis Foundation is not permitted to share any of its licenses, permits, or tax exemption benefits due to IRS regulations.

I would like to give each of my guests a PFF Breathe Bracelet so they can continue to spread awareness. Can I purchase items in bulk on the Shop PFF web page?

As a third party Event Leader, we are pleased to share our *Team PFF* discount code with you in your Welcome Kit. **Items ordered 10 business days before your event are shipped FREE!**

I sent my third party event proceeds to the Pulmonary Fibrosis Foundation but still need to pay for expenses. Will the Foundation be able to pay for the expenses with a portion of the proceeds?

The Pulmonary Fibrosis Foundation cannot pay expenses for third party events. The third party Event Leader should deduct the amount needed to cover expenses from the event gross proceeds and then turn in the net proceeds to the Foundation.

After my event, what are some next steps I can take?

Once your event has concluded there are a variety of things you can do:

- First, evaluate your event. Make a list of what worked well and identify any areas for improvement.
- Second, take time to thank all those who helped you with your event. You can personalize the thank you note in our *eToolkit*.
- Last, please consider setting a date/time for next year's event and let us know so we can include it on our event calendar.

Pulmonary Fibrosis

FOUNDATION

230 EAST OHIO STREET SUITE 304 CHICAGO, ILLINOIS 60611-3201

888.733.6741 PHONE

866.587.9158 FAX

About Pulmonary Fibrosis

Pulmonary fibrosis (PF) describes a condition in which the lung tissue becomes thickened, stiff, and scarred.¹ The medical term used to describe this scar tissue is fibrosis. The air sacs (alveoli) and blood vessels within the lung are responsible for delivering oxygen to the body. As lung tissue becomes scarred and thickened, it is difficult for the lungs to transfer oxygen into the bloodstream. As a result, the brain, heart, and other organs don't get the oxygen they need to function properly.¹ In some cases, doctors can determine the cause of the PF, but in most cases, the cause remains unknown. When there is no known etiology (cause) for the development of PF (and certain radiographic and/or pathologic criteria are met) the disease is called idiopathic pulmonary fibrosis or IPF.^{1, 5, 6, 12}

A SNAPSHOT OF THE DISEASE

- In the United States (US), IPF affects between 132,000–200,000 people.^{2, 4, 11}
- In the US, an estimated 50,000 new cases are diagnosed each year.^{2, 4, 11}
- In the European Union, IPF affects between 37,000 and 40,000 people.^{5, 17}
- In the United Kingdom alone, more than 5,000 new cases of IPF are diagnosed each year.³
- PF can strike anyone, but the disease tends to affect men more than women and usually occurs between the ages of 50 and 70.^{4, 6}

THE DEVELOPMENT OF PULMONARY FIBROSIS IS ALSO ASSOCIATED WITH OTHER CONDITIONS:

- Autoimmune diseases such as, scleroderma, lupus, and rheumatoid arthritis.^{6, 7, 8, 12}
- Occupational and environmental exposures such as asbestos, silica, animal proteins, gasses, and fumes.^{1, 6, 7, 10, 12}
- Certain medications and therapeutic treatments; a few examples are cancer medications (bleomycin, cytoxan), radiation therapy, cardiac medications (propranolol, amiodarone), and sulfa containing antibiotics for urinary tract infections.^{1, 6, 7, 12}
- Pulmonary infections (or recurrent pulmonary infections) both viral and bacterial.¹
- Gastroesophageal reflux disease (GERD).^{1, 6, 7, 12}
- Genetic factors and cigarette smoking (can increase an individual's risk of developing PF).^{1, 6, 12, 13, 14, 15, 16}

Pulmonary Fibrosis

FOUNDATION

230 EAST OHIO STREET SUITE 304 CHICAGO, ILLINOIS 60611-3201

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About Pulmonary Fibrosis (cont.)

WHAT IS THE MORTALITY RATE OF PULMONARY FIBROSIS?

- An estimated 40,000 people die in the US each year from PF.^{2,4} The median survival rate is just two to three years following diagnosis, and more than two-thirds of patients will die within five years.^{6,9}
- The mortality rate from PF has increased significantly, especially in women, and is predicted to continue to rise.⁴

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Event Closing Form

EVENT NAME

DATE

EVENT LEADER PHONE/EMAIL

IN HONOR/MEMORY OF/GENERAL (INCLUDE NAME AND RELATION TO YOU)

CITY

STATE

AMOUNT RAISED

COST OF EVENT

TOTAL CONTRIBUTION

WHAT ABOUT YOUR EVENT WENT WELL (MEDIA, DAY OF, ETC.)?

WHAT WOULD YOU LIKE TO IMPROVE FOR NEXT YEAR?

PLEASE COMPLETE THIS FORM AND SEND IT TO THE PULMONARY FIBROSIS FOUNDATION WITHIN 30 DAYS OF YOUR EVENT:

PULMONARY FIBROSIS FOUNDATION
TEAM PFF/YOUR EVENT NAME
230 EAST OHIO STREET, SUITE 304
CHICAGO, IL 60611-3201