

# team pff event leader guide

fundraising to benefit the Pulmonary Fibrosis Foundation

The mission of the Pulmonary  
Fibrosis Foundation (PFF)

is to serve as the trusted resource  
for the pulmonary fibrosis (PF)  
community by raising awareness,  
providing disease education,  
and funding research.

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Fibrosis Foundation as a public service to our community.**

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# Pulmonary Fibrosis

## FOUNDATION

## thank you!

**THANK YOU** for joining *Team PFF!* Passionate and dedicated individuals like yourself who take action in the fight against pulmonary fibrosis are making a difference in the lives of those affected by the disease.

*Team PFF* Leaders are advocates who actively fundraise, promote, and host third-party events to raise funds and awareness about pulmonary fibrosis. The funds you raise directly enhance patient services, fund research, and support PFF signature programs for the pulmonary fibrosis community. Thank you for joining others from around the globe in letting the world know that we need a cure today.

**If you have any questions, please feel free to contact Angela Perillo, Director, Development, at [aperillo@pulmonaryfibrosis.org](mailto:aperillo@pulmonaryfibrosis.org).** Once again, thank you! We appreciate you taking on this vital role to benefit the pulmonary fibrosis community!

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# about the Pulmonary Fibrosis Foundation

## **WE IMAGINE A WORLD WITHOUT PULMONARY FIBROSIS.**

The Pulmonary Fibrosis Foundation is focused on our mission to act as the trusted resource for all who are affected by this disease. Our signature programs include:

- PFF Care Center Network
- PFF Patient Registry
- PFF Patient Communication Center
- PFF Ambassador Program
- An international network of support groups and online communities
- PFF Summit
- Comprehensive disease education materials

Our expert Medical Advisory Board and the biennial *PFF Summit* allow us to maintain an ongoing dialogue with physicians, researchers, industry representatives, and the patient community. This creates a collaborative environment that will help us achieve many of our goals.

Our peer-reviewed research program supports projects that improve understanding of pulmonary fibrosis and will lead to successful therapies. We have developed significant relationships with industry partners and upheld our position as the honest broker to inform those affected by pulmonary fibrosis of important scientific breakthroughs.

Founded in 2000 by brothers Albert Rose and Michael Rosenzweig, PhD, the Pulmonary Fibrosis Foundation is a 501(c)(3) nonprofit organization dedicated to identifying effective PF treatments and assisting those living with the disease. The brothers experienced firsthand the devastating effects of PF when their sister Claire passed away from the disease. Both brothers were also diagnosed with PF, and it was their vision and dedication that led to the creation of the Foundation.

The Pulmonary Fibrosis Foundation is a 501(c)(3) tax exempt nonprofit organization and has earned the highest distinctions given by both Charity Navigator and the Better Business Bureau.

# welcome to Team PFF!

## 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. *Team PFF* 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. Assign event team members specific tasks to complete.

### SET UP YOUR ONLINE DONATION PAGE

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

### COMPLETE YOUR ONLINE EVENT REGISTRATION

- Once you have finalized your event details, please fill out the ***Team PFF* Event Registration Form** at [www.pulmonaryfibrosis.org/get-involved/fundraise-for-team-pff](http://www.pulmonaryfibrosis.org/get-involved/fundraise-for-team-pff).

### SPREAD THE WORD

- Congratulations—your event will be added to the *Team PFF* event calendar on our website and announced on PFF social media. Now it’s time to invite everyone you know! Post to your Facebook page, send an email invitation, tweet about your event, be creative!

### ENJOY

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

*“Working with the PFF has truly been a positive experience; my phone calls are always welcomed, my questions always answered and my suggestions are always appreciated.” - Nick DeVito*

# event leader basics

We created this *Team PFF* Event Leader 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 as a *Team PFF* Event Leader.

## YOU ARE RESPONSIBLE FOR

- As an Event Leader, you must fill out the ***Team PFF* Registration Form**
- You are responsible for all costs and expenses including permits, liability insurance, licenses—especially those for raffles/games of chance.
- You must ensure that your event complies with all federal, state, and local laws governing charitable fundraising and gift reporting.
- You are responsible for media coverage. Your local newspaper, radio, and television station would love to hear from you!
- You are in charge of recruiting volunteers to help at your event.
- You are responsible for marketing. Advertise your event by creating and posting flyers, and post on social media!
- You are responsible for media coverage. Your local newspaper, radio, and television station would love to hear from you!
- All fundraising for a third party event is to be conducted for the exclusive benefit of the Pulmonary Fibrosis Foundation.
- The PFF requests 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 *Team PFF* Event Leader for the event proceeds.

### **Please mail your check and *Team PFF* Event Closing Form to:**

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

*“It is extremely easy to work with the PFF. You receive a packet of very easy to follow suggestions/instructions and questions are quickly responded to via email. - Michele Peters*

# fundraising faqs

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

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

- Conducting a Dress Down Day/Jeans Day at work
- 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
- Holding a spare change drive
- Creating a personal fundraising page
- Organizing a bake sale
- Bowling to benefit the PFF

*Will my supporters receive tax credit when they donate to my event?*

Contributions made to a *Team PFF* event are not considered a tax donation due to IRS regulations, so your supporters will not receive a tax receipt. We are so thankful for their support, which helps make it possible for us to provide resources to patients and caregivers every day, and maintains our momentum in serving the PF community by increasing research funding, broadening disease education outreach, and enhancing patient support services.

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

The Pulmonary Fibrosis Foundation does not issue tax receipts for in-kind contributions due to IRS regulations.

*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 *Team PFF* Event Leaders or their sponsors.

*Can I use the Pulmonary Fibrosis Foundation's tax exempt status 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, therefore *Team PFF* event leaders are not permitted to use the PFF's tax exempt status in conjunction with their events.

*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.

*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 *Team PFF* Event Leaders.

*I sent my third party event proceeds to the Pulmonary Fibrosis Foundation but still need to pay for expenses. Will the PFF 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 *Team PFF* Event Leader should deduct the amount needed to cover expenses from the event gross proceeds and then turn in the net proceeds to the PFF.

*Will a Pulmonary Fibrosis Foundation representative be able to come to my event?*

Thank you for inviting us! If you would like a PFF Ambassador to accept the check and/or address your guests at your event, please contact our Patient Communication Center at [pcc@pulmonaryfibrosis.org](mailto:pcc@pulmonaryfibrosis.org). To learn more about the PFF Ambassador program, visit [www.pulmonaryfibrosis.org/our-role/signature-programs/pulmonary-fibrosis-foundation-ambassador-program](http://www.pulmonaryfibrosis.org/our-role/signature-programs/pulmonary-fibrosis-foundation-ambassador-program).

*I would like to share educational and awareness materials with my guests?*

It is wonderful that you want your guests to learn more about pulmonary fibrosis! Our Global Pulmonary Fibrosis Awareness Month website at [www.globalPFawareness.org](http://www.globalPFawareness.org) has a lot of great printable material including facts about PF and ways to raise awareness. These materials can be distributed to all of your guests.

*I would like to give each of my guests a PFF Breathe Bracelet so they can continue to spread awareness. Can I receive a discount for the Shop PFF website?*

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

*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 **Angela Perillo, Director, Development at [aperillo@pulmonaryfibrosis.org](mailto:aperillo@pulmonaryfibrosis.org)**.

*I've hosted my event but would like to do more. What I can do now?*

We love your enthusiasm and offer to help! There are a few ways that you can get involved beyond *Team PFF*. You can join us during Global Pulmonary Fibrosis Awareness Month in September and host another event. We would also love to see you at the *PFF Summit 2015: From Bench to Bedside*, which is a unique conference that brings together patients, caregivers, health care professionals, and industry representatives dedicated to finding a treatment and a cure for pulmonary fibrosis.

*I would like to learn more about pulmonary fibrosis. Do you have any educational materials I can use and provide to my supporters?*

We would love to help you learn more and understand pulmonary fibrosis. Please contact our Patient Communication Center (PCC) at 844.TalkPFF (844.825.5733) or [pcc@pulmonaryfibrosis.org](mailto:pcc@pulmonaryfibrosis.org). The PCC makes available the most up-to-date medical information, communicates the availability of support services, and provides information about other essential resources important to patients, caregivers, and health care providers. The PCC also offers current information on available treatments and clinical trials.

*How do I close out my event?*

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, send your **Event Closing Form** and event proceeds to the Pulmonary Fibrosis Foundation
- Third, take time to think all those who helped you with your event. You can personalize the thank you note in this guide.
- Last, please consider setting a date and time for next year's event and let us know so we can include it on our event calendar.

*"I did 'Gearin' Up for Grady' in memory of my father, Grady Usrey. I chose to do a car show because my dad's number one hobby has always been cars. - Sara Dykstra*



# event closing form

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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.)?

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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

# Pulmonary Fibrosis

FOUNDATION

230 EAST OHIO STREET SUITE 304 CHICAGO, ILLINOIS 60611-3201 888.733.6741 PHONE  
866.587.9158 FAX

<DATE>

<RECIPIENT NAME>  
<RECIPIENT ADDRESS 1>  
<RECIPIENT ADDRESS 2>  
<RECIPIENT CITY, STATE ZIP>

Dear Friends and Family,

This year I am excited to join *Team PFF* as an Event Leader. As a *Team PFF* Event Leader I will be <NAME OF ACTIVITY> in <MEMORY/HONOR> of <NAME OF LOVED ONE>. I am making a commitment to raise funds and awareness for the Pulmonary Fibrosis Foundation (PFF) because <YOUR ANSWER HERE>. I am dedicating my efforts to the Pulmonary Fibrosis Foundation because we need to find a cure for pulmonary fibrosis.

Pulmonary fibrosis (PF) describes a condition in which the lung tissue becomes thickened, stiff, and scarred. As lung tissue becomes scarred and thicker, it is more difficult for the lungs to transfer oxygen into the bloodstream. As a result, the brain, heart, and other organs do not get the oxygen they need to function properly. In some cases, doctors can determine the cause of the fibrosis (scarring), but in many cases the cause remains unknown. When there is no known cause for the development of pulmonary fibrosis, the disease is called idiopathic pulmonary fibrosis (IPF.) One recent study estimates IPF affects 1 out of 200 adults over the age of 65 in the US. Approximately 50,000 new cases are diagnosed each year and as many as 40,000 Americans die from IPF each year.

The mission of the Pulmonary Fibrosis Foundation is to serve as the trusted resource for the pulmonary fibrosis (PF) community by raising awareness, providing disease education, and funding research.

I'm asking for your support as I raise awareness and funds for the Pulmonary Fibrosis Foundation. My personal goal is to raise <FUNDRAISING GOAL> and every dollar makes an impact. Please help me reach my goal by making a contribution now. Please visit my personal online fundraising page at <INSERT FirstGiving URL> to make a secure gift online or call the Pulmonary Fibrosis Foundation at 844.Talk PFF. I invite you to join me in making a difference in the lives of those affected with pulmonary fibrosis.

Thank you in advance for your generous support!

Sincerely,  
<EVENT HOST>

sample fundraising letter

[www.pulmonaryfibrosis.org](http://www.pulmonaryfibrosis.org)

# Pulmonary Fibrosis

**FOUNDATION**

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

888.733.6741 PHONE

866.587.9158 FAX

<DATE>

<RECIPIENT NAME>  
<RECIPIENT ADDRESS 1>  
<RECIPIENT ADDRESS 2>  
<RECIPIENT CITY, STATE ZIP>

Dear <GUEST>,

Thank you for attending my event to benefit the Pulmonary Fibrosis Foundation (PFF). Your participation helped me raise critical funds that allow the Pulmonary Fibrosis Foundation to raise awareness, provide disease education, and fund research. Events like <NAME OF YOUR EVENT HERE> are essential to raise much needed funds and awareness for the PFF's mission and I couldn't have done it without you.

I appreciate your participation and hope to see you at next year's event!

Sincerely,

<EVENT LEADER NAME>

sample thank you letter