Team Captain Guide

4 STEPS TO SUCCESS

Stride WITH HDF pride
Thank you for serving as a Team Captain for IDF Walk for Primary Immunodeficiency!

IDF Walk for Primary Immunodeficiency (PI), an initiative of the Immune Deficiency Foundation (IDF), unites all members of the PI community to help create better lives for those affected by these rare, chronic diseases. Because part of their immune system is either missing or functions improperly, people with PI face an increased vulnerability to infections, endure recurrent health problems, and often develop serious illnesses throughout their entire lives. They deserve better, and you can help!

Founded in 1980, IDF improves the diagnosis, treatment, and quality of life of people affected by PI through fostering a community empowered by advocacy, education and research. Since 2013, IDF Walk for PI has brought together the PI community to support the critical work of IDF by raising funds and spreading awareness. The dollars raised by IDF Walk for PI ensure that IDF can continue to:

- Provide educational resources and programs at no cost to individuals and families.
- Power critical patient-focused research that will ultimately lead to scientific advances.
- Lead the way in grassroots advocacy and fight to improve diagnosis and access to treatment.
- Bring together the entire PI community to remind them that they are not alone.

With each step you take with us, we are creating better lives and ultimately getting closer to cures for all types of PI.

The success of you and your team will enable IDF to help even more people affected by PI. We thank you as you Stride with IDF Pride!

To learn more, visit our website at www.walkforpi.org.
WHY WE WALK

The funds you raise through IDF Walk for PI go directly to the Immune Deficiency Foundation to support programs and resources for individuals and their families with primary immunodeficiencies (PI). Take a look at our numbers from last year that help illustrate the impact IDF, with your support, is making!

Education

One of the most frequent requests from those affected by PI is finding information about diagnosis and treatment. Education is central to the mission of IDF.

112 healthcare providers volunteered to present at education meetings attended by 1,877 individuals, where an average of 45% of the attendees were first-time attendees.

16,959 patients and healthcare professionals attended more than 230 IDF educational presentations in 112 cities, 36 states & 2 countries.

298,337 IDF educational materials were distributed to members of the PI community.

IDF Volunteer Network, consisting of more than 500 volunteers created awareness campaigns in their area to recruit and raise awareness about plasma donations.

186 PLASMA COORDINATORS were offered encouragement from Peer Support Coaches, members of the volunteer network.

148 INDIVIDUALS
IDF is proud to be the voice of the PI community—serving as the leader in tackling public policy issues as well as helping people day-in and day-out through individualized assistance. IDF helps navigate the complex challenges people with PI face.

**Advocacy**

**AS OF JANUARY 2019**

- **Public Advocacy**
  - 50 states screening for SCID, covering 100% of all births in the nation.
  - 161 patients and family members participating in over 149 Congressional meetings at IDF Advocacy Day on Capitol Hill.

- **Health Access Advocate volunteers educated legislators about state & federal legislative issues related to PI.**

- **Individual Advocacy**
  - 460 requests
  - 10,142 requests from patients and families seeking education, information and assistance.

  *One of the top needs was to locate a specialist with 2,600 clinicians.*

- 42 Health Access Advocate volunteers educated legislators about state & federal legislative issues related to PI.

Each year, we are learning more and more about PI, and IDF actively participates in, conducts, and supports research of PI. From conducting surveys of patients to supporting the work of dedicated researchers through the IDF Research Grant Program, IDF is looking to the future to improve the quality of life for generations to come.

**Research**

**Patient Powered Research**

- 2,679 people made their individual health information available for researchers to examine the collective experiences of those affected by PI.

**Since 2017**

- The IDF Research Grant Program has awarded 14 grants totaling $500,000

  *The IDF Research Grant Program began because of funds raised from IDF Walk for PI.*

---

Data provided by IDF from those living with PI is often cited in medical journals, government sponsored reports, by media, and has been the basis of several articles in peer-reviewed journals.

IDF is a 501(c)(3) non-profit organization, and contributions are tax-deductible to the maximum extent allowed by IRS regulations. Donors should consult their tax advisor to determine the tax deductibility of contributions.
4 Steps to Success

1. **Lay the Groundwork**

Let’s get started! Now that you’ve registered as a Team Captain, you’ve taken the first step on the path to success. By following these recommendations, you’ll be equipped to run an effective fundraising campaign.

**Set a goal**
Think about the number of people you can get to walk with you! Your network is larger than you think. If you donated just $5 a week for 25 weeks, you would be a sustaining donor with $125 personal contribution. And what if you asked 15 friends to do the same by donating to your page? That’s $2,000 that you’ve raised for IDF! It’s easy to get started and even easier to spread the word.

**Save the date**
Mark your calendar for your city’s IDF Walk for PI. Will you be able to reach your goal by then? We know you can!

**Set up your team and personal fundraising pages**
It’s easier than you think! We’ve developed a guide to assist you with IDF’s fundraising platform. You received the link in your confirmation e-mail. Team Captains will need to set up the team page so that participants can register to their team. After you do that, set up your personal page as well. All donations will be allocated to both your personal page and the team page so that credit is given to Top Teams and Top Participants.

**Write your personal story**
Update your personal webpage with a photo or video and your personal story. There is general information already included there and a photo, but personalizing your page will encourage people to donate and support your team, so make sure your story is from the heart. Let them know why you walk for PI!

**Donate**
Make the first donation on your page. More people will donate if they see a gift already on your page.

---

**FOR WHAT IT’S WORTH**

If you think about what a donation is worth to someone, it can show them how a few dollars can really add up!

**Set a goal**

\[
\text{Number of donors} \times \text{Average donation} = \text{Total raised}
\]

- **$4 COFFEE**
  - 5 days = $20 DONATION
- **$15 NETFLIX**
  - 3 months = $45 DONATION
- **$10 DINNER**
  - 10 nights = $100 DONATION
4 Steps to Success

2 COACH YOUR FUNDRAISERS

The best teams are always coached by a resourceful leader. These are some steps to take your team to the top!

Recruit team members by inviting your friends and family
Your friends and family are the most valuable assets to your campaign. This is your opportunity to get the conversation going about PI, all while raising funds to help people affected by PI.

Get the word out
Share the link to your personal team page through your e-mail contacts and social media followers to let people know you’ve created a team. Hang posters, make phone calls, and approach people in person to join your cause and contribute to your fundraiser.

Encourage team members to donate
It’s hard for team members to ask for donations if they haven’t given themselves. Ask your team members to donate to their personal pages once they’ve signed up.

See if your company has a matching gift program
You and your team members can double or triple the impact of your generosity by getting your employers to match your gifts. It never hurts to ask!

Educate team about registering, personalizing pages, and using the app
Encourage your team members to register and personalize their fundraising pages by following the link to the fundraising platform guide that was sent to them in their confirmation e-mail. Once their page is registered, they can download the app to make it easier for donors to give when they host a fundraiser or ask for donations.

Make being part of your team fun
• Host a team party or get-together
• Offer prizes and incentives.
• Host a bake sale, sub sale, pizza sale, candy sale, or ice cream social.
• Ask employers to conduct a dress down day for their employees and ask for a donation to participate.
• Host a restaurant night. Most restaurants will donate a percentage of sales from guests who have a special pass.
• E-mail IDF, and request paper icons. Paper icons are the paper cut outs that you can buy at a store and the proceeds go towards a charity. At most stores, you write your name on the paper icon, and they plaster them all over the walls. Find retailers near you willing to participate.
• Create your team t-shirt together. Brainstorm on the design and colors to get everyone involved.

Create a Team Party
Dress Down Day for Donations
Offer Prizes
Restaurant Night
E-mail IDF for Paper Icons
Bake Sale
Create A T-Shirt
Host A Team Party
4 Steps to Success

3 CREATE THE SIMPLE DONOR EXPERIENCE

Fundraising can be challenging, we understand, but with so many ways to do it and a variety of samples, we want to make it as easy as possible.

**E-mail**
Upload your contact list from your e-mail provider (Yahoo, Gmail, Outlook, etc.) directly to your account. This is an easy way to track who has joined your team, received your e-mails, or donated. Send an e-mail using our template asking your friends and family to join your team and/or to make a donation.

**Call**
For those who you may not have e-mail addresses for or aren’t on social media, try giving them a friendly phone call! Call the people you are closest with, and ask them to support your efforts. This makes for a more intimate conversation about the importance of their participation.

**Share on social and tag recent donors**
Are you on Facebook, Twitter, Instagram, or some other type of social media? These can be valuable tools for recruiting team members and raising funds. Use the hashtag #WalkforPI in all of your posts. Some of our top fundraisers tag recent donors on Facebook with a quick shout-out—a great way to thank those people!

**In-person**
People are more likely to donate when they are asked in-person than any other form of communication because the conversation is more in-depth and personal. But it can be intimidating! Remember why IDF and supporting the PI community is important to you, and let them know that their donation will help.

**Use the app**
Download the IDF Walk for PI app on your smartphone. Once you’ve registered on the website, your credentials can be used to sign in on the app. You’ll be able to accept donations from your phone—anytime and anywhere!

**Text**
Many people today communicate quickly and easily by text. Copy the link to your personal page, and send to your phone contacts with a sincere message about why supporting the PI community is important to you. Follow up with a request for a donation. Texting is an efficient way to raise money that is both sender and donor-friendly!

**TIPS**
Remind your team members (and yourself) that people will give if they are asked. Don’t get discouraged!
The best days to ask for donations are Fridays, the 15th, and the last day of the month, which are paydays for many.
Always be sure to thank your potential donors for their time, whether they give to you or not!
4 Steps to Success

STRIDE WITH IDF PRIDE

There are many things you can do before, during, and after the walk to really make a difference.

Before the walk
• Hang the IDF Walk for PI flyer in your community.
• Check out www.walkforpi.org for specific logistical details, including the best way to get to the site, parking info, walk route, and more!
• Send any checks to the IDF office ahead of time. Please don’t mail cash!
• Let everyone know about IDF Walk for PI on social media!
• Post photos, thank people for their support, and remember to tag @WalkforPI on Facebook and @IDFCommunity on Instagram and Twitter using the hashtag #WalkforPI!

On the day of the walk
• Unify your team with team spirit: shirts, hats, bracelets, etc.
• Make sure you wear your team t-shirts! (if you create one)
• Take team pictures, and share photos on social media #WalkforPI!
• Stream live, and ask for people to give as you are walking.
• Have fun with your team!

After the walk
• A simple thank you goes a long way, so consider different ways to recognize your team members and your donors. Send thank you letters or e-mails to everyone who participates and donates. Showing gratitude will keep your team and donors excited and will encourage everyone to continue supporting the team!
• Don’t stop now: donations will be accepted until December 15. Send out at least one final reminder for any last minute gifts after the walk!
Frequently Asked Questions

What is the IDF Order of the Zebra?
The IDF Order of the Zebra is an elite group of fundraisers whose efforts make an extraordinary impact on the success of IDF Walk for PI. Each year, if you set a fundraising goal of $1,000 or more on your personal fundraising page and reach that goal before December 15, you will be inducted into the IDF Order of the Zebra for that year. IDF Order of the Zebra is an annual tradition, and we’re grateful for those who reach this level year after year!

What happens if it rains?
Just as the effects of PI go on, so do we – rain, snow, or shine. There will be no rain dates. Please dress accordingly.

What kind of food and activities happen at the walk?
There will be a variety of fun things going on at the walk, including meeting and mingling with other members of the PI community and our supporters. There will be food available. If you have special dietary restrictions, we suggest that you bring along your own snacks.

Do I need to raise a certain amount to participate?
A paid registration fee is required to participate. This fee will guarantee you an IDF Walk for PI t-shirt and food the morning of your walk. After registration, we encourage you to raise at least $125 to help create better lives for those affected by PI.

What do I need to bring with me to the walk?
Any gifts that you may have collected beforehand that you haven’t already sent to the office (no cash please!), comfortable walking shoes, and appropriate dress for the weather.

How can a walker earn incentive rewards?
A walker earns incentive rewards based on their individual fundraising total—not their team total. Donations can be credited to a walker or to the team. By donating to a walker, you are supporting the team the walker is on and, of course, to IDF Walk for PI as a whole. But donations to a team do not count toward an individual’s efforts and their reward redemption. Fundraising incentives are based on an individual’s fundraising success.

What is the Top Team Village?
It’s an exclusive area where the top 3 teams who raised the most funds can hang out, eat snacks, and play games.
We are here to help! Contact us with your questions.

E-mail
walk@primaryimmune.org

Phone
800-296-4433

Web
www.walkforPI.org

Mail
Immune Deficiency Foundation
110 West Road, Suite 300
Towson, MD 21204