

IDFWALK FOR PRIMARY IMMUNODEFICIENCY

An initiative of the Immune Deficiency Foundation



COMMUNICATIONS AND MEDIA GUIDELINES

Thank you for supporting IDF Walk for Primary Immunodeficiency! We're grateful for your interest in promoting your walk to your community. To ensure the quality and consistency of IDF Walk for PI, we ask that you follow the guidelines below when promoting your walk.

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COMMUNICATIONS

We want you to get the word out, and that involves posting flyers and sharing information online. We recommend sharing our:

- **Site specific flyer**
- **Suggested social media posts**

Available at www.walkforpi.org/Static/fundraising-resources.

Although we do not encourage customized material (simply because we want you to focus on fundraising and awareness and not graphic design), **any customized material with the IDF Walk for PI logo or name needs to be approved by IDF prior to production or distribution.**

Please submit the customized material at least fourteen (14) days before the proposed use: walk@primaryimmune.org. We will evaluate the materials submitted for approval within ten (10) days after receipt. IDF reserves the right to not approve the customized material and recommend use of existing IDF materials.

MEDIA

You have the power to tell a great story to the media, and we want to help you! Your options are endless. You can:

Contact your local TV or radio station.

Get a proclamation from your city's Mayor.

Set up a table outside of Walmart.

Make presentations to local groups.

Anything you can do to promote the walk is great!

Over the years, it has been amazing to see how media stories about PI can actually result in the diagnosis of a new patient. This underscores how vital it is to share your story and raise awareness through the media. Perhaps you are an individual affected by a primary immunodeficiency (PI) or your loved one is affected by PI. Whatever your story, it is important to share it with your local media so they understand the local connection to our national effort. Scroll below to view tips when contacting the media. If you have questions about contacting the media, the IDF Communications Department can assist you: **410-321-6647** or idf@primaryimmune.org.

INSTRUCTIONS FOR CONTACTING THE MEDIA

GETTING STARTED

It is important to gather facts and information in the beginning. By navigating through our website, www.primaryimmune.org, you will know where to look for the information you need at any given time. When a reporter wants more information, you will know where to find answers. If you cannot provide an answer about PI or IDF, be honest about it and refer them to the IDF Communications Department at **410-321-6647** or idf@primaryimmune.org. We are always eager to help!

ASSEMBLE A PRESS LIST

Identify reporters, editors, producers, and other members of the media to have your voice heard.

Who are you looking for?

- Any media who you have worked with in the past – even if they cover a topic unrelated to IDF/ health, etc., they can direct you to the right reporters at their organization and are a great foot in the door.
- Health reporters/columnists/editors.
- Feature reporters/editors.
- Community/neighborhood reporters/editors.
- Any reporter that does a regular segment or spot that has made you think, “They should really do a story on primary immunodeficiency (PI)!”.
- Assignment editors (this is primarily for TV).

How do you find them?

Leverage any and all contacts you might have through past work with members of the media, personal relationships, or other connections.

Go to the individual websites of each of the media outlets that you are targeting, and use the search tool, entering terms such as “health,” “local volunteers,” “immune deficiency,” and any other relevant terms you can think of. This will give you a sense of who has been covering related topics.

Use Google or other online tools to identify your local media outlets (you probably are already familiar with some, but this will help find additional publications).

After surveying the media members in your market, set a goal of how many media members you would like to contact and follow up with. A good number to start with is five. The IDF Communications Department can also assist you with putting together a targeted media list. Please feel free to contact us at [410-321-6647](tel:410-321-6647) or info@primaryimmune.org.

FIND CONTACT INFORMATION

Once you have identified relevant contacts, check the publication or station's website to see if they list individual or department emails and phone numbers. If the website only lists a general number, try calling that and asking the main receptionist for the specific contact information you are looking for.



SEND YOUR INFORMATION VIA EMAIL FIRST

- When possible, send your pitch email to all of your media contacts first. This way, they will have a point of reference when you give them a call.
- Send your initial email to reporters as soon as possible.
- Do not attach text documents to any emails sent to the media; instead copy the text of your release or message into the body of the email.
- If you are telling your own story, consider submitting a picture of you and your family. When possible, provide the media with "camera ready" photos or jpg files.

FOLLOW UP WITH A PHONE CALL

- While some reporters may respond to your email directly, many will require a phone follow-up call **the day after you send your email** to make sure they have received the materials and to ask if they have any questions.
- Best times to call reporters are generally between 9 AM and 2 PM. This may vary for TV contacts, but typically, print reporters are on deadline in the late afternoon and will not have time to talk.
- We recommend starting your conversations with reporters something like this:

IDF Volunteer (IDFV): "Hi, my name is [insert name], and I'm checking to make sure you received my email to you yesterday[in the morning/afternoon] on [subject matter] for [name of your media contact]." **NOTE: If not received by intended recipient, re-send fax, or email.**

IDFV: "Do you think someone can come out to cover this event?" ("It's a great story, excellent photo opportunity—families, good cause," etc.)

IDFV: "We'll check back with you at the end of the week. Here is my contact information..."

IDFV: "Thank you and anything you can do will be greatly appreciated..."

- If you leave a message, give the reporter a day and then try again to catch them on the phone, but do not leave multiple messages.

- Follow up calls are a vital part of the media outreach process, and it is ok to be appropriately aggressive with your follow up. Reporters keep busy schedules and just because you are not hearing back does not mean they are not interested in your story idea. Media members sometimes need the follow-up call to jog their memory and prompt a response.

SAMPLE PITCH EMAIL TO REPORTER

Dear <Reporter's Name>,

I have been a resident of <INSERT TOWN> for many years and think it is important to tell my story about living with primary immunodeficiency (PI) to our community so others do not have to go on misdiagnosed and untreated.

PI are a group of more than 450 different types of often widely misdiagnosed rare, genetic disorders that occur in patients in which part of the immune system is missing or functions improperly. People with PI live their entire lives more susceptible to infections, and without proper treatment they may endure recurrent health problems, often developing serious and debilitating illnesses.

<INSERT PERSONAL DETAILS ABOUT YOUR EXPERIENCE WITH PI>.

Media coverage of these disorders will help raise awareness among our community's children, their parents, adults, and the healthcare professionals who care for them. Too often it takes years for people to be diagnosed as having a type of PI. It is amazing to see how past media coverage of patients with PI has led to new patients learning about the disorders and being diagnosed.

<INSERT DETAILS ABOUT YOUR UPCOMING WALK>

I would like to speak with you about my experience and how we can let the people in our community know about PI. I have included my contact information below and look forward to hearing from you so we can discuss this further.

Thank you for your consideration!

Best regards,

<Your Name>

<Your Phone Number>

<Your Email Address>





About the Immune Deficiency Foundation, primary immunodeficiencies (PI), and what it means to be immunocompromised

Founded in 1980, the Immune Deficiency Foundation (IDF) improves the diagnosis, treatment, and quality of life of people affected by primary immunodeficiency (PI) through fostering a community empowered by advocacy, education, and research. Approximately, 2.7% of the U.S. population is moderately to severely immunocompromised. This means that more than nine million people have immune systems that do not function properly. Among them, are people living with PI. There are approximately 500,000 Americans who are diagnosed with PI. These individuals often find it difficult to receive specialized healthcare and proper diagnosis and treatment. Individuals affected by PI also experience difficulties financing their healthcare, finding educational materials on the disease and locating others with whom to share their experiences. IDF helps individuals overcome these difficulties so they can live healthy and productive lives. The constant presence of IDF assures people with PI, their families and their healthcare providers that there is a place to turn for help.

Frequently Asked Questions about Primary Immunodeficiencies (PI)

What is PI?

Primary immunodeficiencies are a group of more than 450 rare, chronic disorders in which part of the body's immune system is missing or functions improperly. These problems lead to an increased susceptibility to infection.

Who does PI affect?

According to IDF, there are approximately 500,000 individuals living in the U.S. with a primary immunodeficiency. Every year, thousands more go undetected. While not contagious, these disorders are caused by hereditary or genetic defects, and although some disorders present at birth or in early childhood, the disorders can affect anyone, regardless of age, gender, or ethnicity.

How is PI diagnosed?

Medical and family history, physical exam, blood and immunoglobulin level tests, and vaccines to test the immune response may be included in the diagnosis process. Early diagnosis of PI is critical. Based on IDF survey data, the average time from symptom onset to diagnosis is between 9 and 15 years. Fifty percent of those patients are 18+ years of age when diagnosed. During this period of time, 37% of patients report permanent functional impairment, including lung disease. With earlier diagnosis, many of these permanent impairments could be avoided.

What are the symptoms of PI?

You should be suspicious if you have an infection that is:

Severe – requires hospitalization or intravenous antibiotics

Persistent – won't completely clear up or clears slowly

Unusual – caused by an uncommon organism

Recurrent – keeps coming back

Runs in the Family – others in your family have a similar susceptibility to infection



If any of these describe your infection, ask your physician to check for the possibility of a PI.

People with PI are more susceptible to infections and health problems that lead to serious and debilitating diseases. It is critical to get an early diagnosis and proper medical care.

How is PI treated?

Treatment for PI depends on the specific type of disorder. Immunoglobulin (Ig) replacement therapy is the treatment for people with certain types of antibody deficiencies. For other types, treatments may include one or more of the following: gene therapy, hematopoietic stem cell transplantation (bone marrow transplantation), interferon gamma, and/or enzyme replacement therapy. Prophylactic antibiotics and/or antifungals are also used by themselves or in combination with other therapies.

Countering Misperceptions

- Having PI does not mean you have to live in a bubble.
- While PI is serious, these disorders vary widely in their severity.
- David Vetter, known as the “boy in the bubble” had Severe Combined Immune Deficiency (SCID), the most serious disorder.
- With early diagnosis and proper treatment therapy, most patients with PI can go to school, work, and live healthy, productive lives.

TIPS FOR CONDUCTING MEDIA INTERVIEWS



If you are fortunate to get an interview lined up with a reporter, the Communications Team at IDF can provide a wide variety of resources for you—don’t feel like you need to go it alone. **Contact IDF as soon as you learn about the interview, and we will help you make the most of it!** Contact us: 410-321-6647 or info@primaryimmune.org.

See below for some basic tips and information to consider.

- Read your talking points ahead of time. If the interview is over the phone, keep the talking points in front of you for easy reference.
- Before the interview, select your top two or three messages that you think are most important to convey and think about what real world examples you can use to best convey those messages.
- Try a few practice questions with one of your friends, a fellow volunteer, or someone else you feel comfortable with. They can play the role of the reporter, and this type of practice can be helpful for getting through initial nervousness and honing your responses.
- If a reporter asks a question that you do not know the answer to, that is OK. Just tell them that you do not know off the top of your head, but that you can find out and get back to them. If this happens, please contact the IDF Communications Department at 410-321-6647, or info@primaryimmune.org, so that we can provide you with the information you need to follow up with the reporter after your interview.
- Keep your answers as succinct as possible, and tie your responses back to IDF and your key messages.
- Repetition is good and effective. Do not worry about being redundant, especially on key points you are trying to make. The more you say something, the more important it becomes, the better it may sound and the more likely it will get included in the media coverage.
- Be yourself. You do not need to take on a different voice or formality because you are talking to a reporter. If you talk like yourself, you will be more comfortable and more authentic.

SAMPLE TEMPLATE FOR MEDIA ADVISORY/PHOTO-OP

Headline

WHEN: <Month> <Day>, <Year> at <Hour>:<Minutes><AM or PM>

WHERE: <Location name and address; include directions if necessary> Include landmarks if it helps.

WHAT: <Clearly state the news. Describe the walk and why you are walking with interesting details—what makes your event unique and fun. Let the media know of anything that would be a good visual.>

WHY: <Make this a compelling paragraph about why you are hosting a walk and why it is important to raise awareness and funds for primary immunodeficiencies. Why is this event relevant to your community?>

WHO: Immune Deficiency Foundation and <your name and any other special guests or speakers>

CONTACT: <Media Contact Name>
<Phone/Pager/Cell to call before the event>
<Phone/Pager/Cell to call during the event>

(centered—this indicates it's the end of your advisory)

Note: Media advisories are straightforward memos to editors, requesting their presence at an event. Keep it at one page. If you are going over a page, revise what you have written and see what information is not indispensable. Your message will be newsworthy if the editor/reporter realizes that your event will interest and benefit your local community.

SAMPLE TEMPLATE FOR CALENDAR LISTINGS

LOCATION. [Day, Date, Time]. Immune Deficiency Foundation Walk for Primary Immunodeficiency [Add more details of the event, limit to 2 sentences or less — i.e., what will happen at the event]. Street address. For more information [insert phone number or website].

Notes:

- For listings in dailies, send information at least 10 days in advance of the event - best to do it two weeks in advance to be safe.
- For listings in weeklies, the deadlines vary from three weeks to one month in advance. It is best to contact them one month ahead just to be sure it gets placed.
- Call paper and ask for who handles community happenings or events. Ask for preferred method of receiving the information (fax? email?). Send info. Follow up to make sure they received your information and ask whether they have any questions.

If you have questions about contacting the media, the IDF Communications Department can assist you: 410-321-6647 or idf@primaryimmune.org.