

## **Contacting the Media for Primary Immunodeficiency Awareness Month 2011**

April is Primary Immunodeficiency Awareness Month! Thank you for your interest in promoting Primary Immunodeficiency Awareness Month 2011. We encourage you to publicize as much as possible. The purpose of seeking publicity is to raise awareness of PIDD, to get your message across to the community, and to get people to attend your event if you are holding one.

All of you have your own story to tell. Perhaps you are a person living with PIDD or you have a significant relationship with someone affected by this disease. Whatever your story, it is important to share it with your local media so they understand the local connection to the national effort.

Attached you will find:

- Instructions on contacting the media
- A letter to send to a reporter or other member of your local media
- A sample press release for you to send to your local media informing them of your event
- PIDD Frequently asked questions sheet to include with the letter and press release
- A template and instructions on submitting information to newspaper calendars
- A template and instructions on submitting a Media Advisory/Photo-Op
- A template and instructions on submitting information to newspaper calendars
- Tips for Conducting Media Interviews and Interview Talking Points

## **INSTRUCTIONS FOR CONTACTING THE MEDIA**

It is important to gather facts and information in the beginning. By navigating our website ([www.primaryimmune.org](http://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 can't provide an answer about primary immunodeficiencies or the IDF, be honest about it and refer her/him to the Immune Deficiency Foundation Communications Department at 800-296-4433 or [info@primaryimmune.org](mailto:info@primaryimmune.org).

### **1. Identify reporters, editors, producers and other member of the media**

#### Who you're looking for:

- Any media who you've 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
- Assignment editors (this is primarily for TV)

#### How to 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 web sites of each of the media outlets that you are targeting, and use the search tool, entering terms such as “health,” “local volunteers,” “awareness month,” “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 such as <http://epodunk.com/search/newspapers.html> to identify your local media outlets (you probably are already familiar with some, but this will help find additional publications)

### **2. Find contact information**

- Once you've identified relevant contacts, check the publication or station's web site to see if they list individual or department e-mails and phone numbers
- If the web site only lists a general number, try calling that and asking the main receptionist for the specific contact information you're looking for

[\*Note: depending on the media outlet, it is possible that they will not give you direct contact information for specific editors or reporters over the phone. In that case, ask if there is a general news desk e-mail or phone number for story ideas and use that]

### **3. Send your information via email first**

- When possible, send the press release or pitch letter to all of your media contacts via e-mail first. This way, they will have a point of reference when you give them a call
- Send your initial e-mail to reporters **as soon as possible**
- Do not attach text documents to any e-mails sent to the media; instead copy the text of your release or message into the body of the e-mail
- 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.

#### 4. Follow up with a phone call

- While some reporters may respond to your e-mail directly, many will require phone follow up to make sure they have received the materials and to ask if they have any questions
- Best times to call reporters are generally between 9:00 a.m. and 2:00 p.m. 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 the news release emailed to you today [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

## **SAMPLE TEMPLATE FOR LETTER TO REPORTER**

<Date>

<Your Name>

<Address 1>

<Address 2>

Dear <Reporter's Name>:

Primary immunodeficiency diseases (PIDD) are a group of more than 150 different types of often widely misdiagnosed genetic diseases.

PIDD is a classification of genetic diseases where part or all of a person's immune system is compromised, making it difficult for the body to fight infection. I have been a resident of <INSERT TOWN> for many years and think it is important to tell my story to our community so that others don't have to go on misdiagnosed and untreated.

<INSERT PERSONAL DETAILS ABOUT YOUR EXPERIENCE WITH PIDD>.

Media coverage of this disease 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 primary immunodeficiency disease. I would like to speak with you about my experience, and how we can let the people in our community know about PIDD. I have included my contact information below, and look forward to hearing from you so we can discuss this further.

Thank you for your time.

Best regards,

<Your Name>

<Your Phone Number>

<Your E-mail Address>

## SAMPLE TEMPLATE FOR EVENT PRESS RELEASE

### FOR IMMEDIATE RELEASE

<Date>

Join \_\_\_\_\_ at \_\_\_\_\_ to Celebrate  
**Primary Immunodeficiency Diseases Awareness Month!**

<City, State>—April is National Awareness Month for Primary Immunodeficiency Diseases, and <your organization's name> is joining with the Immune Deficiency Foundation (IDF) to educate others about these disorders. <Your organization's name> is pleased to announce that we will be doing/holding <explain event> at <\_\_\_\_\_> on <\_\_\_\_\_>, to help educate, raise funds and create awareness for primary immunodeficiency diseases.

In the United States, approximately 250,000 people are diagnosed with primary immunodeficiencies and thousands more go undetected. These diseases are chronic illnesses caused by hereditary or genetic defects in the immune system in which part of the body's immune system is missing or does not function properly. These diseases are not contagious.

There are over 150 different primary immunodeficiency diseases and they affect people differently. For some, the body fails to produce any or enough antibodies to fight infection, while for others; the cellular defenses against infection fail to work properly. Throughout their lives, people with primary immunodeficiencies are more susceptible to infections, endure recurrent health problems and often develop serious and debilitating illnesses.

Please join <your organization's name> in this awareness event for the Immune Deficiency Foundation. The Immune Deficiency Foundation leads advocacy for healthcare needs, provides medical programs for health professionals, supports research and offers services and educational materials for patients and their families. The funds that <your organization's name> raises, will be used to expand the work of the Immune Deficiency Foundation to improve the treatment and diagnosis of patients with primary immunodeficiency diseases. For more information, contact <\_\_\_\_\_> at <phone # and email> with any questions.

### **About The Immune Deficiency Foundation**

The Immune Deficiency Foundation, founded in 1980, is the national non-profit patient organization dedicated to improving the diagnosis, treatment and quality of life of persons with primary immunodeficiency diseases through advocacy, education and research.

There are approximately 250,000 people who are diagnosed with a primary immunodeficiency disease in the United States. These individuals often find it difficult to receive specialized health care, proper diagnosis and treatment. Individuals affected by primary immunodeficiency diseases also experience difficulties financing their health care, finding educational materials on the disease and locating others with whom to share their experiences. The mission of IDF is to help individuals overcome these difficulties and live a healthy and productive life. The constant presence of IDF assures patients, their families and their medical caretakers that there is a place to turn for help. To learn more about IDF, visit [www.primaryimmune.org](http://www.primaryimmune.org)

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## **FREQUENTLY ASKED QUESTIONS TO SEND TO MEDIA**

### **What is PIDD?**

Primary immunodeficiency diseases (PIDD) are a group of genetic diseases in which the immune system's ability to fight off infection is greatly reduced or absent. These problems lead to an increased susceptibility to infection. There are more than 150 different types of PIDD.

### **Who does PIDD affect?**

According to the Immune Deficiency Foundation (IDF) there are approximately 250,000 people diagnosed with primary immunodeficiency diseases in the United States. Thousands more go undetected. PIDD can strike people at all ages, though symptoms often begin to present early in life.

### **How is PIDD 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. IDF estimates that the average length of time between onset of symptoms and diagnosis is an average of nine years. Fifty percent of those patients are 18+ years of age when diagnosed.

### **What are the symptoms of PIDD?**

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 primary immunodeficiency disease. People with primary immunodeficiencies 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 PIDD treated?**

Immunoglobulin replacement therapy is the primary treatment for PIDD. In a recent IDF survey it is estimated that 70 percent of those diagnosed with PIDD reported that they are being treated with immunoglobulin.

### **How can I find out more?**

For more information contact the Immune Deficiency Foundation at 800.296.4433 or visit [www.primaryimmune.org](http://www.primaryimmune.org).

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## **TIPS FOR CONDUCTING MEDIA INTERVIEWS**

- 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 2 or 3 messages that you think are most important to convey and think about what examples, metaphors, interesting points or colorful language 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 don't 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 800-296-4433, or [info@primaryimmune.org](mailto: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.
- Always tie your responses back to IDF and your key messages
- Repetition is good and effective. Don't 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. Don't feel like you 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 communicate more authentically.

## **MEDIA INTERVIEW TALKING POINTS**

### **About Primary Immunodeficiency Diseases (PID)**

- In the United States, there are approximately 250,000 people diagnosed with primary immunodeficiency disease and thousands more go undetected. This means that in the United States, approximately 1 in 1,200 persons have a diagnosed PID.
- Primary immunodeficiency diseases occur in patients born with an immune system that is either absent or poorly functioning.
- There are over 150 different types of PID, all caused by genetic or intrinsic defects.
- People with PID live their entire lives more susceptible to infections, and without proper treatment may endure recurrent health problems, often developing serious and debilitating illnesses.
- Although many types of PID are present at birth, or symptoms occur in early childhood, some patients may develop a primary immunodeficiency in any decade of life.
- Early diagnosis of PID is critical:
  - Based on Immune Deficiency Foundation survey data, the time from symptom onset to diagnosis is between 9 and 12 years.
  - 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.

### **Countering Misperceptions**

- Having PID does not mean you have to live in a bubble.
- While PID is serious, these diseases vary widely in their severity.
- David Vetter, known as the "boy in the bubble" had Severe Combined Immune Deficiency (SCID), the most serious disorder. The only treatment for SCID is a bone marrow transplant, but for some forms of SCID, there have been some promising signs of success from gene therapy.
- With early diagnosis and proper treatment therapy, most patients with PID can go to school, work and live healthy, productive lives.

### **How do you Know if you Have PIDD?**

- IDF and its Medical Advisory Committee have developed a list of five key factors to consider if you are suspicious that you or a loved one might have PIDD.
- You should be suspicious if you have an infection that is:
  - Recurrent: keeps coming back
  - Persistent: won't completely clear up or clears very slowly
  - Severe: requires hospitalization or intravenous antibiotics
  - Unusual: caused by an uncommon organism
  - Runs in the Family: others in your family have had a similar susceptibility to infection

### **Ensuring Patient Access to Intravenous Immune Globulin (IVIG)**

- IVIG is a life-saving and life-enhancing therapy for many primary immunodeficiency diseases.
- Between 35,000 and 55,000 patients with PIDD in the United States depend on IVIG
  - Immune Globulin is the only effective treatment for patients who are antibody deficient.
  - IVIG use significantly reduces the number of infections, hospitalizations, and missed days of work or school for patients who depend on IVIG to maintain their health.
- As a result of inadequate reimbursements, many patients have not been able to access their medically necessary IVIG treatments.
- Legislation has recently been introduced in Congress to fix this problem and it is vital that our legislators take action.
- Visit [www.primaryimmune.org](http://www.primaryimmune.org) to use the IDF Action Alert to contact your legislator and urge them to support this legislation.

### **About the Immune Deficiency Foundation (IDF)**

The Immune Deficiency Foundation (IDF), founded in 1980, is the national patient organization dedicated to improving the lives of these individuals through advocacy, education and research. To learn more about IDF programs, please visit our website at [www.primaryimmune.org](http://www.primaryimmune.org)

## 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.> What type of event you're hosting. Is your event in honor of someone? Describe your event 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 an event and why it is important to raise awareness and funds for primary immunodeficiencies. Why is this event relevant to your community?

WHO: Event Hosts by name (is it an individual, a family, a business, religious organization, school?) <List who is speaking and what they'll discuss.> NOTE: If you will have speakers at your event, let the media know who is available for interview. It makes your event more meaningful and interesting to local media.

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've 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 LISTING

LOCATION. [Day, Date, Time]. Immune Deficiency Foundation fundraiser for primary immunodeficiency awareness month. [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 Web site].

### 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 3 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.