Raising Awareness of Primary Immunodeficiency through the Media

Thank you for your interest in promoting primary immunodeficiency awareness! The purpose of seeking publicity is to raise awareness of primary immunodeficiency diseases, to get your message across to the community, and to get people to attend your event if you are holding one.

Over the years, it has been amazing to see how media stories on primary immunodeficiency diseases can result in the diagnosis of a new patient! This drives home how vital it is to share your story through the media.

Perhaps you are an individual living with a primary immunodeficiency disease 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 our 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
- A template and instructions on submitting information to newspaper calendars
- Frequently asked questions related to primary immunodeficiency diseases to include with the letter and press release
- 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

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 primary immunodeficiencies or IDF, be honest about it and refer them to the IDF Communications Department at 800-296-4433 or info@primaryimmune.org. We are always eager to help!

1. Assemble a “press list” - identify reporters, editors, producers and other members of the media

   Who you’re 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 disease!”
   - 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 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 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).

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 (5).

The IDF Communications Department can also assist you with putting together a targeted media list. Please feel free to contact us at 800-296-4433 or info@primaryimmune.org.

2. Find contact information

   Once you have identified relevant contacts, check the publication or station’s website to see if they list individual or department e-mails 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.

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.
INSTRUCTIONS FOR CONTACTING THE MEDIA (Continued)

- 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 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 9:00 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.
- 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.
<Date>

<Your Name>
<Address 1>
<Address 2>

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 disease (PI) to our community so others do not have to go on misdiagnosed and untreated.

PI are a group of more than 250 different types of often widely misdiagnosed rare, genetic diseases 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 may endure recurrent health problems, often developing serious and debilitating illnesses.

<INSERT PERSONAL DETAILS ABOUT YOUR EXPERIENCE WITH PI>.

Media coverage of these diseases 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 diseases and being diagnosed.

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 time.

Best regards,

<Your Name>
<Your Phone Number>
<Your E-mail Address>
FOR IMMEDIATE RELEASE
<Date>

Join ___________________________ at ___________________________ to Raise Awareness of Primary Immunodeficiency Diseases!

<City, State>— <Your name or your organization’s name> is joining with the Immune Deficiency Foundation (IDF) to educate others about primary immunodeficiency diseases. <Your name or 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 (PI).

PI are a group of more than 250 different types of often widely misdiagnosed genetic diseases that occur in patients in which part of the immune system is missing or functions improperly. In the U.S., approximately 250,000 people are diagnosed with PI, and thousands more go undetected. These diseases are chronic illnesses caused by hereditary or genetic defects, and they are not contagious. People with PI live their entire lives more susceptible to infections, and without proper treatment may endure recurrent health problems, often developing serious and debilitating illnesses.

Please join <your name or your organization’s name> in this awareness event for IDF, an organization that 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 IDF to improve the treatment and diagnosis of patients with PI. For more information, contact <your name or name at your organization> at <phone # and email> with any questions.

About the Immune Deficiency Foundation
The Immune Deficiency Foundation (IDF), 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 (PI) through advocacy, education and research.

There are approximately 250,000 people who are diagnosed with a PI in the U.S. These individuals often find it difficult to receive specialized healthcare, 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 these 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.

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FREQUENTLY ASKED QUESTIONS TO SEND TO MEDIA

What are primary immunodeficiency diseases (PI)?
Primary immunodeficiency diseases (PI) are a group of more than 250 rare, chronic disorders in which part of
the body’s immune system is missing or functions improperly. While not contagious, these diseases are
caused by hereditary or genetic defects. Some types affect a single part of the immune system; others may
affect one or more components of the system.

Who does PI affect?
According to the Immune Deficiency Foundation (IDF), there are approximately 250,000 people diagnosed with
PI in the U.S. Thousands more go undetected. Although some disorders present at birth or in early childhood,
the disorders can affect anyone, regardless of age or gender.

How is PI diagnosed?
Medical and family history, physical exam, blood and immunoglobulin level tests and vaccines to test the
immune response may be include in the diagnosis process. IDF estimates that the average length of time
between onset of symptoms and diagnosis is between nine and 15 years. Fifty percent of those patients are
18+ years of age when diagnosed.

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
to get an early diagnosis and proper medical care.

How is PI treated?
Immunoglobulin (Ig) replacement therapy is the primary treatment for PI. In a recent IDF survey, 70 percent of
those diagnosed with PI reported that they are being treated with immunoglobulin.

What is THINK ZEBRA?
The PI community often identifies with zebras. This is based on an old saying. In medical school, many doctors
learn the saying, “when you hear hoof beats, think horses, not zebras” and are taught to focus on the likeliest
possibilities when making a diagnosis, not the unusual ones. However, sometimes physicians need to look for
a zebra. Patients with PI are the zebras of the medical world. So IDF says THINK ZEBRA!

Patients and family members can be seen wearing zebra striped clothes and using accessories adorned with
black and white stripes. Children identify with zebras and it has been a way for children with PI to describe their
disease to others—they are like zebras.

How can I find out more?
For more information, contact IDF at 800-296-4433 or visit **www.primaryimmune.org**
About The Immune Deficiency Foundation
The Immune Deficiency Foundation (IDF), 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 U.S. These individuals often find it difficult to receive specialized healthcare, 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. IDF helps these 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.
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 two or three messages that you think are most important to convey and think about what real world examples or interesting points 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 800-296-4433, 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.
- Always 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 formalness because you are talking to a reporter. If you talk like yourself, you will be more comfortable and more authentic.

MEDIA INTERVIEW TALKING POINTS

About Primary Immunodeficiency Diseases (PI)

- Primary immunodeficiency diseases (PI) occur in patients in which part of the immune system is missing or functions improperly. The World Health Organization recognizes more than 250 different types of PI, all caused by genetic or intrinsic defects.
- In the U.S., there are approximately 250,000 people diagnosed with and thousands more go undetected. This means that in the U.S., approximately 1 in 1,200 persons have a diagnosed PI.
- While not contagious, these diseases are caused by hereditary or genetic defects.
- People with PI live their entire lives more susceptible to infections, and without proper treatment may endure recurrent health problems, often developing serious and debilitating illnesses.
- Although some disorders present at birth or in early childhood, the disorders can affect anyone, regardless of age or gender.
- Early diagnosis of PI is critical:
  - Based on Immune Deficiency Foundation (IDF) survey data, the average time from symptom onset to diagnoses is between 9 and 15 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 PI does not mean you have to live in a bubble.
- While PI 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 PI can go to school, work and live healthy, productive lives.
How do you know if you have a primary immunodeficiency disease?

- 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 primary immunodeficiency diseases.
- 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 Treatment

- Immunoglobulin therapy (Ig) is a life-saving and life-enhancing therapy for many types of PI.
  - In a recent IDF survey, it is estimated that 70 percent of those diagnosed with PI reported that they are being treated with immunoglobulin.
  - Immunoglobulin is the only effective treatment for patients who are antibody deficient.
  - Ig therapy significantly reduces the number of infections, hospitalizations and missed days of work or school for patients who depend on Ig therapy to maintain their health.
  - It is important to understand that the Ig that is given partly replaces what the body should be making, but it does not stimulate the patient’s own immune system to make more Ig. In addition, the Ig only provides temporary protection.
  - Depending on the route of administration, this may be done by giving small infusions under the skin (subcutaneous immunoglobulin or SCIG) weekly or as often as every one to three days, or by giving larger intravenous immunoglobulin (IVIG) infusions once every three or four weeks.
  - Since Ig only replaces the missing end product, but does not correct the patient’s defect in antibody production, Ig replacement is usually necessary for the patient’s lifetime.

- As a result of inadequate reimbursements, many patients have difficulty accessing their medically necessary Ig treatments.

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, services and educational materials, 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 are 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 will 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 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 LISTING

LOCATION. [Day, Date, Time]. Immune Deficiency Foundation fundraiser. [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.