

Media Guidelines

Developing and managing relations with media is an essential step to successfully raise awareness of PID among the general public and with other target audiences. The following guidelines serve to assist NMOs as they develop local media relations. It includes a simple media check list to guide NMOs on the key steps to be taken to establish relations with journalists prior to an awareness raising event or campaign. The guidelines also offer advice on approaching journalists, writing press releases and writing a press invitation. Additional guidelines for approaching the radio and TV are available on the IPOPI website.

I. Media Check List

Six months prior to campaign/event

- Develop approach: What is your objective? Do you want to raise awareness of PID? Issue a call for action? A petition? How will you communicate with the media: press conference, 1:1 interviews; events, press visits to centres, hospitals, patient homes etc.
- Gather media lists: from sponsors, allied associations; or media contacts. Organise media lists with: contact names, titles, email address, telephone numbers. Identify journalists who are responsible for health, consumer and science. Try to research whether there are any journalists who have covered PID and rare diseases and send them tailored messages referencing their previous articles.
- Identify and brief a spokesperson comfortable with PID. Explain to spokespersons about the public nature of the role and mention that the media may seek to interview family members with PID.

Two Months prior to campaign/event

- Call media to update contact list and alert them about upcoming press activity.
- Write the press releases, prepare background material.

2-6 weeks prior to campaign/event

- Send press kit to media as background briefing.
- Request 1:1 interviews with most important correspondents.
- Follow-up phone calls to media about press releases.

Day of campaign/event/event

- Send a repeat of the press release to media.
- Upload the press release and all background material on your organisation website.

Day/week after campaign/event

- Ensure you have a means of tracking your media results (e.g. Google alerts)!

II. How to approach a journalist

- Target the right person - a journalist who usually covers health, consumer or science related topics.
- Use the direct telephone line/e-mail of the journalist.
- Approach journalists as early as a few months before your event or campaign launch to start building awareness of PID, and make follow up calls to try to build relationships.
- Since journalists are busy, you have only a minute or two to state your purpose. In the first few moments, you must explain the essential points of your story and raise interest. Explain why PID is important and why the journalist should cover it.
- Making calls in the morning gives you a better chance of talking to journalists. It is also when most editors and producers decide what to cover in their evening news or next-day's paper.
- Suggest possible interviews with experts, as well as patients, parents or carers. Ensure that you have briefed all your experts in advance before providing their names. You can also arrange a meeting to discuss additional angles.
- Before ending the call double-check contact details/e-mail addresses etc.
- Take note of the conversation so you can easily relate to the discussion when you call back at a later date.
- Follow up with a written thank you note and a press kit so the journalist has all background information needed to understand the importance of PID.

III. Writing a Press release

- Put the most important information first. Your headline should grab journalists' attention.
- Keep your press release to one side of one page. Make sure the font is large enough to read at least font size 10.
- The lead sentence should summarize what's most newsworthy: When, Who, What, Where, Why
- The most eye-catching messages for the media might be the lack of awareness of the disease, and lack of diagnosis, a clear government strategy and the need for politicians to put in place targeted campaigns to increase recognition of PID. Messages should also be tailored to the issues you want to address in your country. Include up to date statistics where feasible, or interesting local angles e.g. story about SCID babies;
- Insert quotes from your organisation or other prominent contributors from your country to illustrate and enhance your data. It should also involve a PID patient who can give his/her views and a statement or patient case studies (see Patient testimonials on the World PI Week website).
- Use your organisation logo, the IPOPI logo, the World PI Week logo, high resolution pictures, and other relevant logos of allied partners/organisations.
- At the end of the release include 3-4 lines about your organisation.
- Include contact details for further questions or possible interviews.
- Put a ### or ENDS at the bottom of the page.

IV. Writing an invitation

In many countries, an invitation (also called a media advisory) is structured in the following way:

- **WHAT:** stating the context and the agenda.
- **WHO:** the name and titles of the speakers.

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- WHERE: the location name and address.
- WHEN: Time and duration.
- REGISTRATION: who they should contact to register or an exact web address.

V. What to include in a PID press kit

- What are PIDs? detailed information available on IPOPI.org
- Country specific information on PID including: graphs/ statistics, patient testimonials and/ or case studies.
- Q&As tailored with local data
- Global Call to Action – available on World PI Week [website](#)
- European Parliament Expert recommendations for better Management of Primary Immunodeficiency – available on World PI Week website
- IPOPI Principles of care infographics
- IPOPI PID Information leaflets
- High resolution pictures and logos