

Guidelines on Government Outreach

It is crucial to raise awareness of PID at government level in your country if your organisation wishes to affect change, promote early diagnosis and affective treatment. The following guidelines serve to help NMOs to approach government in close collaboration with other key stakeholders.

I Define your goal

Defining the goal for your government activities helps keep your organisation focused. You can start by identifying key challenges you are facing in your country. As soon as you identify core areas which require immediate intervention, you can build messages and plan appropriate activities that address these challenges.

We would like to thank World PI Week for the use of their materials in compiling these guidelines.



22nd - 29th April 2011

II Identifying target audiences

There are a variety of different government groups that need to be targeted in your countries including:

- *Ministers*, heads and staff/experts/advisors of key departments for welfare, children, health and social protection.
- *Directors/heads* of public health bodies and authorities
- *Members of your National Parliament* – national Parliamentarians (elected politicians) with an interest in health, Committee Chairs or other key Parliamentary leaders/decision-makers.

III Message

It is important to have a good understanding of the status of PID in your country in terms of the level of awareness, diagnosis and treatment before approaching and communicating with government. All communication should focus on the need to increase understanding of the disease, promote early diagnosis as well as effective and optimal treatment. You are seeking a clear government strategy and the need for politicians to put in place targeted campaigns to increase recognition of PID. A PID fact sheet for government is available to download on the IPOPI website. Other materials are also available see point VII.

IV Working with allies

In order to pass a strong and united message to government it is crucial to engage with other PID stakeholders (patients, nurses, physicians, scientists, allied healthcare professionals, and industry) and make sure that you can work together and agree on common messages. You can organise a meeting with these groups to share your goals and ideas, and agree how you can work together successfully.

V Awareness raising activities

It is important to get to know and build a relationship with key government contacts in your country/region. Contact can be made and maintained in many ways as follows:

- One to one meetings with identified government target groups.
- Events – invite government representatives or Parliamentarians as guests and/or speakers at events for instance during World PI week.
- Seminars — invite government representatives or Parliamentarians as guests and/or speakers at seminars for instance during World PI week
- Parliamentary lunch/dinner/exposition: Hosted in the Parliament, bring together a small group of interested Parliamentarians to discuss informally the issue of PID with your organisation, patients, other allied professional groups, industry, sponsors etc.
- Set up a Parliamentary working group or expert group to discuss and conclude on the appropriate basis for dealing with PID in your country.
- Organise visits for instance to PID clinics, patient's homes etc so government representatives can experience PID and see the benefits of early diagnosis and treatment at first hand.
- Invite Parliamentarians to serve as patrons of their local PID clinics.
- Disseminate grass root letters from patients and relatives to their local Parliamentarians.

VI Nurturing the relationship

It is important to communicate with government frequently. Thank you letters should be sent after meetings which summarise your key messages and demands. Look at ways to follow up and maintain your contacts by inviting government representatives to your events by adding them to newsletter mailing lists etc. Set up a routine where you regularly meet your government contacts or their staff on a bi-annual basis to review progress on your issues.

VII Tools

Below is a list of the types of documents and guidance that you can find on the IPOPI and World PI Week Websites to help you when communicating with government audiences.

- IPOPI PID Leaflet
- IPOPI PID Factsheet for Government
- 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 10 Warning Signs