

Guide to Government Relations

Making Your Case Effectively

David Page

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1 Introduction

In many countries of the world, people with primary immunodeficiency (PID) do not have access to adequate care. They are held back from reaching their potential as human beings. They suffer great pain and run a high risk of crippling. Death at a young age is not uncommon.

In some other countries, where PID care has been well-developed, authorities are cutting back resources for treating PID and treatment Centres. High-quality care is endangered.

It is the role of National Member Organisations (NMOs) of IPOPI to work with governments and health authorities to raise the level of care so that people with PID can live healthy lives.

The purpose of this monograph is to provide national patient organisations with some practical guidance to improve the effectiveness of these government relations.

Note: The suggestions in this monograph may be very effective in some countries but inappropriate, or even damaging, in others. Readers must decide which recommendations are relevant given the political, social and cultural context in your particular country.

2 Lessons Learned in Government Relations

Create win-win situations.

The PID organisation and the government are partners in the work to improve patient care for people with primary immunodeficiency. If you are successful, people with PID will have better lives and the government will have contributed to improving the health of its citizens. This is a “win-win” situation. The PID organisation should see itself as a partner in finding a solution to the government’s healthcare problems.

Always remember your cause.

It is essential to focus on your cause, whether it is:

- a) outreach to regions and better diagnosis;
- b) the creation of a treatment centre;
- c) access to immunoglobulin or other appropriate therapy for people with a PID
- d) improved comprehensive care.

Your cause is a good one. PIDs can be treated. When they are treated, there is a dramatic improvement in the quality of life of that person and his family members. Avoid being distracted by side issues. If the national patient organisation is distracted, the government will be distracted.

Be patient, but be persistent

Major improvements in PID care do not usually happen overnight. In most countries, they are a slow, gradual process over many years.

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It is important not to be impatient because then discouragement is easy

On the other hand, a PID patient organisation must be persistent. When government officials see that the organisation has a clear idea of people's needs, that it never loses sight of its goals and is prepared to work over the long term, it will be taken seriously and considered a useful partner.

Remember you are not alone

It is easy for a small group of volunteers in a PID organisation to feel alone, especially if progress to reach their goals is slow. But you are not alone. Your members and their families support you. Many will lend a hand if asked.

You also have the support of healthcare professionals – doctors, nurses, physiotherapists, social workers – who work in the field of primary immunodeficiency. They have the same goal: to improve the care of their patients. Other social or religious organisations may be willing to help you, as well. If government officials see that you are not alone, your demands will receive a better hearing.

When good things happen, give credit

Most people are the same: when there is a problem, we get upset and criticize. But when things are going well, we relax and sit back. As a result, we forget to give credit. When government officials do good things, it is important to acknowledge these achievements publicly. And your NMO will be seen as an organisation that recognizes solutions and doesn't just complain about problems.

Never give up

While achieving your objectives may at times seem impossible, it is important to never give up. Times change, governments change, and what was impossible one year may be realistic the next. And people with a primary immunodeficiency need the hope that comes from knowing their organisation will continue to work in their interests.

3 Preparing Your Case

A national PID organisation will usually get only one opportunity to present its case to government officials. If it is not well-prepared and convincing, it may not get another chance for a long time. Therefore it is extremely important to take the time necessary to prepare your case well.

While the benefits of improved care for people with PID are obvious to those who live with it every day, this is not the case for government officials who may know very little about disorders of the immune system. What's more, governments have many challenges in improving the health system. Some problems affect a much larger percentage of

Taking the time

"Before our NMO met government to request greater access to factor concentrates, we took months to prepare. We looked at how many people with PID were diagnosed in the country and how much it would cost to provide them with adequate care. We listed all the individual and social benefits. When we finally submitted our request, it had to be taken seriously. We never regretted taking the extra time."

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the population. Therefore it is your responsibility to make a convincing argument that improved PID care is not only a benefit to those directly affected, but also provides benefits to the country as a whole.

Identify ways in which improved PID care benefits a country

There are many benefits for a country when it improves PID care. These are some of them:

Social benefits

- a) Much pain and suffering, especially among children, is avoided.
- b) There is much less disability among people with PID who receive good treatment and early diagnosis.
- c) This avoids the social costs of caring for them.
- d) People with PID who receive adequate care grow up healthy, can receive an education, work and contribute to society.
- e) Better health and less disability result in less stress on families. Other members of the family can be more productive.

Medical benefits

- a) Morbidity and mortality is decreased.
- b) The outreach efforts needed to diagnose people with PID can be copied for use with other conditions.
- c) With adequate diagnosis and care, there can be less strain on hospitals as people with PID are admitted less frequently. More care is given at home or in and outpatient basis.
- d) The idea of comprehensive care developed for PID (involving a multidisciplinary team including the patient and his family, home care, outpatient care...) can be used as a model to treat other diseases.
- e) The physicians in a country with a national treatment plan can receive valuable information from IPOPI, ESID and INGID.
- f) A well-developed PID care system can ensure that valuable resources are wisely used for the best outcomes and not wasted.
- g) The partnership among health authorities, doctors and patients is well developed in the field of PID in some countries. This is a powerful concept that can be applied to other areas of the health system.

Blood safety benefits

- a) Efforts to increase the safety of blood and blood products for people with PID through improved blood donor screening and testing measures will have a positive impact on all people who require transfusions.
- b) Links among the government, the NMO for PID, PID clinicians and IPOPI can lead to better choices when purchasing immunoglobulin and other appropriate therapies, and even cost savings.

Present good data

Government officials need good data in order to make decisions. It is essential that the PID NMO present the key data it possesses. However, the data must be accurate; otherwise, your organisation will lose credibility.

The information provided by the IPOPI NMO Questionnaire can be used in preparing your case as can information from treaters, the European database and the IDF.

Depending on the information available in your country, this could include:

- a) the number of people with CVID, SCID, XLP, HAE, and so on, registered in the country;

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- b) their average survival;
- c) the *expected* number of people with CVID, SCID, XLP, HAE, etc,
- d) the number of people infected with HCV;
- e) the number of people who have died in the last 12 months;
- f) the current level of Ig usage;
- g) the desired level of care;
- h) the number of PID treatment centres and the services they provide;
- i) current medical resources.

While treatment centres cannot give out confidential patient information to an NMO, they can share collective data on the people they serve. It is important to work with doctors and nurses to ensure that the data you present to government is as complete and accurate as possible.

Present solid arguments

Based on the ways improved PID care will benefit your country and the data you have, you can prepare solid arguments to support your case. Try these arguments with people you know to find out their reactions and discover any holes in the logic. When meeting government officials, it is better to have a few strong arguments that are not easy to contest than a long list of weak ones that are easily dismissed.

4 Before approaching the Government

Know what you want

It is crucial to know what you want. You should build a strong consensus among all your members and the healthcare professionals in the PID field. This will give you confidence in your proposals. You must avoid sending conflicting messages to government officials. If this happens, it will be very easy for them to dismiss your demands. It is worth taking the extra time to work out differences, especially if they are between the patients and the physicians.

Remember! You have the solution to the government's problem. But you may have to begin by proving there really is a problem.

Verify that your requests are the right ones

Send draft proposals of your requests to key volunteers in your NMO and healthcare professionals. Ask for their feedback and incorporate it when useful. This will help make people feel that your proposal is also their own. They will feel ownership and support you more strongly. Make sure your requests are not forgetting segments of your population.

Remember! As an NMO, you represent all people with PID.

Be knowledgeable. Do your homework.

In addition to collecting the data about the PID situation in your country, you need to understand the overall health system. Here are some questions you can ask yourselves.

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- If your country has a federal system, what level of government – national, state or municipal – is responsible for dealing with your request?
- What are the rules governing payment of medical services, including Ig? Make sure you know about all the different systems, including social security, private insurance, the military sector and others. Is there legislation that deals with “catastrophic diseases”?
- What is the current state of the blood system in your country? Are there issues of safety and supply that you need to be aware of?

Identify the right person to approach

A natural instinct is to want to talk to the person “at the top”, for example, the Minister of Health. The hope is that he/she can settle the problem immediately. You may well have an opportunity to meet him/her at a later date. However, the Minister is extremely busy and has little time to understand the details of your request. In any case, he/she relies on advice from the officials whose job it is to evaluate dossiers such as yours.

Therefore it is essential to identify this official since your request will eventually end up on this person’s desk. The official could be one of a number of people, for example:

- a physician in charge of the treatment of rare disorders;
- the director of a hospital where a treatment centre is located;
- an official with the national blood transfusion service;
- a government official responsible for blood diseases and the blood system;
- a government official responsible for the purchasing of blood products.

Your objective is to convince this person to defend your request with his superiors; in other words, create an ally. If you succeed, he/she will be helpful in opening other doors necessary to get action on your request, right up to the Minister of Health.

5 Preparing for the Meeting

There are many ways to request a meeting. If you already know the person you want to meet, a simple telephone call is probably the best way. If you don’t know the person, an official letter from your NMO will probably stand a better chance. What’s more, it will leave a written record of your request. You can follow up the letter with a telephone call several days later. In any case, you will want to tell the official the reason you want to meet and the two or three specific topics you want to discuss. If your organisation is not known to this person, a short introduction is required.

Decide what information to send beforehand

If you have a well-prepared and detailed dossier, you may want to send it to the government officials in advance of your meeting. This will allow them to be familiar with the problem and make inquiries of their own staff. It will also allow you to focus on key issues during your meeting rather than spend most of your time presenting your dossier. You may also want to send documents describing your organisation: its legal status, history, mission, goals and activities.

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Who should attend the meeting?

In most situations, your organisation should not send more than four or five people to the meeting. A larger number can lead to confusion and, in any case, it will be difficult to find a role for these extra people.

Having the right people at the meeting can make all the difference. Be very selective about whom you invite to your meeting with the government. Include only people who have been briefed on appropriate behaviour and protocol for the meeting. Avoid inviting guests who may be unable to follow your guidelines on appropriate protocol.

Typically, these are the types of people who can contribute most:

- a) the leader of your organisation;
- b) a dedicated physician whose medical credibility will add force to your delegation;
- c) a person with a PID or a parent of a child with a PID who can describe the reality of living with the disease and make the problem come alive;
- d) an additional person whose main role is to observe the discussion, take notes and help to keep the meeting focused on the agreed objectives;
- e) in certain situations, a representative from IPOPI.

It is crucial not to invite a person who has different goals for the meeting or who cannot be trusted to follow your plan. There is nothing worse than to appear disunited or disorganised.

Standing room only

"The leaders and volunteers in our NMO were really pleased that we had finally obtained a meeting with government representatives. Everyone was excited, but little was planned. On the day of the meeting, seven people showed up, including an inexperienced volunteer who wanted to learn from the experience! The situation became awkward when the Minister's assistant had trouble finding an office space large enough to hold both our society representatives and the Minister's staff! We could have avoided this problem if our leaders had decided who should go and why, and confirmed that the number was acceptable."

Decide on your goals or key messages

Do not have a long shopping list of goals. Focus on one or at most two. For example:

- government cooperation in an outreach project;
- the designation of a PID treatment centre;
- the purchase of increased amounts of Ig through a national tender process;
- reimbursement of the cost of Ig for those without insurance coverage.

It is often unrealistic to expect to find a solution to the problem at the first meeting. However, you do want to achieve some of your objectives, even if they are modest. Here are some examples.

- a) Make an effective presentation.
- b) Impress the government official with your seriousness and credibility as a representative of people with PID.
- c) Obtain agreement to study your request within a certain time period.
- d) Obtain a second meeting in the near future to pursue the discussion.
- e) Obtain a meeting at a higher level.

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Decide on the roles for each person

It is essential that one person, usually the leader of the NMO, is the chief spokesperson for your delegation. He/she will orchestrate your presentation, makes introductions and requests others (e.g. the physician, the person with a PID, the IPOPI representative...) to intervene to present the information for which they are responsible.

Find out beforehand exactly whom you will meet

It is advisable to have some prior information about the people you will meet. Some of this information can be requested directly of them, for example: name, title and responsibilities. Other information, for example, their ideas about healthcare delivery and patient organisations, may need to be pursued informally through contacts.

These are some questions you should research:

- How many government representatives will there be?
- What are their names and exact titles?
- What power do they have to make changes?
- Do they have any link to PID?
- What have they said/done about PID in the past?
- What are their general ideas on healthcare? On patient organisations?

Find out how much time you have to present

This is essential for your preparation. You do not want to run out of time before you have made your key points.

"The day before our meeting with government representatives, there was a fire in our office. Our registry and other documents we wanted to present were destroyed. We had worked really hard to get the meeting, but upon arrival, we talked only of the fire. By the time we got around to talking about the real purpose of the meeting, it was too late: the Minister stated that our time was up."

Think about the difficult questions

Try to anticipate the questions you will be asked during the meeting, especially the difficult ones such as:

- Why should we invest so much money in PID care when our country has so many other challenges in the health field?
- Why should we purchase Ig when we have antibiotics?
- Why shouldn't we invest in prevention of PID rather than its treatment?

Once upon a time...

"Our immunologist was late for a meeting with the government. When he arrived, we, the leaders of the NMO, had already begun the negotiation process and were handling the situation very well. Instead of joining the process, he started talking about the past, describing how great the immunology institute was before the collapse of the country. This continued for twenty minutes, effectively ending the negotiation process.

He would have made a greater contribution to the meeting if we had briefed him on the objectives of the meeting and proper protocol for negotiations."

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Do your research and make sure you can answer these questions to the best of your abilities.

Determine proper protocol

Often, you will have some control over seating at the meeting. Decide on the approach you want to take to best meet your goals.

- a) Should you sit together so as to seem united?
- b) Should you scatter around the table so as to seem non-confrontational?
- c) Is there one person, for example, the leader of your delegation, who should have a prominent position?

If you have international guests as part of your delegation, they will need extra preparation on the cultural DOs and DON'Ts.

Rehearse

It is worthwhile to take the time to rehearse your presentation in the days before the meeting. Invite all those who will be attending the meeting and several others who can play the roles of the government officials. Provide them with the difficult questions you expect to receive.

Such a rehearsal will allow you to:

- a) be more at ease with your presentation;
- b) make changes to your plan;
- c) ensure you can make your key points within the allotted time;
- d) clarify each person's role;
- e) give you confidence that you are well prepared.

When you are satisfied with your preparation, make notes for use at the meeting so that you will not forget anything important.

Prepare dossiers for each government official

Whether or not you sent information in advance of the meeting, prepare a dossier with key documents for each of the government officials you expect to meet. Hand out this information before your presentation or, if you prefer they listen to you rather than shuffle through papers, at the end of the meeting.

Do not feel obliged to provide a thick dossier. Supply the documents you really hope will be read and understood.

6 At the Meeting

If your dossier is well-prepared and you are well-rehearsed, the meeting is likely to go well. These are some points to remember.

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Things to do

- a) If appropriate in your country, take the lead in the meeting.
- b) Present your dossier as planned.
- c) Focus on your goals and key messages.
- d) Focus on the future rather than dwelling on the past.
- e) Be constructive. Don't just complain.
- f) Be clear but brief when presenting your arguments.
- g) Stick to the roles assigned.
- h) Respect the time allotted to you.
- i) Take notes of key points discussed.
- j) Be polite, yet firm.

Things not to do

- a) Do not get side-tracked on minor issues.
- b) Do not argue about facts.
- c) If at all possible, do not let the government official take over the meeting to discuss issues important only to him/her.
- d) Do not lose track of time.
- e) Do not make promises you cannot keep.

And just one last thing...

"The allotted time for our meeting had come to an end. When the Minister stood up and said that he had to leave for another meeting, the NMO leader kept saying, "Just one last thing that I didn't get a chance to tell you about." The meeting had gone well until that point, but it ended badly because the Minister's time constraints were not respected."

7 After the Meeting

Follow up immediately

What you do after the meeting can be as important as what you do during it. These are some of the actions you can take in the days following your meeting.

Write a letter in the following days to:

- a) express your appreciation for the meeting;
- b) summarize the main points of agreement;
- c) confirm the actions to be done by your organisation;
- d) state your organisation's expectations of government;
- e) supply all the information that you agreed to provide to the government officials in writing.

Follow up over the next weeks

If there has been positive action in response to your request:

- a) Phone the person responsible to thank him/her.
- b) If appropriate in your country, phone the person's superior to express your appreciation.
- c) Write an official letter of thanks.
- d) *Attempt to publicly recognise the contribution of the government officials through:*
- e) Awards at your organisation's functions;
- f) Public recognition in the media.

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If there has been no action

- a) Make inquiries by phone.
- b) Write a letter to the official reminding him of commitments made at the meeting.
- c) If appropriate in your country, write a letter to the official's superior stating that the commitments made have not been respected.

8 Other Ways to Influence Government

Direct communication with the government officials responsible for your dossier is the most effective way to make progress. Unfortunately, sometimes your requests are refused, ignored or delayed. It may then be necessary to take additional action. This should be done in a series of steps, each of which raises the pressure on the government to act.

There is no standard way to influence government. Each national member organisation will have to evaluate the actions that are appropriate in its own particular context. These are some examples of strategies that have been used in different parts of the world and found effective:

- a) an invitation to officials to attend patient organisation activities;
- b) a letter from the NMO to all elected officials;
- c) a letter-writing campaign by members and their families to elected officials;
- d) meetings among members and their families and local elected officials;
- e) a press release which answers the questions: Who? What? When? Where? Why? And How?
- f) public awareness through coverage in print and electronic media;
- g) public support for your request from other health organisations – especially those using, blood products – social support networks or religious institutions;
- h) the intervention of an influential person at high levels of government;
- i) if appropriate in your country, a high-level delegation from IPOPI to meet government officials and give credibility to your request;
- j) the threat of negative publicity about the government in the media, especially in the months before an election;
- k) negative publicity about the government in the media;
- l) the threat of appeals to opposition parties;
- m) appeals to opposition parties;
- n) the threat of legal action to enforce existing legislation;
- o) legal action;
- p) the threat of public demonstrations;
- q) public demonstrations.

Public attention through some of the strategies listed above is a two-edged sword. In some situations, in some countries, it may cause public officials to cut off discussions with the PID organisation. Going to the media can even be dangerous for the individual. *Be sure to carefully assess your particular situation.*

Support your members

In any form of public campaign to influence government, your members will need considerable support from the organisation. If the issue of PID becomes a public one, your members will need to know

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what you are requesting

- a) the actions you are undertaking;
- b) the fact that their names are confidential;
- c) the results you hope to achieve.

If you want members to help with your campaign, they will need even more support, for example:

- a) a communication from the national PID organisation with the two or three key messages to transmit to family members, friends, other groups and elected officials they meet;
- b) a sample letter which they can adapt and send to elected officials;
- c) training and support if they do interviews with the media;
- d) frequent communication with the NMO so they are aware of new developments.

9 Remember

- a) Create win-win situations.
- b) Always remember your cause.
- c) Be patient, but be persistent.
- d) Remember you are not alone.
- e) When good things happen, give credit.
- f) Never give up.

10 Acknowledgments

IPOPI would like to acknowledge its indebtedness to the World Federation of Hemophilia (WFH) for permission to adapt this document.

The WFH would like to acknowledge the contributions of several people whose presentations at NMO training sessions in Spain in May, 2002 and in Panama in November, 2003 inspired this monograph.

Val Bias, United States
Rosemary Daly, Ireland
Cesar Garrido, Venezuela
Tamas Pelyhe, Hungary
Alicia Pereira, Uruguay
Douglas Piquinela, Uruguay
Hector Beccar Varela, Argentina