

National Member Organisations SKILLS MANUAL

CONTENTS:

| | |
|---|----|
| CONTENTS: | 1 |
| 1 INTRODUCTION | 3 |
| 1.1 The conditions and under diagnosis..... | 3 |
| 2 ESTABLISH A NATIONAL GROUP | 4 |
| 2.1 National authorities | 4 |
| 2.2 Attract Awareness..... | 4 |
| 2.3 Involvement of doctors and nurses | 5 |
| 2.4 Involvement of industry | 5 |
| 2.5 Finding volunteers | 5 |
| 3 ORGANISATION OF A NATIONAL MEMBER ORGANISATION (NMO). | 6 |
| 3.1 Committee Chairperson's responsibilities: | 6 |
| 3.2 The Secretary's responsibilities: | 6 |
| 3.3 The Treasurer's responsibilities: | 6 |
| 3.4 Voluntary committee members' job description: | 7 |
| 3.5 Meetings..... | 7 |
| 3.5.1 Annual General Meeting | 7 |
| 3.5.2 Committee Meetings/ Board meetings | 7 |
| 3.5.3 Special Meetings | 8 |
| 3.5.4 Meetings with the Staff..... | 8 |
| 3.6 Teamwork..... | 8 |
| 3.6.1 How to keep your team motivated..... | 8 |
| 4 FINANCES | 9 |
| 4.1 Fundraising..... | 9 |
| 4.1.1 Basics..... | 9 |
| 4.1.2 Continuity..... | 10 |
| 4.1.3 Fundraising strategies..... | 10 |
| 4.2 How to approach potential sponsors/funders | 11 |
| 4.3 Planning of special events for fundraising | 12 |
| 4.3.1 Legal advice | 13 |
| 4.3.2 General advice | 13 |
| 4.4 Planning process | 13 |
| 4.5 Ideas for possible fundraising events | 14 |
| 5 COMMUNICATIONS | 15 |
| 5.1 Public Relations Guidelines | 15 |

National Member Organisations SKILLS MANUAL

| | | |
|--------|---|----|
| 5.1.1 | Introduction..... | 15 |
| 5.1.2 | The Media – General Principles..... | 15 |
| 5.1.3 | Blaming the press? | 15 |
| 5.1.4 | Strategy | 15 |
| 5.1.5 | Good advice | 16 |
| 5.2 | The Media..... | 17 |
| 5.2.1 | Reasons for contacting the media..... | 17 |
| 5.3 | Press and online media | 17 |
| 5.4 | Television and Radio | 18 |
| 5.4.1 | Identification | 18 |
| 5.4.2 | Contacts | 19 |
| 5.4.3 | Copy deadlines..... | 19 |
| 5.4.4 | Programme details..... | 19 |
| 5.5 | Television | 19 |
| 5.5.1 | Public Service Announcements (PSA)..... | 19 |
| 5.5.2 | News Coverage | 19 |
| 5.5.3 | Local Programmes..... | 20 |
| 5.5.4 | Community Television..... | 20 |
| 5.6 | Radio..... | 20 |
| 5.7 | Press Releases..... | 20 |
| 5.7.1 | Writing a press release | 20 |
| 5.7.2 | Press announcements | 22 |
| 5.8 | About news media | 22 |
| 5.9 | About the follow up | 22 |
| 5.10 | Public speaking..... | 23 |
| 5.10.1 | Handling questions | 24 |
| 5.11 | Online presence | 24 |
| 5.11.1 | Website | 24 |
| 5.11.2 | Social media | 25 |

1 INTRODUCTION

The IPOPI National Member Organisation (NMO) Skills Manual has been developed to help new organisations to understand a little of what lies ahead and to encourage better established organisations to improve their own organisation.

1.1 The conditions and under diagnosis

Primary Immunodeficiencies (PIDs) are a large and growing group of over 300 different disorders caused when some components of the immune system (mainly cells and proteins) do not work properly. Whilst PIDs are generally recognized as rare disorders, some are more common than others and taken as a whole they represent an important group of people whose lives are profoundly impacted by their condition.

PIDs are caused by genetic defects of the immune system which are hereditary. The immune system normally helps the body fight off infections by germs (or 'micro-organisms') such as bacteria, viruses, fungi and protozoa. Because their immune systems do not work properly, people with PIDs are more prone than other people to infections. When PIDs are left underdiagnosed or misdiagnosed, the immune system remains defective, often leading to illness, disability, permanent organ damage or even death.

PIDs are currently classified into nine groups: predominantly antibody deficiencies; combined immunodeficiencies; combined immunodeficiencies with associated or syndromic features; diseases of immune regulation; congenital defects of phagocyte number or function, or both; defects of innate immunity; auto-inflammatory disorders; complement deficiencies, based on the main immunological defects; and phenocopies of Primary Immunodeficiencies.

Whilst it is estimated that around 60% of PIDs can be easily diagnosed with a simple and inexpensive blood tests, many PIDs remain underdiagnosed on a global scale. Hopefully, as the technical ability to identify gene defects improves, more and more genetic causes of PID will be identified. Screening for some of the most severe forms of immunodeficiency will also diagnose more individuals and improve treatment outcomes.

Medicine is advancing very rapidly and novel therapies that target the specific cause of the disease are becoming available. These may have significant advantages for PID patients and it is important that patients throughout the world have access to these treatment possibilities.

With appropriate access to the different and very effective therapies which can only happen if early and correct diagnosis is made, many sequelae will be avoided and lives of patients will be saved.

People with PIDs are normally treated by doctors who specialise in diseases of the immune system. How a patient is treated depends on which PID they have, and on many other factors. Treatments for PIDs include: immunoglobulin (IG) therapies, Hematopoietic Stem Cell Transplantation (BMT), gene therapy, Granulocyte-colony stimulating factor (G-CSF), Gamma interferon, PEG adenosine deaminase, prophylactic anti-biotics, among others.

In the case of IG therapies, it is important to know that different IG products are not interchangeable or mixable. IG can be administered intravenously or subcutaneously. They are considered as essential medicines for PIDs by the World Health Organisation. Intravenous immunoglobulin (IVIG) infusion

National Member Organisations SKILLS MANUAL

usually takes 2-4 hours allowing high doses to be given and only needs to be given every 3-4 weeks which may suit some patients better. Subcutaneous immunoglobulin (SCIG) only takes 1-2 hours and can often be given at home by patients themselves, parents or carers. It may therefore be more convenient for some patients. However only small doses can be given by SC infusion, meaning they are given more frequently than IV infusions, usually once a week. A new type of SC infusion containing recombinant human hyaluronidase, known as facilitated subcutaneous immunoglobulin (FSCIG) allows patients to have SC infusions every 3-4 weeks. IG therapy should be chosen on an individualised basis, according to patient needs and preferences.

2 ESTABLISH A NATIONAL GROUP

Your NMO will be the most effective group to work towards improving treatment and diagnosis in your country. It is important to realise that you will be working WITH your doctors, nurses and those concerned with administering the health service in your country at a national, regional, and local level. It is vital that you work as a team, each understanding the other's agenda. The style in which each section approaches the problems will be different – but you will share a common goal: improved access to the best treatments available.

2.1 National authorities

Get to know those involved in making decisions about your health service in your country – they will be in your Health Ministry (or equivalent name) at a national level. Your local elected representative to the national parliament will be able to help you here. Names can also be found in Government handbooks (local library) or on the internet. It is important to establish trust with those people and to show that you want to work with them rather than against them – so, do not be adversarial in your approach: the time may come for that but it will not be in the early stages.

Your message must be:

- Here is what we see as a problem
- We are sure you see it as a problem as well (if not, show them why!)
- We want to work with you – and the nurses and doctors – to overcome this problem
- How can we do it – together!

You will be surprised perhaps to find that they are very willing to be your friend and to work together with you.

2.2 Attract Awareness

In order to gain support for your message you need to make sure that the right people are aware of the facts about PIDs. A lot of material is available from IPOPI and from other well established national member organisations – visit www.ipopi.org – there is a library of material in a variety of languages.

Who needs to know? Do not set out on an ambitious venture to educate the whole of society in your country – that cannot succeed and will be a waste of your limited resources. Decision makers in health need to know about and are familiar with primary immunodeficiencies – so you need to make sure that members of your Parliament understand, and in particular the Ministers involved in health care issues. But it can be even more important to make sure that their staff – the administration, the civil servants –

National Member Organisations

SKILLS MANUAL

know as well because it is the civil service who sets the agendas rather than elected Ministers in the ordinary course of events. And don't target civil servants who are too far up the ladder – find the person who is the bridge between you as a patient and the higher echelons of power in the civil service. That may take a little time but it will be time very well spent.

And then there will be other groups representing other medical conditions who may be running awareness campaigns – look at joining up with those groups. By working together with other groups – other 'rare disorders' – you will have a louder voice that will be better heard by those who make decisions. And there will be those who have been through the same experiences in the past in your own country who may very well have the names and contacts to help you – e.g. haemophilia groups. Look for friends and you will find them!!

IPOPI's EU PID Forums are a good example. IPOPI has organised many Forums in the European Parliament since 2011, each dedicated to pressing PID community issues such as, Principles of Care of PID, SCID Newborn screening, access to treatment, transition care and aging, among many others. They led to questions being tabled to the European Commission, to the release and endorsement of IPOPI Recommendations on relevant topics and to gathering of support for future campaigns.

2.3 Involvement of doctors and nurses

You or your close one will have been diagnosed already and therefore have contact with an immunology doctor and, hopefully, a nurse. You will already know that your local medical staff are your friends: they may be rushed and busy and anxious about paying for your treatment, but they are your friends! Through them you will be able to meet other patients. Also through them you will be able to establish contact with the patients of other doctors and nurses in your country – work patiently at this and in time it will be good for your national group. And never forget: you all work for the same basic objective – improved diagnosis and access to the best treatments available. You may work in different ways and through different people but your goals are one and the same. Therefore, make sure you make and keep your local medical staff as your friends – together you will be a great team working for your cause.

2.4 Involvement of industry

We have in mind in particular the plasma industry. Industry can be a good and close friend to patient groups. It is important that you do not align yourself with one company more than any other and you must NEVER allow financial support from industry to influence the way you work. It is wise to have a disclaimer agreement with any major donor in which it is made clear that grants/gifts of money are accepted on the basis that they will not influence your group's policy or practice.

2.5 Finding volunteers

Your volunteers will almost certainly come from the families and friends of patients with whom you are able to make contact – and a group with a mix of patients, parents, partners, family members and friends will form the basis of your group. You should be sure to look for a mixture of skills and not necessarily limit your invitations to people you like – although that does help! You will be working together as a professional team and 'likes and dislikes' should not be relevant. You may also find that hospital staff are willing to volunteer and give input – see 'Establishing a Board' at 3.1 below.

3 ORGANISATION OF A NATIONAL MEMBER ORGANISATION (NMO).

Nobody can do all the work needed alone! Therefore, you need to gather a few people around you who are equally interested in establishing an NMO.

You need to have at least a Chairperson, a Secretary and a Treasurer and up to seven committee members.

3.1 Committee Chairperson's responsibilities:

- Call and chair meetings as required, making sure that major points and decisions are recorded in Minutes and passed on to others. Meetings can be done by telephone conference call or skype.
- Co-ordinate committee-work, by making sure that the committee members are keeping to the overall plan and that everyone understands the priorities.
- Follow through to determine that plans are being carried out.
- Co-operate with other external committees and organisations – e.g. Government bodies and similar patient organisations involved in the diagnosis and management of rare disorders, especially those using plasma products.
- Make suggestions and recommendations for improving the various aspects of the organisation (guide-lines, systems, etc.). Models will be available from established organisations.
- Support committee members and any staff.
- Maintain regular and frequent contact with committee members.
- Do whatever is possible to assist the next Chairperson in taking over the responsibilities when the term of office expires.

3.2 The Secretary's responsibilities:

- Ensure that all records are complete and up to date.
- Prepare and send out the agenda, all relevant documentation, and minutes of the previous meeting to all committee members at least one week prior to the meeting.
- Attend committee meetings.
- Ensure that correct minutes are taken of the meeting and retain the signed minutes as historical records.
- Ensure that the committee is kept informed about all important matters affecting the work of the NMO.
- Ensure that a list of names, addresses, and phone numbers (to include mobile phone number) and e-mail addresses of all committee members are produced.
- Keep an up to date list of all members of the NMO.
- Ensure that the incoming secretary is made conversant with the responsibilities of the office.

3.3 The Treasurer's responsibilities:

- Ensure the outgoing Treasurer has finalized the accounts for the previous year and has had the books audited by the Appointed Auditor.

National Member Organisations

SKILLS MANUAL

- Check bank signatories, and if necessary, obtain authority to change signatures for the drawing of cheques on bank accounts.
- Prepare annual budgets.
- Keep accurate records and balance the books.
- Bank monies received and issue receipts.
- Ensure that accounts are paid promptly.
- Present a financial statement of income and expenditure at each committee meeting.
- At the end of the year balance the accounts, and forward to the Appointed Auditor.
- Present the Audited Statement to the Annual General Meeting.

3.4 Voluntary committee members' job description:

Many volunteers function without job descriptions. While this can work well, it can also result in unrealistic expectations and demands, a lack of clarity about the work to be done, unreasonable workloads, and repetition of duties. The creation of a job description is a very small but essential task. The benefits are obvious: clearly defined and realistic responsibilities and results, and clarification about who does what.

Both the volunteer and the responsible staff or Board Member should work together on job descriptions, so as to ensure that the needs and expectations of both will be met.

Here is a step-by-step process for developing a job description:

- Agree on the title;
- Outline the general description;
- Clearly define the activities and tasks and time commitment;
- Decide on authority and mechanisms for reporting;
- Identify the skills needed to complete the job;
- Define the results expected so that the volunteer has a clear goal in mind.

3.5 Meetings

Meetings are held to conduct business, but they also have an aspect of socialisation and sharing experiences, and to learn from others with similar problems.

3.5.1 Annual General Meeting

This meeting is held once each year for the purpose of presenting the Annual Report and Financial Statements, electing a new panel of officers, appointing an auditor for the next year, and to consider, deal with, and dispose of such other business as may properly come before the meeting. All NMO-members must be invited to attend.

3.5.2 Committee Meetings/ Board meetings

General meetings may be called at such time and place as designated by the Chairperson, but are best scheduled well in advance – say 12 months ahead so that people have the dates and times firmly in their diary.

3.5.3 Special Meetings

Special Meetings of the NMO-members may be called at any time by the Chairperson or at the request of a majority of the Board or by a majority of the NMO-members. These meetings usually cover something unexpected.

3.5.4 Meetings with the Staff

This is a business meeting and only staff members are present. (These meetings can also be relaxed, friendly, with time to talk and refreshments). The advantage of this meeting is that the staff can address the business of the organisation in depth, without concern for the members who have come for other reasons. The Executive then presents its recommendation to the Committee/Board for approval and implementation.

3.6 Teamwork

For a good team you need people who:

- Believe in the mission and goal of the team and believe they are doing the best they can.
- Believe in the resources of others.
- Believe that more heads are better than one.
- Have supportive environment.
- Believe in the power of the many, not in the power of the one.
- Have the ability to share successes as well as failures.
- Complement and confront each other.
- Believe in yourself.
- Take joy in the accomplishment of the group.
- Take joy in sharing leadership.
- Are able to celebrate.
- Have a deep belief that the team produces a better product than one person.

3.6.1 How to keep your team motivated

You should not have to motivate another person. You should, however, create a climate (atmosphere) which is conducive to an individual's self-motivation.

To keep volunteers motivated ensure that:

- Tasks are explained.
- Aims are clear.
- Purpose is meaningful.
- Success is attainable.
- Praise is given.
- Respect is shown both to the individual and to the job he/she is doing
- Each individual knows that he/she is an essential part of the whole.
- Opinions are asked for and considered.

Needs are met when:

- An individual is doing a job he/she likes to do.
- An individual is doing a job he/she is capable of doing.

National Member Organisations SKILLS MANUAL

- The motivating factors, which brought the individual to your organisation, are being provided for social reasons and altruistic reasons.
- Tasks are adjusted to meet needs and to provide new challenges as the individual grows and changes.

Recognition is an art. When practised sensitively and honestly, it can ensure that volunteers feel acknowledged, accepted, praised and identified as being special. For volunteers who are giving freely of their time and energy, recognition can be a highly potent motivator.

Personal Recognition is the responsibility of all volunteers. It involves all of the finer aspects of communication.

Personal recognition shows itself in:

- Smiles
- Open body language
- Supportive remarks
- Candid praise
- Hugs
- An appreciative nod
- A letter of support and/or appreciation

4 FINANCES

You cannot run a NMO without money, especially not in the phase of establishment. You must raise some funding!

Government and public support

You should investigate if your government or other public authorities will be willing to support your patient organisation. Normally you should turn to your Ministry of Health and your Ministry of Social affairs.

4.1 Fundraising

4.1.1 Basics

Successful fundraising demands attention to four basic principles.

Image:

However maligned and abused the word “image” is, it is vital to getting a supportive response to the cause.

Image is a result and reflection of:

- The quality of the literature that is produced and distributed.
- The sincerity and credibility conveyed in personal contacts.
- The professionalism of public presentations and written applications.
- The follow-through that is organised and monitored with potential sponsors/contributors.

4.1.2 Continuity

Fundraising – even if only a single contributor is involved – should be a systematic process.

It is important to:

- Regularly report to the contributor(s) on objectives, achievements and even setbacks.
- Renew and revive personal contacts periodically.
- Be attuned to, and capitalise on, changes of personnel and policy within contributor organisations.
- Be diligent in communicating changes of personnel or direction within the organisations to all supporters.

Reinforcement:

Public figures not intimately attached to the cause may still influence the success and reinforce credibility.

The press, clergy, society leaders, diverse medical professionals from hospital administrators to psychologists; educators, law enforcement and judicial officials – all of these public figures direct community opinion and even their tacit awareness of the activities can be valuable. Newsletters represent a minimum expense item, which can effectively reinforce, and extend, awareness of the cause and efforts.

Goal orientation:

Few newly approached contributors will respond enthusiastically to general appeals such as a need for “funds to help us continue our important work”.

Appeals that involve specific projects or purchases are more compelling where:

- The need is specific
- The amount of funds needed has been assessed correctly and is relatively exact.
- The timetable for completion is relatively precise.
- The ultimate accomplishment is tangible or, at least, can be clearly documented.

Remember fundraising is also always awareness raising!

4.1.3 Fundraising strategies

Before embarking on any fundraising enterprise, be prepared, when appealing for general community support:

- To present the cause professionally, credibly, knowledgeably, and uniformly.
- To appeal to an empathetic public capable of underwriting the needs.
- To respond to interest (or indifference) rapidly, coherently, and inspirationally.

The first step in planning the fundraising programme is to assess the amount of money required to cover the effective costs of the event/campaign, etc and your related administrative costs (staff costs, communications, etc). The objective is to have an event, which will produce income in excess of expense – i.e. sur plus.

Once the amount of money to be raised is decided, the second step in the planning process is to select an event capable of raising the amount of money previously determined. The success or failure of the

National Member Organisations SKILLS MANUAL

specific event that is selected will be directly related to the care exercised in determining the event. Never select an event because it has been successful for other organisations, or it's the "in thing" to do.

Priority ONE of successful fundraising is to develop a concise, but comprehensive statement of need. Depending on how ambitious the need, this "prospectus" may be a simple project outline in memorandum form or be a more formal literature package that can be mailed and/or distributed widely.

Priority TWO involves assignment of tasks:

- Is this a project that one individual or the staff delegate(s) can manage personally?
- Is it a project that should be conducted under the auspices of the Executive Committee?
- Should an Ad Hoc Committee of volunteers/appointees be formed?
- Is there an individual or group or organisation within the community, which would respond with energy and interest to this cause?

Priority THREE in fundraising efforts involves the "how to" decision.

Basically, there are two choices here:

- Find an individual person or locally based organisation as supporter
- Conduct some kind of fundraising event to attract attention and revenues.

These options present unlimited diversity of approach depending on the need, the resources, and the culture involved.

4.2 How to approach potential sponsors/funders

Corporations and Foundations

The first stage is to compile a list identifying likely targets for funding. You can begin this process by identifying companies within the following categories:

- Businesses that your organisations and its members and constituents use regularly
- Companies for which your members and their families work.
- Companies that sell products to your constituencies. Remember to think beyond blood products and consider companies that make equipment, syringes, and other drugs.
- Business whose activities and products correspond with your programme; for example, consider approaching a toy company for camp funding, a cosmetics company for women's programmes etc.
- Any company with which you have a personal contact.

This list should be clear and concise, listing the companies you would like to approach. Identifying them well in advance of beginning your campaign will enable you to design the most effective way of contacting them.

When putting together your target list you should consider the following criteria:

- Size of company
- Sales/revenue figures
- Number of employees
- Product lines
- Personal connections

Your list should be kept as simple and easy to read as possible so that all those involved will be able to understand it.

Asking for money is not difficult, but it does take some practice to make it easier. It involves putting together a well thought out presentation, being armed with facts and figures, and fielding the occasional unpredictable question by a corporate representative. Anyone who is completely unfamiliar with the corporate or foundation fund raising scene may feel somewhat uncomfortable about making that first call and speaking to someone who is totally unprepared to listen. After all, no one likes to hear “no” or have the door slammed in his or her face.

The major advantage of corporate and foundation fundraising is that while you may hear “no”, once you have the appointment, the door will not be slammed in your face. The reason is that the corporate official knows that you are there to ask for money. Even better, he or she is getting paid, and probably quite handsomely, to listen to you ask for money, so you should not feel guilty about being there. Once you get over feeling apologetic and realise that you are doing the company or foundation a favour by inviting it to become involved in something really important, you will have conquered your biggest obstacle.

A very important part of your presentation, whether it is written or oral, is your “case statement.” If we are going to ask a person or business to contribute, it is essential that we tell them why their support is needed and how their gift will be used. A case statement is a brief written document that explains this in a way that the average person can understand.

The case statement should be modified so that it is of special interest to the person or organisation you are trying to convince. In addition to a general description of primary immune deficiency and the need for your programmes, a case statement should also include the following information:

- An explanation of how the contributor’s money will be utilised. Potential donors are especially interested in percentages of funds raised for management and fund-raising expenses.
- Programme information, including the kinds of programmes your organisation conducts and how they have helped people in your area.
- Statistics about the incident rate and seriousness of primary immunodeficiency. Try to list facts and figures that apply to your community, as well as to the rest of the nation.
- Your case statement should provide the most up-to-date data possible on research advances. For this reason, the case statement should be revised to make sure that it is current.

Make sure that you localise the statement to include statistics for your community, as well as the types of programmes you conduct. All the information you need for your case statement is probably included in your Annual Report, so you should not feel obligated to “re-invent the wheel” when it comes to developing the statement.

4.3 Planning of special events for fundraising

A special event is an opportunity to raise funds, but it is also an opportunity to raise spirits. A successful well-run special event can be fun and fulfil some, or all of, the following goals:

- Educate the public about the Primary Immunodeficiency Organisation
- Attract new members.
- Create good publicity and improve image.
- Deepen commitment of volunteers.
- Raise funds for research and client services.

4.3.1 Legal advice

It is very important to note that laws governing solicitation, contents, lotteries, etc. differ from country to country and should be checked locally.

4.3.2 General advice

One of the most important parts of the special event is the organising committee and its role. Each person on the committee should have a specific responsibility (such as organising publicity for the event, someone to find sponsors and prizes, etc. etc.) This will then ensure that all the areas are covered.

It is also important to plan after the event. That is, the gathering of the monies raised from participants, thanking the donors, sponsors, and publicity etc. and, if a special party is being held after the event, that someone is responsible for organising it. While the Chairperson of the Committee would be best responsible for ensuring that all the committee members are following up on the areas that they are responsible for, the Chairperson should not be involved in the detail of planning receptions, etc. In addition, the Chairperson could take on other assignments as the need comes up, but the priority should be to find someone else to undertake work under the guidance of the Chairperson.

4.4 Planning process

Step One is to access the amount of money required to cover the effective costs of the event/campaign, etc and your related administrative costs (staff costs, communications, etc). The objective is to have an event, which will produce income in excess of expense – i.e. sur plus.

Step Two in the planning process is to select an event capable of raising the amount of money previously determined. The success or failure of the specific event that is selected will be directly related to the care exercised in determining the event. Never select an event because it has been successful for other organisations, or it's the "in thing" to do.

The type of event that is selected will ultimately be determined by the following:

- The availability of human resources: It is important to select individuals who will be co-operative, work diligently and can contribute their talent, experience, and time to the programme.
- The amount of funds to be raised. It is imperative that the amount is attainable. There is nothing more frustrating than to set a goal of a large amount only to come up considerably short due to improper planning.
- The amount of "start-up" funds that is required. Many programmes require these funds for such items as printing, postage, advertising, etc. Due consideration must be given to the amount of "seed" money required for the programme, and where it can be obtained.
- The event you select should have a definite appeal to the audience or market. Review the types of programmes previously undertaken in your community, analysing which has and has not worked, and the reasons for each.
- Market Analysis is important. The event that is ultimately selected should have broad appeal to the specific interest of the market that is to be reached. It would be rather self-defeating to sponsor a tennis event when the majority of the target market is golfers, for example.
- Determining the charge or price for participating in the event is important. The price established has to be appropriate. Too high a price will undoubtedly inhibit participation if the community or

National Member Organisations

SKILLS MANUAL

target market cannot afford it. Too low a price may detract from profits that could have been realised from willing participants.

- Know the competition. Avoid selecting events simply because they worked well for other organisations. It is very difficult to duplicate an event that other organisations have established. Those other organisations usually have an established following of people principally because of their own cause. Be aware of, and alert to, new interest in the market area, which could assist in determining the events.

Step Three in the planning process is to determine the organisational structure. This is accomplished simply by listing the types of committees required, and to whom they report. Each of the committees can be developed into subcommittees, or additional committees can be assigned, depending on the programme selected.

4.5 Ideas for possible fundraising events

Following is a list of some of the possible events that organisations could adopt:

- Christmas cards
With busy schedules and the huge variety of cards available today, many people have found it is less time consuming and more satisfying to support their favourite charity at holiday time by buying cards through them.
- Spaghetti dinners, pancake breakfasts, chilli suppers
Spaghetti dinners, pancake breakfasts, chilli suppers and their regional counterparts are fun events needing the right-sized location, the right number to ticket sellers, the right amount of food prepared by good cooks, and the right date to be successful.
- Garden walks
Many people welcome the opportunity to show off the landscaped grounds of their home. The event could also provide the opportunity to tie in a plant sale or cookbooks geared toward the flowers, fruits, and vegetables in the garden being toured.
- Produce sales
Produce sales events are one of the lowest cost ideas. Produce sales can include flowers, plants, baked goods, handicrafts, candy, cookies, and magazine subscriptions, jewellery and much more. This is another event needing minimal staff time—one that is easily run by volunteers.
- Fashion show
Timing the fashion show is very important. If, for example, the hall has been booked, and a non-refundable deposit has been made, and then another bigger Fashion Show or similar event is scheduled for the same day, this could be very upsetting. Therefore, the message is to do the research and make sure that another charity is not competing for the same funds on the same day.
- Raffles
Raffles have been part of the fundraising scene for several years, and for good reason. They have few up-front costs – mainly the cost of printing tickets – need little, if any staff help, and can bring in solid amounts of money within a period of six weeks to three months. A word of caution – heavy volunteer commitment is necessary to sell all the tickets. Endeavour to get prizes donated by businesses or individuals – and not bought.
It is always a good idea to hold a raffle, however small, during a bigger event as people will always pay one extra dime if they think they might win a prize.
- Walk-a-thon

Special events will often give an organisation plenty of publicity and recognition in their community. One of the most popular forms of special events are “a-thons” – that is, an event that will bring out the general public at large because of the activity.

5 COMMUNICATIONS

5.1 Public Relations Guidelines

5.1.1 Introduction

The Public Relations Guidelines manual is designed for the planning and carrying out of press and public relations events at a local or national level.

This section of the manual is designed to help you respond to media enquiries and to proactively contact the press with news stories in your area.

Every situation is different and every country will have slightly different media situations, but journalists all over the world are basically all looking for a story, and they all work roughly in the same way. Whilst some of the specifics may vary from country to country, the basic principles will stand across the world. Public Relations are one of the most powerful tools we have.

Creating the right image for primary immunodeficiency and our national organisations is crucial to us being successful in influencing the healthcare policy debates in our own countries, fundraising for our activities and communicating a positive image of people with primary immunodeficiencies for the benefit of them and their families and friends.

5.1.2 The Media – General Principles

Have you ever been misquoted, misunderstood, or misled in an interview?

Why does this happen? With a little planning and forethought, you can prevent most of this and maximise the opportunities.

5.1.3 Blaming the press?

Everybody knows that ‘the press constantly misquotes, lies, is unfair, and can’t write decently to save themselves’, - right?

In reality, journalists rarely if ever misquote or lie. It simply isn’t in their interest to do it. They are far more interested in getting your side of the story. But since they are in the news business, they will leap upon mistakes, the ill-considered comment or a disparaging remark about another person or organisation.

5.1.4 Strategy

- Approach the interview as an opportunity to state your positive messages. Decide in advance the key points you would like to see printed in the article, and make these points often during the conversation. Have a ‘bullet point’ list on a card as a reminder!

National Member Organisations

SKILLS MANUAL

- Keep controls as much as you can, trying to maintain control over the direction in which the questions are going.
- You have no obligation to answer a question. Your only obligation is to respond to it. (Henry Kissinger is reputed to have begun press conferences with, “Do you have any questions for my answers?”)
- Do not relax or joke unless you don’t mind seeing what you say in print. Unless you have a long-standing and trusting relationship with a reporter, say nothing off the record.
- Give them quotable – memorable – phrases – that’s what reporters are looking for.
- An interview is not a conversation: so, a number of conventions of courteous conversation do not apply:
- Repetition is acceptable. When necessary, restate positive messages to be sure they get into the reporters notes, increasing the chance that they will get into the article.

5.1.5 Good advice

- Tape-record the interview – but ask the journalist first. This significantly reduces the chance of misquoting.
- Only answer the part of the question that you want to.
- Urge the reporter to call you back if he or she has any additional questions later or if something is not clear in his notes.
- Remember that appearance is important. Your attitude should be positive, friendly and smiling.
- Maintain eye contact and smile, especially during tough questions.
- Use the reporter’s name.
- Determine in advance what you want to say, and say it. Do your homework.
- Say only what you want to say. Don’t let the reporter cause you to say what you don’t want to say.
- Make the messages “poetry”. Make them quotable and memorable phrases.
- Be prepared to provide the interviewer with your biography, and background information on the organisation and issues.
- Be aware of all the skeletons in your organisation’s cupboard and have prepared answers to each of them.
- Stall for time when confronted with the unexpected. If the journalist introduces unexpected bad news, resist the temptation to respond immediately. Explain that you will need to consider that and agree a time when you will get back with your reaction.
- Read the journalist’s recent work and also the last few days’ newspapers, look out for subjects that the journalist may want to find out your views on.

Avoid:

- Responding too quickly. Think first!
- Being drawn into a trap. Beware of Pauses. Beware of “and?” When you have finished, stop talking. Let the reporter ask the next question; you don’t have to fill the silence.
- Lying – at all costs.
- Saying “no comment” If you don’t know the answer, say so, and say whether you ever will. If you can get the answer, tell him when you will be able to respond, and call him.
- Answering if you don’t want to. If you cannot answer, say, “I am not in a position to answer that question.” Explain why, for example patient confidentiality.

- Allowing the reporter to choose your word or to paraphrase you. Use your own words – never his/hers.
- Speculating, even in answer to hypothetical questions.
- Using inflammatory words.
- Repeating critical or hostile words used by the journalist.

5.2 The Media

‘Media’ is a generic term to include TV, radio, printed press, and online newspapers, both national and local. The value of the local press is often underestimated. Although the circulation of regional newspapers in some countries is lower than those of the nationals, their readers are interested in what their local papers have to say about their area/region – and the story will often find its way into the national press. So, do not belittle your local or regional newspapers: they are important.

Always consider who the relevant audience is for your story before targeting the media.

5.2.1 *Reasons for contacting the media*

- It is important for primary immunodeficiency organisations to inform and update the media as often as possible, because this allows the primary immunodeficiency community to communicate interesting and positive stories to a wide audience including potential funders/donors, policy makers and the general public.
- Regular media coverage of primary immunodeficiency reiterates and enhances your organisation’s position as the lead spokesperson on primary immunodeficiency and related issues.
- It creates an opportunity for people with primary immunodeficiency to position themselves as positive and active participants in the local community and society.

By showing a willingness to communicate, the media will consider approaching primary immunodeficiency organisations as a spokesperson for the issue, rather than making general assumptions and turning to others for comment.

There is nothing ‘magic’ about the media. The media is a business just like any other, with tight deadlines to adhere to, similar financial constraints, similar hierarchy, fierce competition, and a sophisticated audience.

5.3 Press and online media

Identification:

When reading your national and local dailies, weeklies, and magazines, pay attention to the names of correspondents and editors who write about health, news and consumer issues. Identify the features’ editor to obtain information about future stories and discuss where primary immunodeficiency can fit in. Understand to which audience they are appealing; it may not be the right audience for you!

Building up a list of contacts:

Contact local newspapers and magazines for names if you don’t already have these and record these on a database. (The sales office of the magazine will usually provide you with a pack of information covering circulation, readership profile, etc.) Update these as regularly as you can. Include the circulation figure, so that you know how wide the potential coverage is, and whether it is worth

spending any time on it.

Follow the same publications online and pay special attention to who authors health news and consumer issue articles.

Copy Deadlines:

Phone or email your local newspapers to find out about their copy deadlines. Different departments of the newspaper have different times when their page(s) 'go to bed'. Once copy deadlines are exceeded, your information has lost its value. Features' Editors usually need to submit stories well in advance (sometimes days ahead) of the publication date and therefore require your input at a different time than, for instance, a News Editor. Record all copy deadlines in your files.

Build relationships:

Contact editors you are most likely to regularly inform about primary immunodeficiency plans and changes. One way to get to know them is by taking journalists out for lunch, but be extremely well prepared, develop a proper briefing, run through all the possible questions you may be asked, and the best way to 'sell-in' your stories.

Inform whom about what?

Think about what they are looking for and therefore see how your story can be tailored. Do not assume that because you are enthusiastic about something, the media necessarily agree!

5.4 Television and Radio

Television and Radio are immediate media. Timing is critical. News stories need to be presented quickly to editors and deadlines are tight.

Nowadays, what is recorded can last forever in parallel online formats. A valuable story can be shared on social media, enhancing your efforts, or highly impairing them. Prepare your arguments well and use social media value in your advantage!

As with print, research the options:

- Get to know the programme directors, researchers and hosts of your local TV and Radio networks.
- Familiarise yourself with the various programmes produced
- Find out deadlines and meet them.

Local television and radio stations are therefore another source for selling in stories containing strong visual elements and details of local events. Television stations may be interested in stories which can be conveyed visually, such as an event involving a local dignitary, the opening of a new treatment centre with hi-tech equipment, etc. Generally, broadcasters prefer to use stories which have not already appeared in the press.

5.4.1 Identification

Watch and listen to local broadcast stations and single out those programmes that have a broad consumer audience.

If you are not sure whether your story/announcement will be published or broadcast, it is worth considering contacting the editor and discussing the likelihood of publicity. Do not assume that because you are enthusiastic about something, the media necessarily agree.

5.4.2 Contacts

Just as compiling a workable file is necessary for the press, it is equally important to set up files for radio and television. Look in the regional radio and TV guides to ascertain relevant programmes. You need to know the names of the programme producers and presenters.

5.4.3 Copy deadlines

Radio and television deadlines are different from press deadlines and you will need to contact your local broadcasting stations to find out their copy deadlines.

5.4.4 Programme details

- If a primary immunodeficiency spokesperson is to be used on a radio or TV station, ask the journalist what areas he/she will be covering in the interview
- The primary immunodeficiency spokesperson should be fully briefed before the interview, and should have answers prepared for the questions to be covered in the interview
- Ask the journalist if anyone else is to be interviewed at the same time or separately for the programme
- Enquire as to whether the programme will be pre-recorded or will be recorded live. The advantage of a pre-recorded interview is that you will have several chances, should you make a mistake
- Check when the interview is to be broadcast and arrange for the programme to be recorded

5.5 Television

Television is perhaps the most popular and appealing media outlet, but it's also the most expensive. Television commercials are costly to produce and airtime, even for a 15 second spot, is expensive.

However, there are other options to consider namely:

- Public Service Announcements
- News coverage
- Interview shows
- Community television programming.

5.5.1 Public Service Announcements (PSA)

Many television stations, both national networks and community stations, do broadcast public service announcements, however their requirements vary dramatically. It is imperative to phone each station and enquire about their particular deadlines and formats for public service announcements. The PSA producer or a public relations' person will be able to help you.

When writing PSA brevity is the goal. Stick to the facts. Time announcements; make sure you include the name and address of the group, as well as the phone number of the publicity co-ordinator.

5.5.2 News Coverage

National Member Organisations

SKILLS MANUAL

TV news coverage is difficult to obtain. Programme directors, like editors, are inundated with news releases and requests for coverage. Many PID patient groups have succeeded in making appearances on TV especially when paired with a national or worldwide event, such as World Primary Immunodeficiencies Week.

5.5.3 Local Programmes

Talk shows and news magazine shows cover a wide range of human-interest stories. They use in-studio interviews as well as on-location shoots. They focus on everything from controversial community issues to celebrity profiles.

5.5.4 Community Television

Although the community television audience is smaller than that of a larger network, community TV is the best bet for in-depth television exposure.

5.6 Radio

Radio offers the public a fast, effortless way of getting information. It's a popular medium and one to take advantage of.

Local stations are often desperate for local news. Radio provides numerous publicity opportunities: public service announcements, newscasts, current affairs programmes, interview programmes and open-line shows.

News Stories

News is any information, which is interesting, or unusual to a newspaper or programme. Regular reading of your local daily and weekly newspapers (including free sheets) will give you an idea of events in your area, which might prove novel to your media. Remember that news is both positive and negative with stories falling into both categories.

What types of stories concerning primary immunodeficiency are the media likely to be interested in? The media are interested in stories which are local, but also national stories with a local angle.

5.7 Press Releases

5.7.1 Writing a press release

Once you have decided that your story is news you will need to write a press release. Gather the necessary facts to convey your story. It is important that these are presented correctly. Use the following guidelines for setting out your information:

- **Title:** A press release should always be titled – try to remain factual and do not attempt to write a “jazzy” headline, unless appropriate. The title should contain the whole point of the story in not more than one sentence.
- **Date:** Always put the date of issue on the front page of the release in the right hand side top corner. Put the details of when the press release can be used in the left-hand corner. Put the details of when the press release can be used in the left-hand corner. In most cases, a press

National Member Organisations SKILLS MANUAL

release can be used on the day of issue and should include “FOR IMMEDIATE RELEASE” in the left-hand corner. The exception is when you are giving information in advance about an event which is due to take place at a particular time and date in the future. In this case, the format is as follows:

EMBARGO: NOT FOR PUBLICATION UNTIL (TIME), (DAY AND DATE).

- Overall content: The most important thing is for the content of the press release to be factual, accurate and to the point. Follow the rules to include details of the following:
 - Who?
 - What?
 - Where?
 - When?
 - Why?
 - How?

Keep it simple and short. Make it clear, to the point, and on one page, if at all possible.

If you have written a release on a particularly technical topic, use generic terminology where possible. The release will most certainly be read by a wide variety of people with varying degrees of sophistication in your subject area.

- **First paragraph:** Try and cover the most important points in the first paragraph – you should try to catch the journalist’s attention here as this may be the only paragraph that a busy or lazy journalist has time to read.
- **Sentences:** Use short sentences and cut out any unnecessary adjectives, with paragraphs containing no more than 40 words. Try to aim for a maximum of 200 – 300 words for the whole press release. A journalist can always ask for more information if interested.
- **Quotes:** Try to include a relevant quote from a primary immunodeficiency representative involved in the story. The person’s name, position and the company name should always be given.
- **Layout:** Type the release in double spacing, using one side of the paper only. If the release continues onto another page, make sure this is clearly marked by putting “more” or “cont...” on page one in the bottom right hand corner. At the end of the release write “ENDS”. Put the heading of the release on each page in case it becomes separated from the rest.
Set wide margins – 20/80 is good. This is for convenience of editors who will be making their copy reading changes.
Be consistent in punctuation and capitalisation. It’s likely that a particular newspaper or magazine will change what you’ve written to conform to their own style. But it’s much easier to edit a release that follows a particular style throughout. Also – be consistent with immune deficiency OR immunodeficiency – do not mix them as that will confuse the reader.
- **Contact Name:** At the end of the release give the name, job title, address, telephone number and email-address of the person or persons issuing the release so that journalists can contact them for further information if necessary.
- **Stationery:** All press releases should be distributed on primary immunodeficiency organisation press release paper. This will enable the journalist to immediately identify who the press release is from.

National Member Organisations

SKILLS MANUAL

- **Internal Distribution:** Distribute copies of your release to key people in your organisation even as you are sending it out to the media. Your leadership shouldn't have to read the news for the first time in the local newspaper.
- **Related media:** Pictures, videos, podcasts, etc, are great ways to illustrate your story and they'll contribute immensely towards placement of your story. Be sure to send good quality visuals and other media as attachments to your press release for easier handling by the recipient.

5.7.2 Press announcements

A press announcement is a similar format to a press release and should be used to inform journalists of forthcoming events such as a fundraising event or opening to which you would like to invite them. The content should answer the questions who, what, where, when, why and how in short paragraphs. The press announcement should be followed up by a press release with further details of the event.

It is important to remember that every press release will be different. The content and length of a press release will depend on the story; for example, a simple announcement may not include a quote.

5.8 About news media

- Send your release to named individuals – not just titles. This is why it is so important to update your media list on a regular basis.
- Provide media with adequate advance opportunity to use your release, particularly if it is featuring an event that has yet to happen.
- Know your media. Their deadlines. Their needs. A notice for a routine meeting may be all that you can expect from one publication. While another may routinely print everything you send them (not likely, of course.)
- Be available for follow-up calls from the media – especially if your name is listed as the contact on the release. Respond promptly to inquiries, with answers within the hour, if at all possible. Get a knowledgeable backup person to respond to press inquiries in case you are called away.
- With a general release, don't play favourites with the media. Mail or distribute the release so that everyone receives it at about the same time.
- If you have people who are available for interviews to support the story, say so. A "note to the editor" will do the job. Don't force the editors, reporters to guess. They may guess wrong.

5.9 About the follow up

- Once your story is out, be prepared to respond to a reporter's follow-up probing questions, which might uncover possible negative aspects of your release. That's news too.
- Don't chastise reporters, editors for not running your story.
- If there is a substantial mistake in the way your story was reported, that should be corrected. And you should let the media know in a respectful, courteous manner. If the issue is clearly a matter of opinion or perspective, however, keep your comments to yourself.
- Be prepared to put the way your story appeared (or didn't appear) in perspective for those for whom you work. Unrealistic expectations frequently sour what was otherwise acceptable coverage.

National Member Organisations

SKILLS MANUAL

- Understand the “oral contracts” that you or other members of your organisation make with the reporters over the phone and in person. “Off the record” is very different from “for non-attribution,” for example. And whether you understand this terminology or not, it is very important that you and the reporter are in complete agreement as to what you both understand about what you or your colleagues are saying. In short, if you don’t want something reported, don’t say it. It does no good to shut the barn door, as they say, after you have let the horses out.
- Take your news release seriously. If you don’t feel comfortable putting it out, seek the expertise of a professional communicator who can do it for you. A shoddy piece of writing is no bargain.
- Any news story will lead to a surge in telephone and e-mail enquiries, so make sure that you have people available to handle those enquiries promptly.

5.10 Public speaking

Making speeches is tough on the digestive tract, but it is good for your soul and your organisation. And once you are up there, once you feel they are with you and you have “got them”, it is a thrill. It is like flying – without a plane.

- A good speech is three-quarters content, one-quarter delivery. What you say is a lot more important than how you say it. In other words, the best presentation in the world won’t turn a hollow speech into a meaty one.
- On the other hand, really good material is totally wasted if it is mumbled and mishandled. If your points aren’t received and remembered, you didn’t make them.
- To begin with, you have to have something say. Then, before you put a word on paper, you have to decide exactly where you are taking your audience. Have both your starting point and your destination clearly in mind before you start figuring how best to get there. Otherwise, you will wander, and so will their attention.
- Don’t trust to luck. Write out every word. Then rewrite it. And polish it. The trick is to make it look and sound spontaneous and the better you know your material the easier that is to do.
- Make it easy on yourself. Double-space your manuscript. Triple space between paragraphs. Underline or highlight key words, key sentences. Number the pages. Don’t staple them together. Then you won’t have to turn pages, rustle paper. Use a paper clip. Slide your pages noiselessly. Anything that attracts attention away from your face and voice is distracting.
- What you are writing is to be said, not read. So keep your sentences short. Keep it tight. And bright. And light. Specific, not vague. Keep it personal. Use your words, your platform. Make sure it is you talking.
- Be sure ahead of time who is in your audience. Be sure of their level of sophistication. Be sure you know what they are looking for.
- Rehearse. At least three times. Time yourself. Be sure you read it on the train, morning and evening, for a week beforehand.
- Mealtime speeches are much tougher than speeches in an auditorium. More chance of kitchen clatter in back of you and snoozers and boozers in front of you.
- Don’t take a drink beforehand, ever. This is an unbreakable rule, and there are no exceptions.
- Visuals are dangerous; handle with care. If you are using PowerPoint (MS Windows), Keynote (Apple), a film or charts, bring your own computer if possible, if not, do test the facilities before speaking.
- Always check your presentation ahead of time. Always warn IT personnel of any videos or special requirements you may have. If possible hand them a marked script of your presentation.
- Take your time. Once you get up there, make them wait while you take a couple of deep breaths and look the situation over. Remember: they want to like you. They want you to be good.

National Member Organisations

SKILLS MANUAL

- Keep your head up, your voice up, your pace up.
- Don't use profanity, ever.
- Make contact. Pick out someone toward the back of the room and beam everything you are saying directly and personally to that person.
- Never talk longer than 20 minutes.
- Don't tell jokes but be surprising and fresh with your speech.
- Say what you believe – and believe what you say. Be sincere; be enthusiastic. Be anxious to have them believe it as much as you do.
- Expect the worst to happen. Expect a fuse to blow, your slides to be upside down, a phone to ring in the back of the room, or the mike to start squealing and then die, while you are talking. You may be sure that sooner or later these things will happen.

5.10.1 Handling questions

- Good answers can make the difference between winning and losing.
- Anticipate questions
- Ask for questions
- Listen carefully to the question, and show that you are listening
- Try to “read” any hidden implications in what the questioner's asking
- Repeat or restate the question (with bigger audiences only)
- Reply in summary first
- Substantiate your answer with any explanation or evidence to support it
- End with a positive conclusion
- Split multiple questions, and then answer each individually.
- Ask for colleagues' views if any are present with you.
- If you don't know the answer, say so frankly. Offer to find out, make a note of questioner's name and remember to follow it up.

5.11 Online presence

Online presence should be the second step after forming an NMO. This is where people can go to find more information about your patient group, your activities, about PIDs and your contact details. It is important to be as professional with your online presence as with all other aspects of running an NMO.

If budget allows you to cover all costs related to having a website (domain, hosting, design, technical maintenance, etc) go for it, preferably, with assistance from dedicated professionals.

Social media presence is also very important. If your budget is short you may consider starting by having one or more social media pages and develop a website at a later stage. The most important thing is that the information you convey in policy, awareness, etc, efforts has an online referral.

5.11.1 Website

Consider what you want to achieve, your audience and your message. Depending on your country's PID environment and on the functioning of your NMO you might want to centre it more around PID awareness or perhaps more around fundraising.

Your home page should be very clear to read and navigate and include:

- Your logo
- Tag line

National Member Organisations SKILLS MANUAL

- News
- Highlights
- Partners
- Main menu

Subsequent pages can provide further information about the NMO mission and objectives, contact details, main events, etc. A website is a living thing so make sure you add to it and keep it updated. Make the website responsive to mobile devices and each page easy to share on social media.

If you are using web developers pass them a briefing outlining your goals for the website and what it should include. Be available to accept advice from these professionals as they might contribute greatly to your NMO having a good end product.

5.11.2 Social media

Social media are great tools to help your message grow stronger and reach further audiences. There are many to choose from and they keep changing. It is good to stay on top of what's trending and to consider where you may or may not find your followers and supporters. Your most dedicated followers and supporters can connect to your NMO through social media as can those related to them.

For identification of your NMO you should also use your logo, tag line or mission on your social media pages. Whenever there is a new article on your website share it also on your social media pages. When you want to recognise your volunteers or partner this is also a nice way to do it publicly. Statistics made available through them will help you evaluate your performance and do better each time.