



**INTERNATIONAL PATIENT ORGANIZATION
FOR PRIMARY IMMUNODEFICIENCIES**

**NATIONAL MEMBER ORGANISATIONS
SKILLS MANUAL**

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1. INTRODUCTION

The IPOPI NMO Skills Manual has been developed to help new organisations to understand a little of what lies ahead and – maybe – to encourage better established organisations to look again at their own organisation.

1.1 The conditions and under diagnosis

Primary immunodeficiencies are genetic diseases. They are a diverse group of more than 100 immune disorders, many of which result from multi- or single gene defects that may affect one or more components of the immune system and lead to a characteristic increased susceptibility to recurrent and persistent infections.

When primary immunodeficiencies are left undiagnosed or misdiagnosed, the immune system remains compromised often leading to illness, disability, permanent organ damage or even death. Primary immunodeficiencies are chronic diseases but with early diagnosis and adequate treatment most people with a primary immunodeficiency can live a near normal life.

Primary immunodeficiencies can appear at any age. The US National Cancer Institute reports that people with primary immunodeficiencies also have a 200 fold greater risk of developing cancer.

It should be recognised that primary immunodeficiencies do not refer to “one” disease, but cover a spectrum of over 100 recognised (and more as new primary immunodeficiencies are officially defined each year) diseases which have immune deficiency as the common denominator. IPOPI is therefore concerned with a range of related diseases – and should not be regarded as narrow in scope, nor one-disease specific.

Primary immunodeficiencies can be diagnosed with a simple and inexpensive blood test which can identify 95% of the disorders. Treatments include primarily antibody replacement therapies (immunoglobulins) and bone marrow transplantation.

While the majority of symptomatic and treatable primary immunodeficiencies - collectively estimated at 1:10,000 - are classified as rare diseases, experts* estimate that 70 –90% of primary immunodeficiencies remain undiagnosed, and incidence could be as high as 1:500**. (*Prof L Notorangelo and ** Prof L Hammarstrom presenting to European Parliament Scientific and Technological Assessment Unit, March 2004).

If current scientific evidence is correct about the *estimated* prevalence of primary immunodeficiencies, early and accurate diagnosis of those conditions is essential.

In undiagnosed or misdiagnosed sufferers, treatments are focused on the frequent and long term use of high dose antibiotics. Improved diagnosis of primary immunodeficiencies could therefore have a positive impact on the reduction in use of antibiotics, better use of health facilities and an improvement in the quality of life for the individual.

2. ESTABLISH A NATIONAL GROUP

Your national patient organisation 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 others 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 primary immunodeficiencies. Much material is available from IPOPI and from other well established national member organisations – visit www.ipopi.org – and then go to 'About IPOPI' and from there to 'Members' – there is a library of material already there 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 understand something of the primary immunodeficiencies – so you need to make sure that members of your Parliament understand something, 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 – know as well because it is the civil service who set 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!!

In Europe IPOPI developed an awareness campaign by establishing contact with the Scientific and Technical Advisory group of the European Parliament and an invitation to present to the Committee was the outcome. That in turn led to participation in a Europe-wide Rare Disorders conference and later to a grant to run a European Consensus Conference – and IPOPI is here to offer help as well based on those experiences.

2.3 Involvement of doctors and nurses

You 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 is 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. So make sure you make and keep your local medical staff as your friends – together you will be a great team working together for good.

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 align yourself with one company any 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 and 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 six committee members.

3.1 Committee Chairperson 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 by telephone conference call.
- 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 organization (guidelines, 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.
- 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 socialization and sharing experiences, and to learn from others with similar problems.

3.5.1 Types of meetings

3.5.1.1 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.

3.5.1.2 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.

3.5.1.3 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.

3.5.1.4 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 organization 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.

How to keep your team - motivation

You **should not** 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.
- The motivating factors, which brought the individual to your organization, 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 have to 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 program is to determine realistically the net amount of money to be raised. The objective is to have an event, which will produce income in excess of expense – i.e. profit.

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 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 organization to underwrite the need,
- 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, such as banks, accounting firms, printing companies etc.
- 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 concerns whose activities and products correspond with your program; for example, consider approaching a toy company for camp funding, a cosmetics company for women's programs 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 fund raising 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 programs, 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.
- Program information, including the kinds of programs 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 programs you conduct. All of 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 advise

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 decide on the amount of money to be raised. The objective is to have an event, which will produce income in excess of expense – i.e. profit.

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 program.
- 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 programs 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 program, and where it can be obtained.
- The event you select should have a definite appeal to the audience or market. Review the types of programs 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 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 program 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 dinner's 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 time 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 the world over are basically all looking for a story, and they all work in roughly 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, fund raising 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 said 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!
- 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 the broadcasting press (TV and radio) as well as the printed press, national as well as regional. The value of the regional press is often underestimated. Although the circulation of regional newspapers in some countries are 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

Identification: When reading your regional 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.

Copy Deadlines: Phone all 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. Stories will not last. Timing is critical. News stories need to be presented quickly to editors. Deadlines are tight and, with electronic news gathering, getting tighter.

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 in your locality
- 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

TV news coverage is difficult to obtain. Programme directors, like editors, are inundated with news releases and requests for coverage. Television news has little time for soft news and human-interest stories.

5.5.3 Local Programmes

Local programmes, rather than newscasts, may be the best option. 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. In most cases, a press 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 e-mail-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.
- **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.
- **Pictures:** Pictures may be helpful (sometimes absolutely necessary) for placement of the release. However, they should be 8x10 or certainly no smaller than 5x7, black and white glossy prints. Leave borders for the editors’ crop marks. Don’t write on the back of pictures – the marks will show through and make them valueless. A picture that works both vertically and horizontally will increase your chances of publication. It is very important, however, that the picture be identified. The best way to accomplish this is to tape an outline or supporting information which has been typed onto a piece of paper on to the back of the photograph. The paper should be long enough to extend below the photograph so that the outline is visible. It can be folded for mailing purposes, but when the editor unfolds it, the picture and outline should be together. Digital photographs are best of all.

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 fund raising 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 fact 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.
- 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 in to 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's 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, slides or film or charts, bring your own computer, projector, your own projectionist, and your own easel, your own everything. Bring an extra fuse. Bring an extra extension cord. Have a tiny flashlight in your pocket in case the light on the lectern goes out.
- Have a pocket mirror along in case the screen is behind you; that way you can tell which slide is on the screen without turning away from the audience. Always check your presentation ahead of time. Always have a marked script for the projectionist.
- 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.
- 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. Don't say, "Standing up here today reminds me of the one about..."
- Be surprising. I like to surprise people with something they don't expect.
- 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.
- Address everyone, not just the questioner. Follow the 25% (questioner) 75% (audience) rule.
- 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 The Internet

If you are new to the world of computers, it can look like a scary world. It is not. You just need to learn the basics. Before you know it you will have the words, phrases, and terms as a regular part of your vocabulary.

You should first know about computers and feel comfortable with them.

Computer programmes do not involve a lot of learning. Most computer programmes do all of the work for you. They just leave the fun to you.

Next you should learn as much as possible about the Internet: what is it? How can you use it? Is it hard to use?

5.11.1 A brief introduction

The Internet is a data network – that is, a communications medium. To gain a better understanding of a communications medium, consider another common communications medium – radio waves. Radio waves carry many “standard” classes of information: radio programs, television programs, cellular telephone calls, military communications, satellite information, navigational systems, etc.

The Internet provides two-way (peer to peer) communications and allows messages to be routed from the sender to the recipient in such a way that everyone on the network does not have to listen to the message.

Some of the more common classes of information carried on the Internet include:

5.11.2 Electronic Mail (also known as e-mail).

E-mail enables users throughout the world to exchange machine-readable messages with each other – even though the sender and the receiver may be widely separated in both time and space.

These messages can be simple text messages typed into a computer by one person and intended for delivery to the computers of any number of other people. The messages are usually delivered very quickly. Often in a matter of seconds, and may be stored and read at any time after delivery. E-mail provides an excellent medium for discussions.

One of the many useful applications of e-mail is electronic discussion lists, also known as mailing lists. A mailing list is a special mail address, set up by an administrator that automatically distributes mail sent to that address to all the users who are subscribed to the list. If the other subscribers choose to respond, it is possible to have lively and timely discussion with people across great distances and many time zones. Messages can be archived to allow an organisation to build an information database of electronically searchable messages.

5.11.3 World Wide Web Pages/homepages/websites

Browsing the web is similar to having a book with an infinite number of pages each listing the next page you can (easily) turn to if you want to find out more about something you see on the current page. It allows for a mixture of text and graphics, and commonly contains both.

Occasionally, there are also sounds and tiny movies. Having your own Web Page or Web-Site is similar to having your own publishing house. You can place information on your site, and it becomes globally accessible 24 hours a day. The Web provides an excellent medium for publishing large amounts of (possibly frequently changing) information, and even for gathering information from people who fill out electronic forms associated with your site.

5.11.4 Newsgroups (also known as Netnews, or News)

These public discussion forums resemble a computer bulletin board in which thousands of global users post ‘articles’ that can then be viewed at any time in the future by other readers. Often, readers will reply to messages that are posted. News differs from e-mail in that it is public, not private, delivered more slowly (over the course of hours or days), and is segmented into discussion forums. Also, while users do subscribe to specific news groups, they must actively check those groups for new messages (and there are often MANY new messages.) Electronic mail, however, simply arrives in a user mailbox. E-mail is more directed, timelier and more manageable in volume.

5.11.5 Internet Relay Chat (IRC) (also called chat-rooms)

The IRC program includes hundreds of public and private chat areas with topics that span the entire gamut of human interests. People chat in English and dozens of different languages by connecting to the appropriate area and typing on their computers. Everyone connected to a particular area can see what others connected to that area is typing, as they are typing it.

5.12 Using e-mail in a primary immunodeficiency organisation

For those running a national organization, e-mail can be incredibly useful. Need to send someone the latest proposal to give to a funder? A quick e-mail and, wherever they are they have the information. Today some hotel phones hook up to a laptop. If you have people on the road, email can save the day. From sending out routine memos to transferring updated documents, going "online" can save paper and time. Best of all, coming to a decision by consensus is a lot easier to accomplish when people can all discuss the issue via email.

First: See how many of your board members have e-mail at work or home. Send out email versions of your newsletter so that people can use them as references for events. Also, allow people to 'register' for your email on your Web Pages.

Set up the necessary procedures for using e-mail in your board:

- All e-mails should go to all board members.
- The subject must be clear.
- If you want to address one specific Board member, start the main text with naming her/her. The rest of the board will be kept informed.
- Set a date for answers.

Phone. Bulk mailings. Posted fliers. These are the traditional means of reaching people quickly and easily. Add to this list e-mail a new way to reach people. E-mail allows the creation of lists that enable you to let everyone know the big news, at the touch of a button. This is especially useful when time is critical. Those people with e-mail tend to check it everyday. What better way to let them know about your important event than when he/she is at the computer and near a diary?

5.12.1 Website (homepage)

Special concerns for a primary immunodeficiency organisation in considering a presence on the Internet.

The reason for building a website and thereby establish presence on the Internet is:

- To draw the attention of as many people as possible towards your organisation.
- To communicate your message to a huge audience

5.12.2 Planning your website.

Step 1

Have something to say – You have ideas about what you want to say. Now it is time to put those ideas into words. In other words, how to say what you want to say.

Step 2

Know how to say it – You can have the best message in the world but if you don't say it properly no-one will listen. You must know how to reach your target audience.

How you word your message is very important. You know what is said about first impressions. Poorly planned Web pages look awful. Bad margins, faded colours, and poor flow of text and graphics will do your organisation more harm than good. No presence is better than poor presence. If a visitor is turned off in the first instance they will not come back and all the hard work that has gone into creating the Web pages will be wasted.

Step 3

Know what the Internet represents and what it is about. Ask yourself the following questions:

- Do I understand the Internet?
- Can I use it effectively to find a large number of my target audience?

- Can I afford to use the Internet as a resource?
- Will I need help setting up on the Internet?

You must put thought into what you are doing. Don't expect to throw together a few lines of text and some graphics and have people running to your doorstep. You must look at this project just as if you were creating a TV ad with one of the big advertising firms. The result, what people see, is the same. Because it is an evolutionary process, you will be constantly changing and enhancing your Web pages.

Step 4

If you have made it this far and still feel the Internet is the place to be, you now need to create a plan of things to be done.

The most important words to have on the first page (usually called the home page or the front page) are those that describe your mission, objectives, target audience, and contacts.

The general page layout is:

- Your logo
- Mission
- Objectives
- Target Audience
- Picture
- Links to other pages
- Contacts

If you need additional space, provide links to additional web pages. This is normally done by creating a main menu. Don't put too much on one page. And remember to leave room on the page for graphics. The home page should have your logo or a picture of an event sponsored by your organisation. Keep the graphics small. Don't put too many graphics on one page. It is movement of the picture (down-loading) from the Web server to the location of the person that takes time.

Step 5

Put the plan into action! An HTML expert can be an invaluable resource in the setting up of a web site. Look for volunteers or individuals who can assist you. Large organisations will generally charge high rates but there are many enthusiastic individuals keen to demonstrate their creative and technical skill.

There are various ways to set up on the Internet:

- You could purchase your own hardware and software to create your own server.
- You could lease space from an Internet provider.
- You may be able to have space donated to you by an Internet provider.
- Securing sponsorship for space from a donor.