IFPA

INTERNATIONAL FEDERATION
OF PSORIASIS ASSOCIATIONS

A Guide to Developing a Psoriasis Patient Organization

Introduction

The International Federation of Psoriasis Associations is very supportive of the formation of national psoriasis associations worldwide. Each psoriasis association functioning in the world brings education, hope and support to those who suffer from psoriasis and psoriatic arthritis. Once an individual, or group of individuals, discovers a need for a psoriasis association in their country, it may seem to be a daunting task, but extremely rewarding in knowing that an organization exists to help people who live with psoriasis and psoriatic arthritis.

The International Federation of Psoriasis Associations (IFPA) offers the following suggestions in forming an association that is "national" in scope, though the information may be helpful in creating regional or local associations as well.

Why start a psoriasis patient organization?

- To provide support, encouragement, and a sense of community to psoriasis patients
- To be the voice of psoriasis patients – to the medical community, to the government, to officials making decisions about healthcare and access to treatment
- To be an authority on the disease
- To create awareness that psoriasis is a serious, noncommunicable, systemic disease
- If *you* don’t speak for those suffering with psoriasis, who will?

Legal Establishment of a Patient Association

Patient associations usually begin when a group of interested people come together and decide they want to form a patient organization. The first step is to form an interim board and draft the bylaws and constitution. Once the organization is established, apply to be an association, and get legal/formal recognition.

Contact your governmental or legal agency within your country that oversees the formation of local, regional or national non-profit organizations for guidance on the specific rules, regulations or laws that govern such activities. Registering your association may be a time-consuming process, but needs to be done to legitimize your organization.

Elect a Board/Executive Committee: The Board or Executive Committee should be democratically elected at the first official assembly of the association by involved persons or members. The Board ideally should consist of a majority of persons who have psoriasis, or who have relatives with psoriasis or are in a profession, such as a dermatologist, nurse, etc., who works with psoriatic patients.

The Board will oversee the management of the association and eventually, once the organization has grown and has an operational budget, hire an executive director. It is also advantageous to the organization, if possible, to have board members who are experts in legal matters, medicine, financial/accounting, public relations, etc. Officers should include a President, Vice-President, Treasurer and Secretary, but also may include a Member-at-Large, Alternates/Substitutes, etc. Committees, such a Finance, PR, Outreach, Fundraising or Development and for specific programs, such as World Psoriasis Day, may be formed within the Board members selected to Chair and lead each committee. Board members should be democratically elected by the association members periodically at a General Assembly meeting, usually every two-to-three years. An election committee should be formed which puts forward a suggestion for new board members and then presents the candidates for a vote to the General Assembly. Most associations require that Board members *not* be employed by psoriasis-service providers or any other conflict of interest.

The following are suggestions of principle areas of responsibility of the Board. Board members should:

1. determine the organization's mission and set of policies for its operation, ensuring that the provisions of the organization's charter and the law are being followed
2. develop the organization's charter and constitution
3. set the organization's overall program or plan from year to year and engage in longer range planning to establish its general course for the future
4. establish fiscal policy and boundaries, with budgets and financial controls
5. select, evaluate, and if necessary, terminate the appointment of the chief executive
6. develop and maintain a communication link to the community, promoting the work of the organization[i]

For future Board members, and for the sake of the association's continuity, the association should develop a Board Manual so newly elected Board members have a thorough understanding of their responsibilities and roles. The Manual can include:

1. articles of incorporation and the mission statement
2. bylaws
3. list of current trustees, their short biographies and contact information
4. list of committees and their members
5. structure of the organization, with staff member titles and areas of responsibility
6. brief history of the organization
7. description of roles (President, Vice-President, Treasurer and Secretary), responsibilities, and requirements of trustees
8. travel and meeting expense reimbursement policy
9. minutes of current fiscal year meetings
10. annual report for the last fiscal year[ii], past and current annual budget
11. information on the organizations programs and projects
12. strategic plan
13. annual calendar
14. promotional material (the organization's brochure, etc.)
15. current funder list

Develop a Mission Statement for your non-profit psoriasis association. A mission statement defines what your organization does. The mission statement should contain both a broad statement of purpose and a detailed framework from which your organization will develop its activities. Everything your organization does will revolve around the mission statement. For example, the mission statement of the National Psoriasis Foundation/USA is: "Our mission is to improve the quality of life of people who have psoriasis and psoriatic arthritis. Through education and advocacy, we promote awareness and understanding, ensure access to treatment and support research that will lead to effective management and, ultimately, a cure."

Develop and file a Charter or Articles of Incorporation, or similar documents within your country's government that describe your association (name, address, and other pertinent information required by the legal system) with the appropriate authorities that oversee nonprofit organizations.

Create a Constitution or Bylaws that dictates how your psoriasis association is governed and managed. Bylaws go beyond the general material contained in the charter and discuss more detailed and specific procedures affecting the trustees themselves. For example, the bylaws set out the number, terms, and election procedures for trustees and discuss how and when meetings are called, how officers are elected and what their powers are, how votes are taken, how board vacancies are filled, and a host of other small details essential to the smooth operation of the organization.[iii] IFPA is willing to share their bylaws with you.

Suggested Constitution format (based on IFPA Constitution):

1. Name and legal domicile of the Association
2. Purpose, mission and goals of the Association
3. Organizational structure of the Association
4. Membership criteria and rights of the members
5. Meetings
6. Election procedure
7. Executive Committee (purpose, structure, roles, authorization, responsibilities)
8. Publications
9. Financial year, accounts, budget
10. Winding up and liquidation policy
11. Alteration of the Constitution

Look to other non-profit, health-related associations in your country for structure and content of their Charter and Constitution. Set forth your Mission Statement and Bylaws according to the laws regulating nonprofits within your country. The constitution and charter should be reviewed by the Board periodically and updated when needed.

Principles to remember: once you have legally established a psoriasis association, it is necessary to remember that non-profit organizations follow the following principles:

- Designate that your national organization is specifically organized for the benefit of people who have psoriasis and psoriatic arthritis.

- Income for operating your organization is principally obtained from the public (individuals, government, etc.) or non-commercial interests.

- Membership is open to all citizens in your country or to all citizens within a region separated due to linguistics or other circumstances.

- Non-profit organizations do not take direction from commercial enterprise or parties who have a vested financial interest in psoriasis therapies (directly or indirectly) that could compromise the objectivity or credibility as an organization representing people who have psoriasis and psoriatic arthritis.

- Create and provide programs that reach out to serve all regions of the country defined by linguistics.

- Make sure your organization demonstrates that it represents a national constituency in it communications, fund raising, and volunteers

- Identify medical professionals, dermatologists or nurses, who are supportive of the cause and expert in psoriasis and psoriatic arthritis care. Ask them for support by helping provide guidance with medical issues. For example, in preparing educational literature to distribute to the public. Make sure the information is free of bias.

- Join IFPA and form a partnership with other psoriasis associations for around the world. IFPA member share information and resources that may be of benefit in assisting the people you serve – contact IFPA member organizations and ask for advice and guidance (www.ifpa-pso.org/membership).

Practical advice on starting a national association

Volunteers start most associations but at some point it will be necessary to hire a professional staff to succeed. A professional staff gives the organization permanence and is capable of ensuring on-going programs and services. Contact local universities or colleges to find trainees or interns who could offer trained help with marketing, public relations, website development, fund raising, finance or journalism. Trainees may be transitioned into part-time or full-time employment. Think small in the beginning and pick projects that can be completed successfully so volunteers or staff members do not become overwhelmed.

Membership

Membership should be open to all citizens in your country or to all citizens within a region separated due to linguistics or other circumstances. Once your association is established, it is time to open up membership.

Promoting your association to attract members: Advertise the association and patient meetings wherever you can. Although it is safe to assume that there are people who have psoriasis in every town and city, this does not mean there are people with psoriasis who want to join an association. Areas with smaller populations may have a smaller number of people with psoriasis.

Be Creative: The more ways you can think of to spread the word about your association, the more the association will grow. Promotion is a critical, ongoing component of a successful association. Keep constant promotions of your group going by alternating different approaches. Make sure to ask new members how they heard about the association; this way you will know what is working and where you should spend the majority of your time and energy when promoting the group in the community.

- Press releases—This is a great opportunity to develop awareness about your association and about psoriasis/psoriatic arthritis. If you are aiming for local psoriasis awareness, preparing a well-written press release is crucial. Find and write a compelling and interesting patient's story. Editors always love featuring human interest stories in their publications. It may take several efforts before getting a newspaper to write a story, but it is well worth it when it happens.

- Internet—Josef de Guzman, President of PsorPhil, started his search for members on the internet: "I posted my story on at least a dozen of yahoo and msn online support. I indicated in my post that I was looking and searching for psoriasis patients from my country and would leave my contact details there. Then a couple of Filipinos replied. Then the three of us searched for more using my technique. After the first month, we were just 7 including my nurse who joined as a volunteer. My nurse would ask the patients from their clinic to join us while the rest of us would constantly search the internet for more members. At this point, I have created the yahoo group support..and would use the yahoo group as a chatroom to increase its activity and to put us up on the search engine."

- Association flyer—A flyer may be one of the simplest ways you can get the word out about your association. By producing a flyer, you will have a tool that can be used for a number of different promotional ideas. Distribute flyers to dermatologist offices (see Medical Profession below), hospitals and health clinics in the area, and post the flyer, if possible, at markets, schools, health clubs and anywhere else that will reach a large number of people. Do not forget to put the contact numbers or address on the flyer. Make sure the flyer will guide the patient reading your flyer what to do next. ←

- Seek help from doctors/hospitals/clinics: Talk to doctors to help increase awareness and membership by asking their psoriasis patients to join your organization.

Membership fees: Initially, patient associations usually don't charge a membership fee when they are forming because finding members and bringing psoriasis patients together is the top priority. Once you reach a target number of members, you can decide if it is time to charge a minimal fee to help cover costs. Many patient associations ask for a donation or membership fee of anywhere for $2.50 to $35.00 to $60.00 USD, or more. Should you decide to charge a membership fee, some members may be unable to pay, but should not be excluded from the organization. For those with a low income, membership fees can be reduced or paid in increments throughout the year. For example, one association charges three separate low fees for those under 18 and students, for the unemployed and disabled, and for senior citizens 65 and over.. If members cancel their membership for reasons of economy, some associations offer a very low membership fee for a year in hope that the member's financial situation will improve over time. Another association approaches higher-income members and asks them to pay for those who cannot afford the fee, as a sign of goodwill and to help the organization.

All new members should be given some sort of welcome packet including a "welcome to the association letter", and information about the association and psoriasis. Some associations include skin care samples, magnets, buttons, window decals or stickers, etc.

Membership communication ideas:

- Build a database to keep track of members and contacts
- Communicate through e-mail, SMS, phone calls, paper mail or postcards. ←
- Publish a newsletter to keep members up-to-date on psoriasis news and to advertise meetings, educational events, etc. Newsletters can be published once a month, bi-monthly, etc.
- Many established associations publish monthly/bi-monthly, quarterly or yearly magazines
- Develop a webpage or website
- Start a Facebook page or a free online social network

Member meetings: For many psoriasis patients, an association meeting is the first time they will meet, face-to-face, another person that suffers with psoriasis – which is often extremely important for the patient. It is important, then, that it is a positive experience.

Psoriasis patients come to meetings for a variety of reasons:

- To be assured they are not alone and to be with others just like them
- For support and understanding
- To vent frustration and anxiety
- To receive information about their disease and treatment options
- To ask questions

Ideas on conducting member/patient meetings: Members meetings can be informal or formal. For an association that is new and developing, a series of informal meetings may be best, such as meeting over a cup of coffee to discuss ideas for the association, as well as the challenges of living with psoriasis. Try to keep it a pleasant experience, especially for new members.

Be sure to greet everyone who comes to a meeting, don't put people on the spot (they may not be ready to talk about themselves yet), leave it open and just introduce everyone, encouraging people to speak if they wish to. You may want to write meeting guidelines about keeping an environment of trust and openness, and allowing everyone a chance to talk. Keep the conversation positive but at the same time allow the members to express their anxiety and frustration. If you plan to have a speaker, leave room for questions for the patients. The most important thing is that the patients get to talk. Ask for suggestions about future meeting topics from the members. Some organizations write up a questionnaire or other form that allows patients to choose topics.

Meetings can be focused on educating psoriasis patients about their disease (see Meeting topics: “Programs”) or Social Events, which can be extremely important in member support. These can include celebrating birthdays and anniversaries, family picnics, holiday dinners or parties, and field trips somewhere fun or having to do with health, like a spa. Social events build a sense of community and support, especially when they involve a spouse or the family.

Family members of psoriasis patients: Don’t leave family members out! Family members bear the burden of living with psoriasis too. Invite the family to an education seminar so that they can learn about the disease. Plan a family picnic so families can interact with one another and draw support, or invite them to special family meetings. Oftentimes family members report that they never really understood what it was like to live with psoriasis until they attended a meeting or event, and this gives legitimacy to the physical, psychological and socio-economic problems that psoriasis patient’s face.

The Medical Profession

Identify medical professionals, dermatologists or nurses, who are supportive of the cause and experts in psoriasis and psoriatic arthritis care. Ask them for support by being Medical Advisors to the association, to help provide guidance with medical issues, and to communicate on your behalf to the medical profession in dermatology. Also, your medical advisors can help prepare or review educational literature to distribute to the public. Make sure the information is free of bias.
Ask physicians expert in psoriasis or psoriatic arthritis treatment to act as your advisor on medical matters. Having medical professionals as advisors will help add legitimacy to your association.

Another important way to work with the medical profession is to keep dermatologists and rheumatologists informed about what your organization is doing:

- introduce yourself in person, if possible, or send a letter of introduction and information about your organization
- communicate periodically with updates, new flyers, and newsletters
- invite dermatologists personally to attend a meeting or event.
- ask the doctor, nurses, and office staff to promote your organization to patients and make sure they have something to hand out to their psoriasis patients (business cards, magnets, brochures, etc.)

Ask your members about their dermatologists – does the doctor understand psoriasis well? If not, download psoriasis educational materials from the IFPA and other association websites and send it to the doctor – peak their interest in psoriasis.

Fundraising and Development

Fundraising from individuals: For some countries, raising money to fund a non-profit association or a program from individuals and the general public is part of the culture, but for other countries it is not. For those that do, there are many avenues to fundraising: an association can ask the members for donations for general operating costs and to fund certain programs. When a non-member requests information about psoriasis, the association can fill the request and include a donation form. An association can hold informal fundraisers, such as a bake sale, rummage sale, or a raffle. More complex fundraisers can be an organized, such as a “Walk for Awareness” the National Psoriasis Foundation in the U.S. developed, or other routes like direct mail to all association members and supporters. The website can also be used as a fundraising tool by allowing members and non-members to donate directly online.

Fundraising from corporations: Depending upon the legal regulations of your country, you may or may not be able to access funding from corporations, so the first thing to do is it check with the legal guidelines. There may be specific pharmaceutical guidelines that must be obeyed to be legal and ethical, and it's best to know what they are upfront. Once aware of the legal and ethical parameters, research the psoriasis treatments that are available in your country and the pharmaceutical company that manufacturers them. Contact information for your region or country is usually available on the company's website. If you have a relationship with a dermatologist's office, someone there may be able to give you the business card of local pharmaceutical representatives.

Pharmaceutical companies: offer funding and grants to patient organizations, and can be restricted to specific programs or unrestricted (see "programs" below). Pharmaceutical companies can be divided into two categories: those that manufacture prescriptions drugs for psoriasis and those companies manufacturing over-the-counter products, such as skin care, lotions, ointments and hair-care specifically for psoriasis.

Non-pharmaceutical companies: this category includes everything else. There may be a national or local company that has a philanthropic extension and wants to do good in the community. They could be approached asking for support of a specific community project, either for cash or for in-kind donations. For example, company could provide the beverages for a social gathering.

What could be funded:
- Mailing and printing costs
- Printed publications: newsletters, magazines, bulletins, programs
- Advertisements for your organization: business cards, brochures, magnets
- Educational programs
- Social events for your organization
- Psoriasis camps
- Awareness-raising activities: for example, if your organization holds a psoriasis walk or other physical activity, a company could provide water/coffee/tea, balloons, t-shirts, tables and chairs, tents, snacks, goody-bags, etc.

Government grants: another avenue could be to look for funding from government or health ministry programs for non-profits, or find companies that have philanthropic interest. If there are other health-related patient associations in your country and that you have access to, look and see if they access any funding and from where – you may be able to apply for funding for your association too.

Volunteers and Staff

Collect and maintain a list of everyone who contacts your organization. Solicit their help in building your psoriasis association by volunteering to the cause.

Volunteers start most associations but at some point it will be necessary to hire a professional staff to succeed. A professional staff gives the organization permanence and is capable of ensuring on-going programs and services. Contact local universities or colleges to find trainees or interns who could offer trained help with marketing, public relations, fund raising, finance or journalism. Trainees may be transitioned into part-time or full-time employment.

Educational materials about psoriasis

IFPA offers information about psoriasis and related issues that can be downloaded from the website. Other psoriasis organizations also have educational information about psoriasis that can either be downloaded from the website or sent by mail. If you use another organization's information, either ask permission or give an acknowledgement for using their work. You can also seek out reliable sources of information, like dermatologists or dermatology associations, to create your own publications and other educational materials. Materials should say “for more information please contact” and contact numbers, emails and/or address of your associations must be indicated.

Some associations provide psoriasis brochures to dermatologist offices, hospitals and general doctor’s offices so that they are available to psoriasis patients. This is also a good way to promote your association.

Promoting and Marketing

The best way to attract members and public attention is promoting the organization on an on-going basis. Create posters to post in your community and enlist volunteers to post them in other communities. Promoting and marketing your association takes time, so take on the quick and easy ones things to do first, and then work the remaining in as you can. Another tactic is to think about which approaches would have the most impact in your area and do those first. Be creative!

Keys ideas to promote the association:

- Get your information on a Web page and include a friendly, personal welcome. Let psoriasis patients know why they should join your organization and attend a meeting or event, and how they can be involved. Don’t forget to e-mail meeting announcements to the people who have signed up on your Web page.
- Make flyers to give or mail out
- Attach a copy of your flyer to your e-mail reminder notices. Ask people to print them off and post them or hand them out in their area or to their contacts.
- Let the medical people in your area know about your association and ask them to refer patients. A personal visit is best, but a phone call or a mailed or faxed flyer works too.
- If you cannot get around to the doctor’s offices, email or mail details of your group and give them your contact information.
- Post flyers at hospitals, libraries, health clinics, pharmacies, doctors’ offices, grocery stores, churches, community gathering places, and anywhere you can. Ask others to post flyers in places where they have access. Ask office staff if they would prefer having the flyer displayed in a plastic frame or on their bulletin board rather than distribute flyers.
- If your association publishes a newsletter, send it to the media, to the hospitals, health clinics, doctors and health insurance companies to inform them of your activities.
- Contact hospitals and clinics and see if they have a quarterly magazine that will list your group as a resource.
- Advertise in public transportation (bus, tramway, underground) with posters or flyers.
- Contact any pharmaceutical company representatives in your area. Let them know about your association and ask them to help get the word out.
- Perhaps a doctor or the nurse might call a few patients and let them know about the association. Try asking your doctor what he or she can do to help promote the group.
- Post on online community blog, forum, calendar and event sites.
- Post about your meeting on the Foundation message boards at Check back at anyplace you display or post to replace and update information[iv]
- Hype World Psoriasis Day (WPD). WPD can become your passport to the media. Invite them to be a part of history by covering your association as you join the international community in celebrating World Psoriasis Day. Can radio stations, TV and newspapers to tell them about WPD, and use statistics provided by the WPD campaign to get your message across that psoriasis is a serious disease.

Working with the media: Getting a newspaper or television station to run a story about your organization or through compelling stories of someone with psoriasis is priceless publicity. Contact the press and see if they will print information about psoriasis and your organization, and World Psoriasis Day. The media are usually attracted to compelling human interest stories and may be interested in writing an article about the struggles of a psoriasis patient, which would be great PR for your association. Start to take notice of who writes or reports on human interest stories or health articles and contact them about psoriasis.

Let the public know about your association and psoriasis any way you can. Newspapers may offer free postings for health/support meetings. Look in the health section of the newspaper, if any, and see what other patient organizations are doing and how they promote their association. Call the paper and ask where to post if you do not see anything. Radio stations and local TV stations often have announcements of meetings. Write a letter to the editor.

Programs

Create and provide programs that reach out to serve all regions of the country or regions defined by linguistics. Think small in the beginning and pick projects that can be completed successfully so volunteers or staff members do not become overwhelmed. The "perfect" program will meet the nature and needs of the association and member, and the goal of the problem should follow directly from goals intended to meet specific needs of your members.

Your association may be able to get funding to cover the costs of a program. Oftentimes, to get a government or pharmaceutical grant, an association needs a program plan and an estimated budget, which may be crucial to getting the grant. Grants usually require:

- Background information about your association
- Goals and objectives of the program and how your association will accomplish the goals
- Expected results of the program
- Estimated budget

For example, if the goal or mission of your association is to educate psoriasis patients about psoriasis, then a program can be an educational seminar on the "Basics of Psoriasis." To accomplish this goal, you need to approach a dermatologist and ask if he or she would be willing to participate in the program as a speaker. You will also need to find a venue or somewhere to hold the event. To reach the greatest amount of people, you may want to promote the event to entire city, so you will need to design a flyer and a poster, and plan for printing and postage costs.

Your association is much more likely to get financial support if you have already done the legwork and have a well-organized program plan and budget.

Educational Seminars: possible speakers can be:
Dermatologists
Rheumatologists
Cardiologists and other professionals that cover psoriasis co-morbidities
Psychologists, stress therapists
Natural or holistic practitioners

Program Topics can be anything related to psoriasis and physical/mental health, such as:
Basic Facts about Psoriasis: ask a dermatologist to explain to your members exactly what psoriasis is, e.g. What are the psoriasis plaques and how do they form? What happens with the immune system? What is inflammation and where does it comes from?
Psoriasis Treatment Options: general overview of options available in your country
Psoriasis on specific areas: scalp and nail
Basic Facts about Psoriatic Arthritis
Psoriasis Co-morbidities, i.e. heart disease, Crohn's disease, metabolic syndrome, etc.
Sun and Phototherapy/Skin Cancer
How the Immune System Works and its Role in Psoriasis
Youth and Psoriasis
Living with a Chronic Disease
Stress Reduction Techniques
Basic Skin Care: how to moisturize your plaques effectively, how to bathe and care for your skin
Be aware of what is "new" in the world of psoriasis, and then plan a discussion around it and ask the appropriate speaker

Psoriasis Camp can be anywhere from a weekend to a full week. Some associations provide a camp just for children, but most are for any age. Members usually pay a fee to attend, which helps cover the costs of food, lodging, staff and operational costs. The bulk of the cost may be covered with grants from various sources, depending on your society (such as donations, pharma grants, government funding, etc.) Camp schedules usually involve some sort of educational discussion with a dermatologist or other medical professionals, social activities, programs for children, some sort of light physical exercise, and discussion groups.

Social Events can be extremely important in member support and can include family picnics, holiday dinners or parties, and field trips somewhere fun or having to do with health, like a spa or mineral baths (such as the Blue Lagoon, the Dead Sea, etc.). Social events build a sense of community and support, especially when they involve a spouse or the family.

Awareness-raising events and World Psoriasis Day

Awareness-raising events can be an activity of your association at any time during the year, but specifically can be used for promoting World Psoriasis Day, October 29. World Psoriasis Day is a primary project of IFPA, and IFPA members and psoriasis associations worldwide promote and celebrate WPD every year by developing various awareness-raising activities.

What is World Psoriasis Day? World Psoriasis Day, launched in 2004 by members and non-members of psoriasis associations around the world, is an annual day specially dedicated to people with psoriasis and/or psoriatic arthritis. Conceived by patients for patients, World Psoriasis Day is a truly global event that sets out to give an international voice to the 125 million people with psoriasis/psoriatic arthritis around the world. Formed by a global consortium of patient associations from around the world, World Psoriasis Day aims to raise the profile of a condition which needs to be taken more seriously by national and international authorities.

Aims of World Psoriasis Day

- Raising awareness: to let people with psoriasis know that they are not alone and to raise the profile of this devastating skin disease and the misery it can cause. To dispel myths about the condition, such as the mistaken view that psoriasis is contagious.
- Improving access to treatment: to encourage healthcare systems, governments, physicians, carers and all those responsible for psoriasis care to allow psoriasis sufferers access to optimum therapy. For too long, psoriasis/psoriatic arthritis has been low priority.
They are debilitating diseases and must move up the healthcare agenda.
- Increasing understanding: to provide information to those who are affected by the condition as well as the general public in order to educate people about the condition so that they can discuss it more openly and confidently.
- Building unity among the psoriasis community: to provide a platform from which patient voices from around the world can speak as one and be heard by key decision makers.

Awareness-raising activities: Each year a wide variety of activities take place around the world, these have ranged from the distribution of leaflets and postcards to large events, which have make each World Psoriasis Day a huge success and generate worldwide media interest.

For a more information and a comprehensive list of past year's WPD activities, go to www.worldpsoriasisday.com. Any of these activities can be used during the year to raise awareness, especially for WPD. Also, pay attention to what other awareness-raising activities nonprofit associations in your country hold.

Political action or advocacy

What is your country or community lacking for psoriasis patients? Is there a way that you and your association can be a voice for psoriasis patients to your government, health ministry, local school district, etc.? Anywhere that a psoriasis patient is discriminated against or stigmatized, you may be able to help by speaking to an elected official or person of influence about the needs of psoriasis patients in your country. You and the members of your association are experts on what it means to live with psoriasis and/or psoriatic arthritis, what it means to be discriminated against, the need to access effective treatments and the need for a cure. You can speak firsthand about living with psoriasis and why viewpoints need to change. For more information and a Guide for Political Action for Psoriasis Associations, please contact the IFPA Secretariat.

Reasons to speak out about psoriasis:

- Lack of public awareness and misperceptions of the disease – will help lessen discrimination, stigmatization
- Lack of medical profession knowledge and recognition of psoriasis
- Lack of access to treatment(s)
- No national statistics for how many people suffer with psoriasis in your country
- There must be research towards a cure!

Website

Build a website with factual, documented information about your organization and it's activities, and materials about psoriasis. For ideas, look at Psoriasis-related websites, such as IFPA (www.ifpa-pso.org), the National Psoriasis Foundation, U.S. (www.psoraisis.org), and IFPA member associations (see member organization on the IFPA website). If you don't know how to build a website, contact a school or university in your area that offers courses on website design – you may be able to get a student to design your website as a project or for practice.

Strategic and forward-thinking

Once an organization is established, a major responsibility of the trustees is to engage in planning both for the short term (the next year), the medium term (the next five years), and the long term (the next decade), Planning involves the setting of broadly stated goals and specific objectives. To establish goals, the board must decide on directions for the organization and determine what they want to see accomplished.[v]

Objectives, one set, allow for two additional activities to take place. One is the drafting on an action or implementation plan by which the objectives will be achieved. It lays out the actual schedule of activities, use of resources (both human and financial), and logistics. The second activity that should follow is the establishment of an evaluation process to determine whether the organization actually achieves the objectives in the time allotted.[vi]

Questions that can help you get started on a strategic plan are: What is the vision you have of your organization? Where do you see it in one year, three years and 5 years? Having a general idea and vision helps you to plan and become organized. It's okay if you simply want to grow your organization from 5 members to 20 in one year, and then to 100 in three years. However, you may also vision that within three years, you want to have government support for psoriasis in your health-care system. When you plan strategically, you can develop steps to get to your goal.

Program Evaluation

How do you know your organization is succeeding in its mission? Are you supporting psoriasis patients in your country and providing for their needs? It is always a good idea to periodically evaluate your organization's activities and programs to ensure that your association is fulfilling the mission.

Program evaluation can:

1. Understand, verify or increase the impact of services on members. These "outcomes" evaluations are increasingly required by nonprofit funders as verification that the nonprofits are indeed helping

their constituents.
2. Evaluations can identify program strengths and weaknesses to improve the program.
3. Verify that you're doing what you think you're doing - Typically, plans about how to deliver services, end up changing substantially as those plans are put into place. Evaluations can verify if the program is really running as originally planned.
4. Facilitates the board or staff to really think about what their program is all about, including its goals, how it meets it goals and how it will know if it has met its goals or not.
5. Produce data or verify results that can be used for public relations and promoting services in the community.
6. Produce valid comparisons between programs to decide which should be retained, i.e., in the face of pending budget cuts.
7. Fully examine and describe effective programs for duplication elsewhere.[vii]

You can collect information by questionnaires, surveys, interviews or forming focus groups. To analyze the data or answers to interviews, focus groups, or questionnaires, organize the comments into similar categories, e.g., concerns, suggestions, strengths, weaknesses, similar experiences, program inputs, recommendations, outputs, outcome indicators, etc. and label the categories or themes, e.g., concerns, suggestions, etc. Attempt to identify patterns, or associations and causal relationships in the themes, e.g., all people who attended programs in the evening had similar concerns, most people came from the same geographic area, most people were in the same salary range, what processes or events respondents experience during the program, etc.

To interpreting the data, attempt to put the information in perspective, e.g., compare results to what you expected, the promised results; any common standards for your services; original program goals; indications of accomplishing the desired outcomes; description of the program's experiences, strengths, weaknesses, etc.

There are many publications in print and on the internet that can guide an organization through the evaluation process – check your local library, bookstore or the internet.[viii] Monitoring and evaluation allows the association to be open to feedback and to adjust programs accordingly

What IFPA can provide:

Join IFPA and form a partnership with other psoriasis associations from around the world. IFPA members share information and resources that may be of benefit in assisting the people you serve. Contact and ask for advice and guidance from other national non-profit organizations.

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[i] Managing a Nonprofit Organization in the Twenty-First Century, Thomas Wolf, Fireside: New York, NY, 1999, p. 48

[ii] Managing a Nonprofit Organization in the Twenty-First Century, Thomas Wolf, Fireside: New York, NY, 1999, p. 67-68

[iii] Ibid, p. 50

[iv] Based on the National Psoriasis Foundation’s “Marking your Group”

[v] Managing a Nonprofit Organization in the Twenty-First Century, Thomas Wolf, Fireside: New York, NY, 1999, p. 52

[vi] Ibid.

vii Basic Guide to Program Evaluation, Carter McNamara, MBA, PhD, Authenticity Consulting, LLC. Copyright 1997-2007. (Adapted from the Field Guide to Nonprofit Program Design, Marketing and Evaluation.) http://www.managementhelp.org/evaluatn/fnl_eval.htm, 2.22.08

[viii] Materials used in this section came from Basic Guide to Program Evaluation, http://www.managementhelp.org/evaluatn/fnl_eval.htm, 2.22.08

IFPA-International Federation of Psoriasis Associations
Gustavslundsvägen 143
167 51 Bromma, Sweden
Phone: + 46 739 402 252
e-mail: info@ifpa-pso.com
www.ifpa-pso.com