

SUGGESTIONS ON HOW TO SET UP AND RUN AN INTERSTITIAL CYSTITIS/BLADDER PAIN SYNDROME PATIENT SUPPORT GROUP

Starting a patient support group needs motivation and determination. You may be a patient or a partner of a patient or a small group of patients and feel you would like to help other patients and to raise awareness and knowledge of Interstitial Cystitis/Bladder Pain Syndrome (IC/BPS) and associated disorders in your country, region or community. Be assured that lack of experience in this field is no reason not to go ahead! Many support groups around the world have been set up by patients who have never done anything like this before in their lives. Although it is not easy when you yourself are a patient, it is nevertheless fulfilling to know that you are contributing towards helping other patients get the right diagnosis and the right treatment at the earliest possible stage. And that you can help people to learn to cope with their illness and bring about a change in their lives for the better. A support group can help to empower patients to achieve much more in your country.

Although there is nothing to stop one person - a patient or partner or other interested party - going ahead alone, it is easier and advisable if there are two or three of you. Gradually you can build up a working committee. Do not try to do everything yourself, learn to delegate and pace yourself or you will end up with burnout! Above all, prioritize.

Market Research

Before making a start, you need to do some “market research” and decide whether you are going to aim for a traditional support group, an online/social media support group or a combination of the two.

Take a look online at IC/BPS support groups, websites, blogs and Facebook pages around the world and also at any other patient organisations for different disorders that may exist in your country. See what they offer their members and how they present themselves. Don't hesitate to contact them and ask advice. See what information you can obtain from any national umbrella patient organisations about setting up a support group in your country and your culture. Every culture requires a different approach and every country in the world has different medical facilities and treatments available and above all a different health economy!

An important aspect is to look at the legal situation in your country or region and what regulations you may have to comply with, including privacy laws, even if you have an informal group.

Make a list of health professionals with expertise in this field in your country (urologists, urogynaecologists, pelvic floor physiotherapists, urology nurses, pain specialists, etc). You will need their help.

Tasks and activities

Before you start, you will be faced with a choice of possible tasks including:

- raising awareness of IC/BPS among patients, health professionals at all levels including primary care, hospitals/clinics and the general public; in countries with remote areas this can include local health-workers or district nurses in rural areas.
- providing patients and their families with practical and medical information and emotional support,
- providing the possibility of an online question and answer forum for patients and/or a telephone helpline,
- providing the opportunity for patients to connect with each other either online or through traditional meetings,

- helping patients to find experienced health professionals in the field of IC/BPS and also associated disorders when necessary,
- participating in research projects and initiating projects such as patient surveys,
- cooperating with support groups and their representatives worldwide,
- giving presentations about the patient perspective and the support group at meetings for patients and/or health professionals.
- Organising a stand with information about IC/BPS and your support group at meetings and conferences.

The best advice is to start small and basic and build up slowly.

Setting up a support group as a legal entity

Every country has its own rules and regulations for setting up a charity/support group and may offer different variations.

If you have a central national organisation, such as a charity commission, in your country, you will be able to obtain information from them. If not, a lawyer or notary will be able to provide information and advise you which option will be best. One important aspect to ask about is liability and how the committee members will be protected. Another very important aspect concerns privacy laws.

You will first have to find several other people willing to be committee members since you will need a chair, secretary and a treasurer (to look after income and expenditure and provide annual accounts). You need to choose a name for your support group and create a “mission statement” (the purpose of your support group), keeping it as general and flexible as possible. A lawyer will be needed to create your governing document or articles of association. Setting up a legally established charitable support group will cost legal fees. Ask your local lawyer or notary about the different options and how much it will cost. At the end of the process, everything will have to be registered with the relevant authority in your country.

Funding

When setting up a legally established patient support group, potential members have to be able to apply for membership. Today this often means providing an online application form and setting up a bank account into which subscription fees can be paid. The bank account can often only be opened once the support group has been formally registered. Once you have some members paying a subscription, you will have a small income to expand your activities. You will need more financial support to start off, particularly to set up websites, email address, telephone etc. Sponsors or other funding sources will be needed to cover bigger expenses. Since it is valuable for patients representatives to attend medical meetings (urology, gynaecology or specialised IC/BPS meetings) to build up their knowledge, sponsors will be needed to help out with funding for this. Potential sponsors are often pharmaceutical firms who produce or distribute medicines or other products (i.e. catheters) for IC/BPS patients. You should investigate whether it is possible to get a government grant or subsidy. However, it is difficult to obtain government assistance or other sponsoring if you are not yet a registered charity.

Information and contact

Before publicising your group or going online, you need to have some simple information ready in your own language: at least a basic text or fact sheet explaining what IC/BPS is (see our basic IPBF information leaflet). If you have a text which can also be downloaded and printed as a leaflet, this can

be distributed to hospital and doctors' waiting rooms, used for potential sponsors and for handing out at urology or gynaecology meetings.

In addition to your basic information leaflet/fact sheet, you will need an email address which patients can contact and possibly a telephone number to be used as a helpline.

Website and social media

While in the past support groups relied on physically distributing leaflets and holding meetings, today most patients around the world want to be able to access information online and have online contact with other patients and support group leaders, preferably using their smartphone. Online support groups can reach far more patients than was the case in the past. Having an official website can help prevent this kind of informal contact from becoming fragmented and can ensure that reliable, accurate (medical) information is (also) provided.

You should decide whether you are going to start with a website or a Facebook page, Twitter, WhatsApp group, blog etc. and how much public access you want to provide and what should be reserved for members with a password. Privacy laws need to be considered here. You will need a webmaster and someone to moderate any online groups.

Medical Advisory Board

It is essential to find one or more supportive IC/BPS doctors and/or urology nurses who will help you through the medical maze and serve as a basis for a medical advisory board. Have at least one urologist or urogynaecologist supporting you who is willing to help out with writing medical information for patients, speaking at a patient meeting or online webinar. This doctor may also be able to put you in touch with other patients who would either like to help organise a group or become a member. He/she could hang up an advert in his waiting-room calling for enthusiastic patients and hand out a leaflet.

Education and training of patient representatives

Patient representatives and committee members should seek as much information as possible about IC/BPS and the latest treatment and developments. It is particularly important to know what treatment is available in your specific country so as to be able to inform support group members. Books for both patients and professionals are available on all aspects of IC/BPS, often in English but there may be something available in your own language. Scientific medical information can be found in the urology journals available online or via PubMed (<https://pubmed.ncbi.nlm.nih.gov/>). Here you will find the "abstracts" (summaries) of articles, but full articles often have to be paid for. However, some articles are today being published with "open access" which means that the full article is free of charge.

Try to ensure that at least one committee member attends any medical symposiums or presentations on IC/BPS, either in person or virtually, and reports back to everyone else. There are many possibilities both nationally and internationally and this is the place to gain maximum information about diagnosis and treatment. In this way you can gradually build up knowledge within your group. This aspect is becoming increasingly important as patient representatives are being expected to participate in advisory roles in research projects.

In recent years, due to the Covid lockdown, many conferences became hybrid meetings. This has had a knock-on effect and many webinars are now being held for patients and professionals on a regular basis worldwide. This trend is continually increasing and will be of great value to patient organisations and their advocates who have problems in travelling due to a) lack of funding and b) health issues.

For further information, contact:

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