

# A Guide to Starting a Patient Support Group

While it may take some effort, with a few basic steps, anyone can start a support group to help patients and their families connect and spread the word about rare diseases.

By Abbie Cornett



**ONE OF THE MOST DIFFICULT** things in life a person or family must face is the diagnosis of a rare or chronic disease. Challenges range from finding the appropriate medical care, to navigating the maze of insurance approvals, denials and appeals, financial hardship and the feelings of isolation that many times accompany a diagnosis. Patients frequently don't know where to turn, and that is where a support group can help.

Patient support groups are not all the same; they range from very large groups whose mission is very broad such as the National Organization for Rare Disorders (NORD), an umbrella group for more than 7,000 rare diseases, to very small local groups offering support to patients on a one-on-one basis. Regardless of their size, all patient support groups are started with the same goal in mind: to help patients and families cope with the many problems associated with chronic illness. They are formed to empower patients by allowing them to share their experiences and frustrations with other people facing similar challenges. This sharing of common experiences reduces feelings of isolation and frustration that patients and family members often feel by offering them a safe venue to discuss their experiences, hardships and feelings. Support groups further act as a resource where patients can go for information regarding their disease and serve an important role in raising awareness of diseases through advocacy and education. Many groups become very involved in issues of healthcare policy and legislative initiatives to promote change in laws that affect patients.

While there are many patient support groups for chronic diseases, there are several reasons why patients might want to start their own support group. For instance, sometimes, there isn't a group established to benefit patients in a specific region. Or, the groups already established may not serve the specific needs of some patients. Here are some basic pointers for those whose goal is to start their own support group.

### **The Founder's Role**

A patient support group can be started by anyone; no special training or experience is necessary. Groups are frequently founded by patients or family members who want to help others by bringing them together in an informal setting where they can discuss the challenges they face, to offer additional sources of information and to promote awareness of the disease. Groups may also be started by healthcare providers and physicians who are concerned about access to information for their patients and families.

Still, starting a support group places demands on you that you may not have considered. Before doing anything, you need to ask yourself a few very important questions. First, do you have the time? Leading a support group requires a level of commitment you may not be prepared for. People in need will be depending on you to be there for them. You cannot cancel a meeting because you are tired, or just decide you don't want to do it anymore. Second, how will you finance the group? Starting a group can be a financial drain if you try to do it without donations. You must consider the cost of phone calls, flyers, postage, refreshments and the meeting location. Ask for assistance whenever you can. Don't feel guilty about asking for donations; the money is going for a good cause. When your group is formed, pass the hat at meetings; patients and families will be happy to help when they can.

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Before starting a group, do your research to see if there is already an existing group that serves the patient community you are concerned with. If a national group exists, it may be beneficial to affiliate with them. Affiliation with a national organization will give your group credibility and access to resources that might take longer to achieve than if you start from scratch. However, if you decide to affiliate with a national group, it will have guidelines that your group must follow. It may also have a different set of goals. For instance, while its goal may be lobbying, your primary concern may be education and support.

Remember that you are one person, and you can't do everything on your own. Once you have determined you are committed to starting a group, whether it's affiliated with a national group or not, you need to pick a co-leader. You will need at least one other person in the beginning you can depend on. The number of people you need to help you will grow as the group grows. Pick people who are good leaders. They must be able to run the group if you are unable to be there.

## Defining the Group's Goals

Now is when the real work begins. What will you name your group? The name should reflect the group and be inviting to potential members.

Next, you need to define the goals of the support group and what will be discussed when you meet. A good way to start is to write a mission statement that should include what you would like to accomplish. For example, NORD's mission statement reads: "NORD is committed to the identification, treatment, and cure of rare disorders through programs of education, advocacy, research, and service. The National Organization for Rare

Disorders (NORD), a 501(c)(3) organization, is a unique federation of voluntary health organizations dedicated to helping people with rare 'orphan' diseases and assisting the organizations that serve them. NORD is committed to the identification, treatment, and cure of rare disorders through programs of education, advocacy, research, and service."

## Choosing a Venue

Once you have a mission statement, a co-leader and have identified your audience, it's time to find a venue. Choosing a venue can mean not only the location of your meeting but what type of group you form. You can choose a traditional group or an online group. If you choose a traditional group, the location of your meetings should make people feel comfortable. While you can hold smaller meetings in a private residence, a better choice is a public place such as a local church, library or hospital. These are good options for many reasons. Not only are they more approachable to new members, they are usually close to public transportation. In addition, they have available parking and are handicap-accessible. If such a venue is unavailable, you may need to look at local hotels or restaurants, which are a good option particularly for larger meetings. The only drawback to these locations is they will charge you for the meeting space.

Next, determine how often the group is going to meet, how long the meetings are going to last and how many people you want to attend. It is better to start small with fewer meetings. You can always increase the frequency of meetings after you are established. And, because people are depending on you, you have to make sure the meetings start on time, end on time and follow the published agenda.

## Brick and Mortar vs. Online

With today's technology, you may want to consider starting an online support group rather than the traditional brick-and-mortar group. This option has the advantages of not requiring a physical meeting space, costing less to form and maintain, and allowing people from anywhere in the world to participate. This means that you can reach a much larger and diverse group of

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**WHY** » Patients look to a support group because it can empower them, allow them to share their feelings, reduce feelings of isolation and frustration, provide a safe venue and provide resources for more information



**GOALS** » Naming the group and developing a mission statement that describes what the group plans to accomplish will help to define the group's goals.



**BRICK AND MORTAR VS. ONLINE** » With the ability to connect with others online, support groups no longer have to be restricted to regional locations. Decide what's best for your group, but keep in mind the unique problems that can exist with both.



**VENUE** » Regional groups that meet face-to-face will want to meet in a location that will make people feel comfortable and that are easily accessible.



**PUBLICITY** » Traditional media are no longer the only option for publicizing the formation of a support group. Social media sites such as Twitter, Facebook and others are a perfect option for getting the word out.

patients. Online groups also offer anonymity to participants, allowing them to ask questions they might be uncomfortable asking in person.

While an online support group offers many benefits, it also has unique problems that don't occur in a traditional group. The anonymity afforded by an online group can be a drawback since patients can experience feelings of isolation and loneliness because of their disease that an online group may not be able to address. Many patients want the physical connection that is found in a traditional group. In addition, information is more difficult to manage in an online group. Frequently, an online page has too much or misleading input. As the leader, you will have to closely monitor the group's page for misinformation and be diligent in deleting inappropriate posts.

If you decide that an online group is your best option, you will need to follow many of the same steps as those for starting a traditional group. However, there are some differences. You must purchase a domain name as soon as possible. Most domain names can be purchased for a nominal amount. Then, you will need to pick a platform that allows you to control the group membership and settings. For instance, you must be able to remove people from the group that post negative or harmful comments.

## Getting the Word Out

Whether you choose a traditional group or an online group, publicizing your meetings is very important. People can't come to the meetings unless they know about them. There are many good ways to get your information out. Today, the world is focused on social media. Go viral with your group. Start a Twitter account, a Facebook account and an online chat group. Tell your story! If you are a patient, a family member or a caregiver, you have some personal reason for starting the patient group. Starting a blog is a great way for people to learn about you. You can be your own best publicist.

Use the media. They can be a great free resource. Many radio stations and newspapers set aside ad space for public service announcements for groups like yours. Write press releases about the formation of your group with the date and location of the first meeting. Directly contact the local newspaper editor to suggest the paper publish a story highlighting the disease and how it affects patients and their families in the community. Design a flyer, and post copies in locations where potential members will likely see them such as in hospitals, doctors' offices, pharmacies and public information boards. Send your group's information to the local social service and community agencies, and ask them to include your group in their directories. Be sure to personally

invite people you know who would be interested. A personal invitation is still the most effective way to engage people.

## Your First Meeting

For your first meeting, preparation is key. Make sure you know what you're going to say. It must be relevant and interesting to the group, as they will be looking to you for information and support. Also, make sure that the meeting room is comfortable and accessible for all people. Most important, start the meeting on time. Nothing frustrates people more than unpredictability.

*Starting a blog  
is a great way for people  
to learn about you.*

Since this is a new group, make sure everyone understands that they are in a safe environment. To establish trust, explain the rule that what is said in the group, stays in the group. Introduce yourself, and tell them your story; explain why you felt the need to start the group. Many people will be uncomfortable at a first meeting and hesitant about talking. By sharing your story first, you will give people a feeling of security. Then invite the group to introduce themselves and share what they are comfortable with. While people are speaking, be sure to be an active listener and to encourage all to ask questions and share. And thank everyone for their participation!

## You're Connected!

When your first meeting is over, pat yourself on the back and remember that all of the work was worth it. You have put yourself out there to support people in situations similar to your own. With relatively little effort and cost, you've established a patient support group to make new connections that provide encouragement, information and a sense of cohesiveness to all participants. ■

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## Sources

1. Goldberger, S. How to Start a Cancer Support Group in Your Community. Cancer Support Community, Dec. 13, 2012: [blog.cancersupportcommunity.org/2012/12/13/how-to-start-a-cancer-support-group-in-your-community](http://blog.cancersupportcommunity.org/2012/12/13/how-to-start-a-cancer-support-group-in-your-community).
2. Richards, K.L. Starting a Support Group. Health Central: [www.healthcentral.com/chronic-pain/coping-439459-5.html](http://www.healthcentral.com/chronic-pain/coping-439459-5.html).
3. Tools to Change Our World. Community Toolbox: [ctb.ku.edu/en](http://ctb.ku.edu/en).