

Making Connections in the PI Community

When living with chronic illness, you don't have to go it alone; a support or networking group can help. From in-person to online options, choose the one that's right for you.

By Trudie Mitschang



PRIMARY IMMUNODEFICIENCY diseases (PIs) affect people in different ways, but like anyone living with a chronic illness, individuals living with PI tend to battle feelings of isolation. In addition to seeking out the most effective treatment plan, it is vital to identify ways to reach out to others who are facing similar challenges. According to the Immune Deficiency Foundation (IDF), it is particularly important to build and maintain strong relationships, both inside and outside your immediate family, and to remain connected socially: “Individuals living with chronic illnesses, especially unusual or rare disorders such as primary immunodeficiency diseases, often feel isolated and that they are struggling alone. Contact with other individuals who live with these diseases is a way to both gather knowledge and acquire an important sense of connection with others who share your experience.”¹

Networking with National Organizations

An excellent place to begin looking for patient-to-patient connections is through recognized organizations created specifically for PI patients. IDF offers a number of programs and resources to get you started, including:

Peer Support Program. This program gives you the opportunity to interact with one of IDF’s trained volunteers who has personal experience living with PI. This free resource is for anyone personally affected by PI, including patients, parents or other family members, friends or caregivers.

IDF Friends. This private social network and discussion forum is exclusively for patients and family members who live with PI. The online community gives people affected the opportunity to offer and receive peer support, ask questions, make suggestions, share their stories and connect with others through words, pictures and video.

Get Connected Groups. The IDF Get Connected Groups are designed to connect individuals diagnosed with PI and family members in their local communities. The meetings can occur at a local community room, library, coffee shop or other venue. Through the groups, individuals and families can connect to share experiences, receive information and gain support. These groups do not include medical presentations or industry exhibits.

Common Grounds. This is a private social network and discussion forum exclusively for PI teens. This online community gives teens the opportunity to offer and receive peer support, ask questions, make suggestions, share their stories and connect with others.

Contact IDF at (800) 296-4433 for information on these and other opportunities to get involved at the local, regional and national levels.

Pros and Cons of Traditional Support Group

For many people, a health-related support group may fill a gap between medical treatment and the need for emotional support. While support groups may be offered by a nonprofit advocacy organization, clinic or hospital, they may also be run entirely by group members.

Formats of support groups vary, including face-to-face meetings, teleconferences or online communities. A lay person — someone who shares or has shared the group’s common experience — often leads a support group, but a group also may be led by a professional facilitator such as a nurse, social worker or psychologist. Some support groups may offer educational opportunities such as a guest doctor, psychologist, nurse or social worker to talk about a topic related to the group’s needs.

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One of the advantages of a traditional support group is the common experience among members often means they have similar feelings, worries, everyday problems, treatment decisions or treatment side effects. Participating in a group provides you with an opportunity to be with people who share common challenges and goals.

Benefits of participating in a support group include:

- Feeling less lonely, isolated or judged;
- Reducing distress, depression, anxiety or fatigue;
- Talking openly and honestly about your feelings;
- Improving skills to cope with challenges;

- Staying motivated to manage chronic conditions or stick to treatment plans;
- Gaining a sense of empowerment, control or hope;
- Improving understanding of a disease;
- Getting practical feedback about treatment options; and
- Learning about health, economic or social resources.

It's important to note support groups, regardless of format, can have drawbacks as well. Common concerns arise from disruptive or domineering members, an excessive amount of complaining, lack of confidentiality, spreading of unsound medical advice and competitive comparisons of whose condition or experience is worse.

A strong and experienced facilitator can usually help the group steer clear of these types of pitfalls. Before joining a group, ask about the facilitator's qualifications or training, clarify the confidentiality guidelines and then try it out for a few weeks. If it doesn't feel like a good fit for you, consider a different support group or a different support group format such as online.

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Exploring Online Support

Online support groups and social media pages offer a sense of community and connection that can alleviate feelings of isolation, especially for those who are housebound by illness and/or who do not live in close proximity to local networking groups. Many have discovered immediate connections and lifelong friendships thanks to the wonders of social networking. "Social media groups have been the best for me," says Dona Darr, whose 16-year-old daughter lives with PI. "They are a wealth of information regarding the realities of dealing with the disease and navigating insurance, schools, etc. They can also give you perspective; through online networking, I learned there are many patients who deal with more severe challenges than the ones my daughter and I have faced."

For Jessica Leigh Johnson, an *IG Living* columnist, blogger

and mother of three boys with X-linked agammaglobulinemia (XLA) and one who passed away from XLA, social media has led to both online and real-world connections: "We've connected to families with our diagnosis through the XLA Facebook group. It's an excellent way to connect with people who share your struggles. There are members from all over the world, so it's not hard to find people who live in the same state or who even see doctors at the same hospital you do."

Health writer Samantha Gemmell agrees: "When you are first diagnosed with a rare condition, Facebook groups can be a godsend. They are filled with people who understand, who can offer everything from a great specialist and day-to-day survival tips to someone to talk to when insomnia hits at 3 a.m. You are no longer lost in the storm. There are others to hold your hand and tell you 'yes, that is a normal symptom,' and 'no, it's not ridiculous to want to throttle your mother/sister/in-laws/friends when they say insensitive things or wonder about the validity of your condition.'"²

Gemmell advises there are also downsides to relying on social media networking, noting members have a tendency to "overshare." Differing opinions on treatment plans can also lead to unhealthy online bickering and even bullying that can leave you feeling angry, misunderstood and discouraged.

"We all have pride in what we can achieve and feel a greater connection to those who have faced similar circumstances," says Gemmell. "But, when you post daily updates on symptoms, medications and bad days, you might be constantly focusing on your condition. Where you focus is where your energy goes, and chronic illness is a black hole for energy, constantly sucking up every little dreg." In the end, Gemmell says she "unfollowed" a majority of the Facebook pages that initially offered a lifeline in the early stages of her illness, and today follows only those pages and resources that leave her feeling uplifted and inspired.

If you want to get started in the social network world, you can begin by using Google or another search engine to check for pages featuring the name of your diagnosis. To connect to larger chronic illness communities, check out one of the following support group pages, or follow them on Facebook, Twitter or Instagram:

Invisible Disabilities Association (IDA). IDA's mission is "to encourage, educate and connect people and organizations touched by illness, pain and disability around the globe." You can locate the association on Facebook and Instagram.

I Told You I Was Sick Support Group. This is a small closed support group, meaning you need permission from the site

administrator to join, and only approved members can view posts. If you are looking for an intimate and safe group to test the waters, this might be for you.

CrazyBoards.org. If you like your support groups more sarcastic and less politically correct, this site might fit the bill. It is primarily centered on mental health concerns, but it does have a space for chronic pain support. It also features an active chat room.

TreatmentDiaries.com. This is a good support group for people living with chronic pain. You connect with others by writing diary entries and waiting for those with similar experiences to comment on them. The site also allows you to list the specific conditions you're living with, so you can get more personalized support.

But You Don't Look Sick. Started in 2003, the mission of ButYouDontLookSick.com is "to help everyone with a chronic illness or invisible disability, in order for them to live their lives to the fullest and not feel isolated and alone." The founder originated the "spoon theory" commonly referred to by chronic illness patients.

Volunteering, Fundraising and Other Ways to Connect

Volunteering for an organization that provides support for your particular illness can be a very positive way to meet others in the PI community, while also giving you a sense of purpose and accomplishment. Begin by doing some online research to identify opportunities that fit your particular needs, desires and physical limitations.

Many organizations offer various types of volunteer options, including working one-on-one with other patients, being part of a volunteer team, assisting a paid staff member or becoming a peer support mentor.

IDF offers a nationwide network of volunteer opportunities designed to increase awareness of PI. Depending on your time and interests, IDF can connect you with others who are passionate about everything from political advocacy and fundraising to educational awareness and even plasma center support.

If you are physically able, an awareness walk can also be a great way to connect with others in the PI community. IDF sponsors national Walk for PI events in major cities around the country. For those unable to participate in person, the organization also offers a "virtual walk" that gives you the opportunity to raise funds and partner with others who share your passion for raising awareness. "I have only been involved with IDF for two years, and the first thing I did was

participate in one of their PI awareness walks," says PI patient Whitney Ward. "That was the first time I saw there were people out there like me who completely understood what I was going through. Our diseases may have been a little different, but there were more similarities."

Another national event that provides networking opportunities is the annual Invisible Disabilities Week (IDW) hosted by IDA each year in October. All events are free, and the IDA website offers numerous suggestions for how to get involved, including downloadable social media badges, IDA wristbands and accessories, photo and video contests and fundraising ideas. Each year, the organization also hosts a fundraising gala. Learn more at invisibledisabilities.org.

Reaping the Rewards of Networking

There are many national and online resources whose sole purpose is to help PI patients connect with one another. For those who have been recently diagnosed, reaching out can feel daunting, but the rewards can be significant. Sometimes it's best to start small by asking your local healthcare provider, pharmacist or patient advocate to assist. "When our boys were first diagnosed, our specialty pharmacy actually set us up with three other patients/families with the same diagnosis," says Johnson. "The pharmacy asked them if it would be OK if I called them, and they agreed. One mother of three XLA boys had also lost a child under the age of 1, so I felt an instant connection with her since we had so much in common. I emailed her whenever I had questions, and I was able to meet her in person when we were traveling on the East Coast where she lives."

For Ward, who has lived with a very rare type of PI since infancy, networking and becoming a part of a larger PI community brought a sense of emotional healing. "To know there are others who lived with the same medical issues I did made me feel less like an anomaly. I could just talk about what I was feeling and what I had gone through, I didn't have to explain because they just knew. I gained a community of friends I never knew existed. To go from not knowing anyone similar to me to finding out there is a foundation that caters to your type of disease — it gave me joy, closure and an acceptance I had never experienced before." ■

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References

1. Immune Deficiency Foundation. Accessed at primaryimmune.org.
2. Gemmell, S. Why I Left Almost Every Online Support Group I Joined. *The Mighty*, Feb. 29, 2016. Accessed at themighty.com/2016/03/why-i-left-the-chronic-illness-support-groups-i-joined-on-facebook.