

# Social Media & The Chronically Ill

By Trudie Mitschang



For those living with the stigma of illness, escaping into a virtual world to connect with others who share similar experiences can provide much-needed support and encouragement.

All of us, regardless of our age, background or economic status, have a need to feel connected. Trending experts say more and more people are turning to online communities to find the support and encouragement they crave. The popularity of online gathering spots like Facebook, Twitter and interest-specific blogs speaks to this trend, which is particularly on the rise among those living with chronic illness.

A report released in March by the Pew Internet and American Life Project and the California HealthCare Foundation revealed that one in four Internet users living with a chronic ailment has gone online to find others with a similar health condition. In addition, the report states that the Internet and social media seem to play a part in the healing process by providing people with chronic illnesses opportunities to communicate about health and/or to escape into a virtual world where their health is not the focus.<sup>1</sup> "If they can break free from the anchors holding them down, people living with chronic disease who go online are finding resources that are more useful than the rest of the population," says Susannah Fox, associate director of digital strategy at Pew and author of the report.

*IG Living* magazine joined the virtual world in January 2010, and our readers responded enthusiastically; as this story went to print, our Facebook page had more than 800 fans, with many actively posting comments and opinions daily. Our *IG Living* blog also has garnered quite a following, offering a platform for those in the IG community to share experiences, good and bad. "Before I found social media, I was completely alone with my PIDD illness. It was close to impossible to meet others like me," says *IG Living* fan Kelly Clardy. "Now, thanks to Facebook, I have close to 200 other friends who get IVIG [intravenous immune globulin] treatment. They help with information, we share experiences, and we commiserate together and try to help keep our spirits up."

### **Giving Patients a Voice**

A quick Google search reveals a vast number of websites and blogs that address patient issues and concerns, from insurance and reimbursement challenges to the social stigmas associated with invisible illness. One popular site, *But You Don't Look Sick* ([www.butyoudontlook sick.com](http://www.butyoudontlook sick.com)), has nearly 30,000 Facebook fans and more than 4,000 Twitter followers. The site, and its related social media outlets, was founded by Christine Miserandino, a patient herself. Frustrated after constantly being told "but you don't look sick" by people who disbelieved her diagnoses of chronic fatigue syndrome, Epstein-Barr and lupus, Miserandino intuitively recognized that her experience was not uncommon, and the seed of an idea took root. Her hunch was right, and today the site has expanded to include an online store featuring products bearing the site's logo, webcasts and even healthy recipes and personal care products, and its founder is a frequent speaker at various media outlets and health symposiums.



*Jenni Prokopy, who has fibromyalgia, manages her online community and blog, [ChronicBabe.com](http://ChronicBabe.com).*

Miserandino is far from alone in her quest to create a platform where the patient's opinion matters. Jenni Prokopy was diagnosed with fibromyalgia in 1997 and was frustrated by the lack of connection she felt in traditional support groups. Today, Prokopy manages her own online community and blog, [ChronicBabe.com](http://ChronicBabe.com), and says her website averages 18,000 hits per day. She has about 32,000 subscribers to her online newsletter, and close to 3,000 Twitter followers. "For a lot of people, social media has opened up lines of communication that were never available to them before. Even people in rural areas who don't have access to the Internet can get online through MING on their cell phones," she says. "We reach a lot of people who felt very isolated before this was available."

Prokopy's weekly chat room discussions have opened the door to global conversations. Participants log in from as far away as New Zealand to hash over hot topics ranging from parenting chronically ill children to dosing advice. And the connections are not just patient-to-patient either; even physicians are starting to get in on the conversation. "I've built relationships with doctors just by being on Twitter," Prokopy says. "Building those relationships with them is important — there's a lot of doubt and frustration on the patient side, and many patients mistrust the medical community. I think online dialogue can begin to build a bridge between the communication gaps that exist."

### **Docs Slowly Embracing the Trend**

While many in the medical community have viewed online health forums with skepticism and mistrust, others

have embraced and even helped pioneer communication channels. Dr. Kevin Pho, a board-certified primary care physician in Nashua, N.H., is widely known as “social media’s leading physician voice.” His blog, [KevinMD.com](http://KevinMD.com), debuted in 2004 and has since skyrocketed in popularity; his viewpoints are often cited by major media, including *The Wall Street Journal*, *The New York Times*, *The Washington Post*, *Los Angeles Times* and *USA Today*. More than the musings of a single physician, Pho’s blog voices the viewpoints of various medical experts and patients alike. “Social media provides a certain amount of transparency and allows doctors and patients to see things from each other’s perspective,” Pho says. “When you talk to doctors, they often complain about what’s wrong with our healthcare system, but no matter how bad we have it, patients have it worse. Logging on and reading patient blogs, following Twitter or Facebook, allows us to better understand things from the patient’s viewpoint.”

Critics of healthcare websites and blogs often express concerns that patients might access and share erroneous medical information online, potentially putting them in harm’s way. While there is little question that bogus medical claims abound on the Internet, most patient-centric social networks make it clear that the information on the site should not substitute for medical advice. In fact, the Pew study found that just 2 percent of adults living with chronic diseases report being harmed by following medical advice found on the Internet.

### Creating Community Through Shared Experience

When blogger Laurie Edwards launched *A Chronic Dose* ([www.achronicdose.com](http://www.achronicdose.com)) in 2006, she did so as a way of reaching out to other young adults diagnosed with chronic illness. Many of her postings evolved into a book titled *Life Disrupted*, which Edwards markets on her site. Edwards was diagnosed with primary ciliary dyskinesia (PCD) and bronchiectasis in her twenties, and she says social media helped her deal with the isolation she felt living with a rare disease. “There are several reasons why online support groups and chat rooms are often attractive to patients,” says Edwards. “The opportunity to hear from other patients and get advice on treatment and therapies and share common experiences is invaluable.”

Edwards emphasizes that for some with rare diseases, online communities may be the only way patients have of finding someone with a shared experience. But she’s quick to note that the isolating nature of diagnosis and illness in general is a universal concern that drives even patients



Laurie Edwards, who has primary ciliary dyskinesia and bronchiectasis, launched her blog, *A Chronic Dose*, in 2006.

with more common diseases to seek solace on the Internet. “For the newly diagnosed, it’s helpful to hear from ‘veterans’ and see positive outcomes; for more seasoned patients, it is often really helpful to have a built-in community to ask questions and offer input,” she says.

*While many in the medical community have viewed online health forums with skepticism and mistrust, others have embraced and even helped pioneer communication channels.*

“My sense is that the utility of these groups and chat rooms ebbs and flows with the trajectory of the illness in question. For instance, hearing from patients in similar situations was so important to me when planning for our extremely high-risk pregnancy because there simply isn’t a lot of data out there. Anecdotal wisdom and experiences were incredibly helpful.”

## Online Communities for the Chronically Ill

- Inspire ([www.inspire.com](http://www.inspire.com))

This online community boasts a membership of more than 180,000 who have written 2,773,838 posts about the health issues that are important to them).

- A Chronic Dose ([www.achronicdose.com](http://www.achronicdose.com))

This blog is about chronic illness, healthcare and writing.

- Alliance Health Networks ([alliancehealth.com](http://alliancehealth.com))

This site creates social health networks that connect people to support communities for a growing number of health conditions.

- But You Don't Look Sick ([butyoudontlooksick.com/boards](http://butyoudontlooksick.com/boards))

This is a website, blog and resource for those with chronic illness.

- Chronic Babe.com ([www.chronicbabe.com](http://www.chronicbabe.com))

This online community is for younger women with chronic health issues who want to be their best.

- Facebook CVID group

([www.facebook.com#!/home.php?sk=group\\_2342973945](http://www.facebook.com#!/home.php?sk=group_2342973945))

This group was formed by a patient for people who

have common variable immunodeficiency or for those who know people who have CVID.

- GBS/CIDP discussion forum

([www.gbs-cidp.org/forums/index.php](http://www.gbs-cidp.org/forums/index.php))

This forum was created to promote awareness, education and communication in an atmosphere of mutual respect.

- IDF discussion forum ([idffriends.org](http://idffriends.org))

This online community is where individuals can learn about and share their experience with primary immunodeficiency diseases.

- Neuropathy Association on Facebook

([www.facebook.com/NeuropathyAssociation?sk=wall](http://www.facebook.com/NeuropathyAssociation?sk=wall))

This Facebook page was created by the association for the million Americans living with neuropathy.

- Pediatric PID

([health.groups.yahoo.com/group/PedPID/Myositis](http://health.groups.yahoo.com/group/PedPID/Myositis))

This group was started and is maintained by parents of PIDD kids.

Of course, baring your soul — and symptoms — online has potential pitfalls for all types of patients; the unintentional sharing of private health information could have negative ramifications, from identity theft to being denied insurance coverage. And with many people in chat rooms using make-believe monikers, it's hard to know exactly

*For some with rare diseases, online communities may be the only way patients have of finding someone with a shared experience.*

whom you are talking to. Then there's the potential emotional toll: hanging around chat rooms where erroneous or negative postings abound also can create problems; patients seeking validation and support may come away feeling fearful, sad or discouraged. "If you hang out on a message board where people are very

negative, you can easily adopt a negative attitude about your disease," said Paul Albert, digital services librarian at Weill Cornell Medical Library in New York, who has researched how social networks meet the needs of patients with chronic diseases. "On the other hand, if people are hopeful, you might be better off."<sup>2</sup>

For Laurie Edwards and many of our *IG Living* readers we've spoken with, the latter has proved true. "More than anything else, participating in online dialogues has shown me that there is a thriving community of patients who are younger adults — people trying to manage education and professions and relationships while balancing chronic illness," says Edwards. "I've met inspiring people who have become friends, and I've had the good fortune to have this incredibly supportive network of readers, followers and fellow social media users. As a writer and as a patient, these relationships are incredibly important." ■

**TRUDIE MITSCHANG** is a staff writer for *IG Living* magazine.

### References

1. Shute, N. People Coping with Rare Disease Are Internet Power Users. Accessed at [www.pewinternet.org/Media-Mentions/2011/NPR-People-Coping-With-Rare-Disease-Are-Internet-Power-Users.aspx](http://www.pewinternet.org/Media-Mentions/2011/NPR-People-Coping-With-Rare-Disease-Are-Internet-Power-Users.aspx).
2. Cain Miller, C. How Social Networks Help the Chronically Ill. Accessed at [americanmedical.com/tag/social-networks](http://americanmedical.com/tag/social-networks).