

# Power to the People

**Mark Adams**

**T**hey gather across the globe to talk about what's ailing them. They discuss medicines they take, or those they've heard are in development. They talk about treatments, about doctors; they share alternative medicine tips and homegrown wisdom. They talk about what they've heard, what they've seen, and quite often, simply what they feel. And they don't even have to leave the house.

Patients are banding together in cyberspace in growing numbers to share information and educate themselves. There is strength in their alliances, evidenced by the recent Novartis decision to speed development of a leukemia drug that came to the attention of patients and supporters largely through information shared on the Internet, creating a public outcry that could not be ignored.

Peripheral neuropathy (PN)—a disease that strikes nerve endings in the extremities, particularly the feet and lower legs, leading to a loss of feeling and muscle control and, in some cases, causing

chronic pain—has brought one group of patients together in an online exchange.

Every day, in online forums set up by the Department of Neurology at Massachusetts General Hospital ([www.braintalk.org](http://www.braintalk.org)), the patients share their thoughts. Additional Web forums have been set up at the site for patients to gather and discuss everything from muscular dystrophy and multiple sclerosis to late-talking children and restless leg syndrome.

This article looks at the kinds of information the patients involved with the PN forum are gleaning and sharing on the Internet and what they do with it. It discusses patients' reactions to the content provided on the Web by pharmaceutical companies and gives their suggestions for improving it. It also discusses how patients feel about something else the Internet offers: emotional support in cyberspace from people sharing the same medical condition, whether they live in West Virginia or Western Australia.

## Patients Link Up

Louisiana resident Carol Stultz contracted neuropathy the hard way—in the spring of 1997, she took an awkward spill into a hole, resulting in nerve damage. After trips to several doctors, she was finally told she had PN. But the physicians she visited didn't give her much help.

Stultz, who uses "Sunny" as her user name on the PN bulletin board, experienced increasing pain but said her doctors seemed to be bluffing their way through her visits.

"They weren't educated enough to know how to help me," she says. "The big question was 'How can I help myself?' I have never been a weak little thing that



allowed myself to be defeated, but I didn't know where to go."

Enter providence, in the form of her husband, who had been suggesting that she get a computer to get her mind off things.

"He finally broke me down," she says. "We bought the computer and set it up."

Stultz started slowly, but one day she found a medical site. Following links to other medical information, she became driven to find information about the disease. It was readily available.

"I became angry because doctors could have helped me," says, Stultz, "but they didn't have the information, particularly about the chronic pain caused by PN. I didn't need to suffer as long as I did or as harshly. The Internet saved my sanity, possibly my life."

With the information gleaned from the Internet in hand, Stultz found doctors who did help, and something else as well—relief:

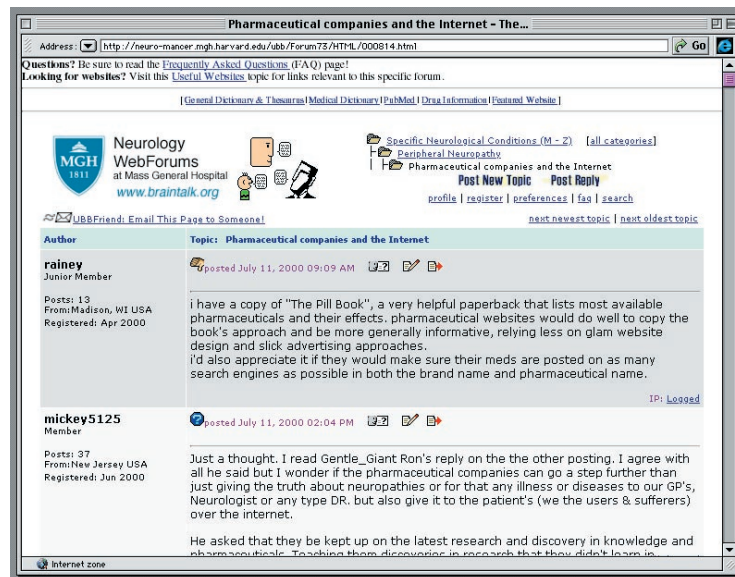
"I found other people like me, with the same pain, the same questions, fears, and needs. People all over the world have become my family."

## Patients as Participants

A healthcare professional who goes by the user name Mrs. Doubtfyre is one of the more learned members of the neuropathy forum. She began using the Internet in earnest several years ago to find medical solutions to problems she and her family were facing, even finding a diet that healed her cat's acne.

Mrs. Doubtfyre must take Lasix (furosemide), a diuretic, to treat a swollen optic disc in her eye. Sensory PN is a side effect of the drug. She says many doctors still use traditional medical solutions and sources of information.

"I think most doctors are terrified by the Internet," she says. "Many I talk to don't even own a computer. Many don't know how the drugs they prescribe work.



Peripheral neuropathy patients share information in a forum set up by the Department of Neurology at Massachusetts General Hospital.

They don't understand the complex chemistry involved when drugs enter the body."

Mrs. Doubtfyre says she sees an erosion of patient–doctor information exchanges. "When a patient asks a doctor about something they read on the Internet, the usual response is negative. Doctors want to keep the patient interview short, brief, and under their control. A patient that asks questions or brings in outside information is often considered problematic."

## What are they talking about?

Patients in the PN forum talk about everything. Recent topics posted on the bulletin board for discussion include antibiotic relief for nerve pain, Neurontin (gabapentin) and hair loss, Agent Orange and PN, neuropathy and disability, the difference between PN and neuritis, and a "Rate Your Physician Here" posting.

Participants also talk about medications that may aid problems associated with peripheral neuropathy, including chronic pain and insomnia.

Asked what kinds of information they get from pharmaceutical

companies on the Internet and what they think could be done to improve it, members of the forum gave an instructive variety of responses:

► "All I find is a reiteration of what companies are telling doctors," says Mrs. Doubtfyre. She wants more than FDA guidelines provide and thinks competition among pharma companies is often more important to them than getting information to patients.

► The Gentle\_Giant, another frequent contributor to the PN forum, says he would like to see pharma companies help educate doctors on neuropathies:

"General practice doctors and neurologists should be kept up on the latest research and discoveries in PN. E-mail them studies that prove to them that this is real. Doctors have to be motivated to learn what we who suffer are learning about PN, or at least be willing to listen to us and believe what we say."

► Mickey5125 backs up the Gentle\_Giant's comments but goes further, saying patients should also be privy to the latest research conducted by pharma

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## A DOCTOR RESPONDS

Daniel Sands, MD, MPH, Harvard Medical School

**Q** Are you seeing an increase in the number of patients armed with information they've gleaned from the Internet?

**A** It is on the rise, but not as common as you might think in most practices.

**Q** What do you think of the quality of information being offered?

**A** Quality varies, and in general, there is no way to know the quality of information that is found. One can find peer-reviewed medical journals as well as backyard publications. At the extremes, patients seem to know the difference—they can usually identify utter junk.

**Q** In your experience, what is the reaction of doctors to patients armed with Internet information? Do some feel threatened? Why?

**A** Doctors feel two things: Threatened, because they're used to knowing all the answers. And frustrated, because they don't understand what information is on the Web, and they don't have time in the context of a 10-minute visit to review and explain the concepts to their patients.

companies. "Give it to the users and sufferers over the Internet," he says. "It seems we are the ones who do all the research, and take the information to our physicians. Doctors don't seem to be as informed as patients on this forum or others I've visited."

► Jeff H would like to see the latest developments in reversing PN posted prominently on the Internet. "The latest thing I saw

► Frosty, a forum regular who lives in Western Australia, would like to see pharma companies publish Web information on all adverse reactions to drugs they produce, particularly those causing PN. She says, "The trend seems to be to hide that information as long as possible."

► PN forum participant Isn would like to see more information on the harmful effects of drugs listed on the Internet. "Doctors don't have time to keep up with them," she says. "I have read they are more influenced by ads in medical journals than they are by the articles. I'm really tired of seeing those sugarcoated pharma ads on TV with the side effects mumbled in a numbing monotone. The drug companies make a mint off of us; they owe us the whole truth."

► Another frequent contributor to the forum is Rose, who hammers long and hard at patients to make sure they have proper levels of vitamin B12 in their bodies. "I'm not going to hold my breath, but I would like to see the pharmaceutical compa-

nies at least educate doctors on how to prevent the side effects of the drugs they sell," Rose says. "For instance, how many doctors test at all—much less properly—for vitamin B12 deficiency in patients for whom B12-depleting pharmaceuticals are prescribed? Many patients are being damaged unnecessarily."

► Trinity Rules wants complete information on pharmaceuticals available for various conditions, as well as links to comparable drugs that have the same effect. She also wants to know about adverse reactions a product might cause when ingested with foods, herbs, and other medications.

► A medical professional who goes by Huskylover and posts in the neurology department's chronic pain forum is interested in two things from pharmaceutical companies: information on potential drug interactions available on the Web and medicines that are affordable. "There are some interaction charts out there but few studies," Huskylover says. "I also believe that, because of the fear of potential litigation, the pharmaceutical industry drops it all on doctors or prescribers."

He would also like to see lower prices for products like the painkiller Oxycontin (oxycodone). "On these forums," says Huskylover, "we see patients so desperate for pain relief they are willing to go abroad and to potentially illegal sources for meds."

► Charli, another chronic pain forum visitor, says pharma companies should do more to educate patients about medications. "I have a neighbor who lives in pain but is terrified of becoming addicted to pain medications," she says. "I've tried educating her, but, of course, I'm just the drug user next door."

► Lavenderlou, a forum regular with Parkinson's disease, has a friend who was prescribed medication that made a similar condi-

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came from a link on this forum," he says. "It was about combining nerve growth factor with a modified herpes virus to reverse PN. I found a few references to that using Google, but nothing on its current status." He refers to the Novartis experience with the leukemia drug as an example of what patients can do with the latest information: "If we have knowledge of the latest research, we have the power to speed it along."



tion worse. She says, "I would like to see a drug interaction site where one can type information on products we are prescribed and see if there is any type of drug interference." She also thinks there should be more personalized help for those with degenerative

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diseases, and perhaps online Q&A sessions organized with professional—including pharma company—representatives.

► Nancy would like the official package insert for all medications to be published on the Internet and information about the drugs that should not be taken before surgery.

► Sponsor has a question on medications that carry the instructions "don't take with food": "I want to know 'why not?' for every medication. Does that flat instruction include a ban on coffee or tea? When a pill sticks in my throat, why can't I have a soda cracker? I dislike instructions that attempt to change my lifestyle without giving a good reason for doing so. I want them to explain, expound, elaborate."

► Several patients want to know why drugs cost so much. Anger on the subject comes easily. "What can the drug companies do to help me?" Hilltop asks rhetorically in the chronic pain forum. "How about a big fat check to cover the thousands of dollars all of us have paid them over the years? We make a comfortable living, but I don't know how others make it. It's really sad when it comes down to choosing whether to eat or to take the medicine you need to survive."

### The Webmaster Weighs In

John Lester, information systems director for the Department of Neurology at Massachusetts General, says the experience of building Web forums from scratch is an experiment in social and cultural anthropology.

"It's a complex social network that could only exist using these electronic tools," he says of the rise of patient groups on the Web, which allow someone in Australia to be in immediate contact with someone in Europe and Alaska.

To say that the Internet simply takes support groups that have always existed and puts them online is an oversimplification, he says, sort of like comparing the Web to a big electronic library. He points out, "This is instant and free communication with anyone on the globe" with virtually limitless opportunities to research topics relating to individual medical conditions. "It's not just interpersonal chit-chat—you have patients and caregivers with access to the same information physicians have."

Lester sees patients take that information and share it, both in online forums and their own Web sites. "They're not just talking back and forth, they're creating information resources."

Pharmaceutical companies can take advantage of that thirst for information, Lester says, but they have to do it in a way that is credible to patients. He sees pharma companies as being at odds with themselves in what they're currently doing. For example, he says Pfizer has developed a valuable depression-screening tool, "but if you visit their Web site, it's hard to find. It's like they created something wonderful and then stuck it in a drawer."

On the other hand, the biggest mistake he sees companies make is blurring the line between valid content and simple marketing material, a practice patients are

sensitive about. "You've got to be honest and put all your cards on the table, and if you screw up, the world will know," he says, referring to the propensity of Web detectives to share their findings with everyone.

One way to build credibility is to establish partnerships with academic institutions or independent researchers, Lester says, perhaps providing unrestricted research grants that will help develop content for pharma Web sites and valuable educational resources for patients at the same time.

What everyone interested in advances in online healthcare must realize is that patients and their caregivers are driving it. "They have the time and an incredible vested interest" in helping themselves, says Lester, and they're doing everything they can to glean and spread information on the Net.

The phenomenon is destined to get bigger and more sophisticated as time passes. Patient movements born in the online environment have become more self aware and are starting to realize their power as they gather resources. As those groups evolve, create their own databases, organize campaigns, chip in a dollar each and amass a war chest of millions, the result will have serious implications for those in the healthcare field. Patients are talking, and pharmaceutical companies should be a part of that, not just observing or reacting.

"It's all about communication, and you have to join the conversation, not pretend there's nothing happening on the other side of the door," Lester says. "Eventually, there'll be knock, and when you answer it, there'll be a million people there, all demanding that you do something." ■

Mark Adams is *Pharmaceutical Executive's* Associate Editor.