

Virtual Support

The benefits of joining an online neurology community.

BY ORLY AVITZUR, M.D.

Karen Cormac-Jones took her 9-year-old son, Ted, to 22 doctors over two years, but no one could find the cause of his nausea, vomiting, and weight loss. Bobbi Jerome had been going to the same rheumatologist for 10 years, but still had no definitive diagnosis. She didn't respond to anti-inflammatory medications, so her doctors decided that the problem was psychological and referred her for psychiatric evaluation.

What these two women have in common is that they ended up receiving help from people they had never met—members of online communities who had become experts in their neurological conditions.

Cormac-Jones found the Celiac/Gluten Sensitivity forum on BrainTalk (brain.hastypastry.net/forums) one day while doing an Internet search for her son's symptoms. "This forum saved my son's life," she says. "Had I not stumbled across this community, I would never have learned about the tests that led to Ted's cure."

In Jerome's case, a BrainTalk member-physician detected tell-tale signs of ankylosing spondylitis, a form of arthritis affecting the spine and joints. He urged her to get screened for it with the HLA-B27 blood test. "My doctors reacted with stunned disbelief when it came back positive," says Jerome. "It was as if a dark cloud suddenly lifted—the symptoms were no longer disjointed but had a cohesiveness that finally made sense."

BrainTalk is one of many online communities where neurology patients and their caregivers share stories. "Many of the people on boards such as BrainTalk come by their hard-won knowledge of complicated conditions through extensive research," says Glenn Ribotsky, who participates in several neuropathy discussion boards.

Jerome feels that the freedom that distinguishes online forums from in-person



support groups also makes them attractive. "We can come and go as we please, and we aren't expected to meet criteria for participation," she says. "BrainTalk is available 24/7—how many off-line support groups can say the same?"

GET PRACTICAL ANSWERS TO EVERYDAY QUESTIONS

"The newly diagnosed are typically scared," says Rick Everett, who developed Parkinson's disease at a young age. And, several forum members told *Neu-*

rology Now, physicians either don't have time for all their questions or simply lack the answers for many of the mundane issues that come up. Patients, in turn, are often left to fend for themselves.

Jan Richardson discovered that members of the multiple sclerosis (MS) forum on BrainTalk often know how to cope with medication side effects and symptoms like fatigue, spasticity, and bladder problems. Diane Zabel joined BrainTalk shortly after undergoing deep-brain stimulation surgeries for essential tremor.

“There are day-to-day frustrations that come with this disease...being unable to feed ourselves or drink from a cup or full glass,” she explains. “The forum is the place for answers.”

Pamela LaBlake, who sought out BrainTalk when her son Matthew was diagnosed with Tourette’s syndrome, says that she can ask any question, no matter how “insignificant,” without feeling intimidated. “The answers come from the heart because other parents have gone through the same things... increased tics, difficult school issues, problems with medications.”

REALIZE THAT YOU’RE NOT ALONE

“It had been an excruciating and lonely experience,” NeuroTalk (neurotalk.org) member Kim Helton told *Neurology Now*. Helton, who has trigeminal neuralgia, says she “was desperate to speak with one person like me...the thought of talking to many was almost beyond my comprehension.”

For people whose isolation is compounded by geographic seclusion, discussion boards are a godsend. Richardson lives in a small Canadian town in Ontario. It takes five hours to drive to the nearest MRI center or the closest neurologist. “The forums make the world feel smaller and a bit safer,” she says.

“On the forums, I can find people who walk in my shoes,” says Carolyn Stephenson, who has Parkinson’s disease. “Doctors have clinical knowledge, but can’t make the connection with a patient that another patient can.” A member of the NeuroTalk forum, Stephenson is also the Web master of the Northeast Tennessee Parkinson’s Support Group (tennesseepd.net).

DISCOVER THE LATEST TREATMENTS

Members are often up-to-date on the latest studies, and frequently post links to journal articles and breaking news. “It’s

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wonderful to be able to access the latest research and anecdotes at one site,” says Ted’s mother, Cormac-Jones.

Richardson notes that the MS forum is chock full of informative links—to clinical trials, scientific abstracts, other MS web sites, journals, and press releases about research advances. “Theories are discussed, snake oil cures are debunked, and support is given to all,” she says, emphasizing that no question is “stupid.”

The overwhelming majority of moderators are not physicians, but because members are hungry for credible research and advice, online communities are surprisingly effective at catching faulty information. “BrainTalk is not a replacement for my physician, neurologist, or pharmacist. It’s just another approach to continuing education for an illness that’s often unpredictable,” Richardson says.

LEARN TO TAKE CHARGE OF YOUR MEDICAL CARE

The forums also change the way members communicate with their doctors. “I no longer go in accepting what is said to me. I have the courage to ask questions,” says Braintalk member Cormac-Jones. She says she also feels more comfortable discussing different approaches or treatments.

“I learned that you have to be in charge of your health,” says Suzanne Thompson, who lost her father and her sister to aneurysms. “Finding these communities helped me to find myself, and later inspired me to become proactive about awareness and education.”

Members of the Hydrocephalus Forum urged Kathi DeGrand to talk to her neurosurgeon about seriously considering a shunt revision. Without their support, DeGrand

believes that she would have been unable to advocate for the surgery that put an end to her headaches.

SUPPORT EACH OTHER THROUGH THICK AND THIN

“When you can reach out and help someone who is going through what you have, it comes full circle,” says Thompson. “You start out looking for support, and eventually you are the one helping others.”

Paula Wittekind, a member of the NeuroTalk Parkinson’s disease forum, says her experience dates back to the days of the forum’s inception. While there, she was inspired by a well-known Parkinson’s activist. She went on to create a site called grassrootsconnection.com and became a charter member of the pdpipeline.org, advocating to improve clinical trials.

Wittekind says that the forums also serve as a means for sharing good times and bad times.

“We discuss how our diagnoses affect our family life and social life, how hard it is to have to leave the workplace, and how our illness affects our relationships with our spouses and children,” she says, reflecting, “We know that we are always there for each other.” NN

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For more on reliable information sources about your condition, see [RESOURCE CENTRAL](#) on page 46.