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Michael Macor / The Chronicle

Google employee Adriana Boden hopes to share with the general public lessons she learned about working with the health care system.

MEDICAL INFORMATION

Help for navigating health care

By **Victoria Colliver**
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Adriana Boden was a healthy 33-year-old woman until one day in March 2007 when she felt like an explosion went off in her head.

Although she went to her doctor immediately, it would take nearly a year of doctor visits, diagnoses of everything from migraine headaches to encephalitis, unnecessary drugs and treatments before a physician finally figured out what was wrong with her.

It was a relatively simple test — one that Boden, through her own research, suggested and was eventually ordered by a physician who listened to her — that led to her diagnosis of epilepsy. Because her symptoms weren't typical — she

didn't appear outwardly to be having seizures — doctors didn't consider epilepsy. Once on the proper medication, her pain disappeared and she was able to return to work and other activities.

Boden, a sales manager at Google Inc. in Mountain View, wants to take what she's learned and use her technological know-how to help other patients better navigate the fragmented health care system.

Along with San Francisco dentist and author Julia Hallisy, she founded a nonprofit organization and Web site called the Empowered Healthcare Community, which will officially premiere at a conference in San Francisco on May 16. Speakers at the Empow-

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Tips for patients

The Empowered Healthcare Community, formed by a Google employee and a San Francisco dentist, offers these tips to navigating the health care system:

- ▶▶ Have a health advocate. Make sure someone helps you through your medical crisis, especially if you are hospitalized.
- ▶▶ No news is not necessarily good news. Check on your test results if you don't hear from the doctor.
- ▶▶ A second — or third or fourth — opinion is appropriate at any time during your treatment, not just in the early stages of diagnosis. A doctor who does not appreciate other opinions might not be your best choice for a provider.
- ▶▶ Be aware that federal law guarantees patients access to their medical records. All patients have a right to copies of their records, and they should make it a practice to ask for a copy of everything.
- ▶▶ Always check your medications for drug interactions. A good tool can be found through the Physicians' Desk Reference at pdr.health.com.
- ▶▶ If you need surgery, find out information about your hospital at the U.S. Department of Health and Human Services site at hospitalcompare.hhs.gov.
- ▶▶ If you are having surgery, ask your hospital to use the World Health Organization surgical checklist.

Source: Empowered Healthcare Community

Health care battles may benefit others

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ered Healthcare Conference include UCSF professor and author Dr. Dean Ornish, along with patients, doctors and health care advocates.

Many Americans — even those with insurance and access to care — are frustrated by the U.S. health care delivery system. About half the public believes the American health system has a “major problem” with patients receiving unnecessary tests and treatment, while two-thirds agreed the major problem lies with patients not getting the tests and care they need, according to a survey released this week by National Public Radio, the Kaiser Family Foundation and the Harvard School of Public Health. That same survey found 44 percent of respondents reported having problems coordinating care among doctors.

Boden said there were many things she wished she had known at the onset of her illness that could have helped or shortened her search for a diagnosis and cure. “I needed to learn how to be a patient, and I needed to learn how to research and how to partner

with a doctor,” she said.

She formed the organization in part because most of the patient advocacy and networking groups she found were specific to certain diseases or didn’t offer her the kind of help she needed. She wants the group to offer advice and resources, as well as serve as a networking tool and clearinghouse for patients.

“I want to give people confidence and help them find the courage to help themselves,” she said. “One thing that happens when people get sick is they feel isolated. They often lose jobs, their income and have challenging situations with their families. They suddenly go from very independent to dependent.”

Hallisy, the group’s co-founder, spent virtually her daughter’s entire life — from the time she was diagnosed with cancer at five months until her death in 2000 at age 10 — pursuing the treatment her daughter needed. She said sometimes she felt the system was working with her, while other times she had to do her own research and take charge.

Hallisy last year published “The Empowered Patient” to

► The Empowered Healthcare Conference will be held at UCSF’s Mission Bay Center, Robertson Auditorium, 1675 Owens St., in San Francisco. The conference is open to the public and registration is \$80. Limited scholarships are available. For more information, go to: empoweredhealthcon.com.

give patients practical tips about their rights and safety issues.

“Our goal for the organization is to give patients an unprecedented level of information they don’t have access to,” she said. “They may have access to information, but it’s very fragmented. We want it to be a hub, a portal, a place for people to go.”

Boden’s physician, Palo Alto internist Darren Phelan, said patients and doctors need to work together now more than ever due to the information age.

Doctors, he said, have a tendency to get stuck in the patterns they know. Meanwhile, patients don’t always find the right resources.

“You can search on the Internet and find a study that will support or refute a lot of things,” he said. “By looking at one bolt in the airplane of medicine, you’re not going to see the whole picture.”

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