

e-Patient Dave: visitor from the future

In January 2007 Dave deBronkart, aka e-Patient Dave, was diagnosed with stage IV kidney cancer that had spread throughout his body and given a median survival time of 24 weeks. His story has a happy ending, thanks in large part to deBronkart taking an active role in his treatment. DeBronkart used the Internet to learn from other patients as well as from Novartis, which manufacturers the drug Proleukin. Now pharma's learning from him.

"After the shock, you're left with the question of what do I do," says deBronkart. "I Googled like crazy and found every source online I could and did everything in my power to help myself. The patient community was the best source of accurate information about treatments. There are legitimate reasons for this. Encyclopedia-style sites and pharma sites have to publish verifiable, generic information that's not germane to any individual."

DeBronkart, who turned 60 in February and lives in Nashua, NH, built his career on marketing analytics. He's now increasingly active on the healthcare front, running e-patientdave.com, managing the blog e-patients.net, which reaches about 10,000 people a month, and consulting and speaking about e-Patients and participatory medicine. The term "e-Patient," coined by the late Dr. Tom Ferguson, refers to "equipped, enabled, empowered and engaged" patients. Last year, deBronkart and his primary care physician Dr. Daniel Z. Sands were elected founding co-chairs of the The Society for Participatory Medicine.

When deBronkart was diagnosed with cancer, Sands directed him to the Association of Cancer Online Resources (ACOR), a nonprofit social network that reaches about 1.5 million people a week. Through ACOR, other cancer

Dave deBronkart

Healthcare consultant

2009–present

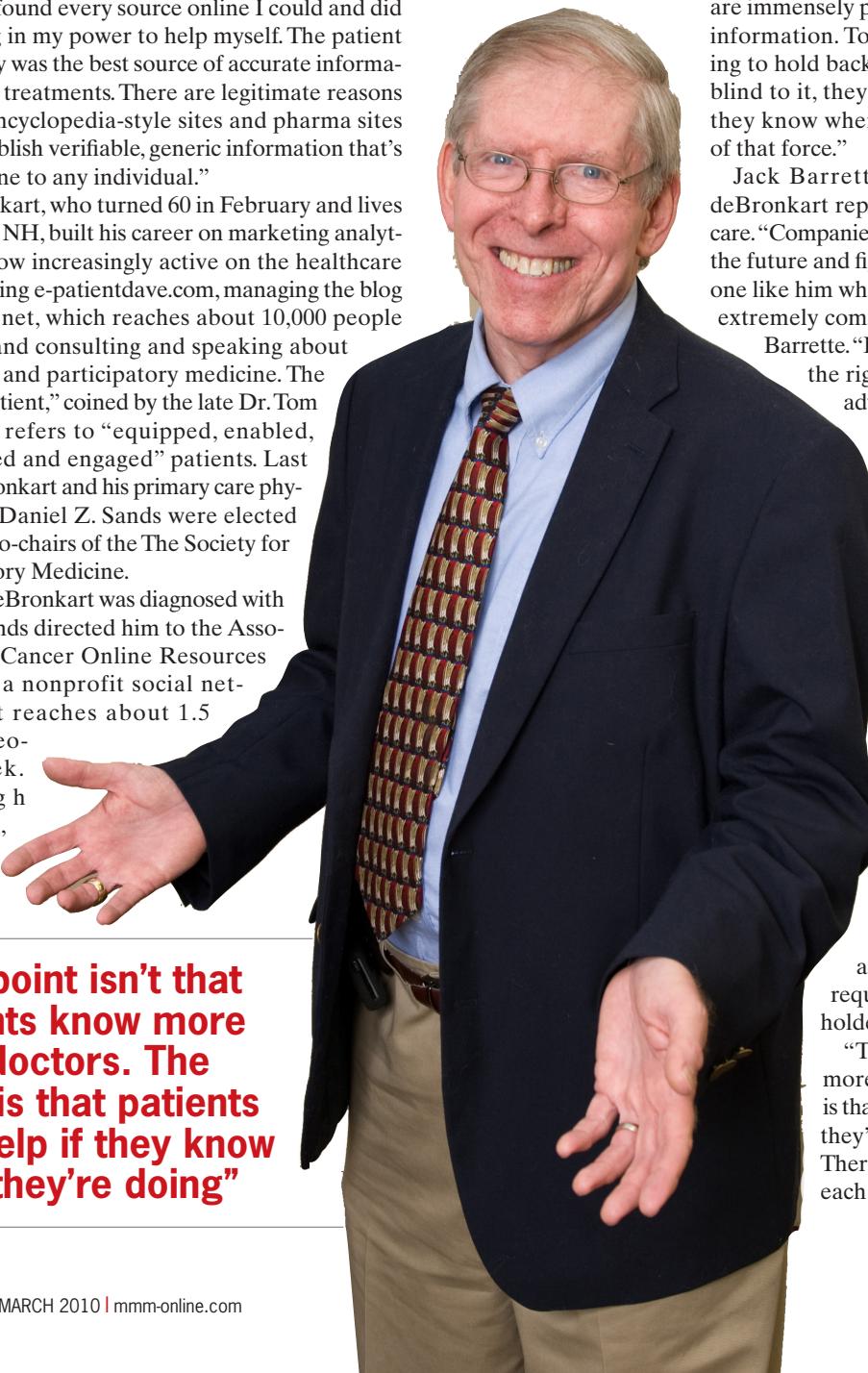
Healthcare consultant

2006–present

Dir., marketing analytics,
TimeTrade Appointment
Systems

1989–2006

consultant, graphic arts technology, senior analyst for PODi



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patients told deBronkart about drug treatment and advised him to get to a specialist hospital. They also steered him to Novartis.

"The Novartis site had dry clinical statements—it's like saying 'If you go to a certain neighborhood in Rome there's a risk of pick pockets,'" explains deBronkart. "When you talk to six people who've been to Rome, you find out what you really need to know. There's so much value in a patient community that pharma cannot legally deliver. Let patients talk to each other. Within the patient community, there are immensely powerful currents of knowledge and information. To try to stop this would be like trying to hold back the tide. If medical marketers are blind to it, they're at a major disadvantage. But if they know where it's happening, they can be part of that force."

Jack Barrette, CEO of WEGO Health, says deBronkart represents the future of self-managed care. "Companies should look at him as a visitor from the future and figure out how to interact with someone like him who is passionate about his health and extremely comfortable with technology," explains

Barrette. "His skill in beating bushes and asking the right questions has made him into an advocate who knows how to reach tens of thousands of people online."

Creating online tools for patients is a way deBronkart thinks pharma companies can contribute to patient communities.

"Pharma companies would do well to provide tools that help patients help themselves," he says. "Even if they're not promoting a product, they can offer it as a service of their company. Then people who are swimming around in the current talking to each other say good things about the company because it helped them."

DeBronkart was surprised to learn of the "enormous stress" in the healthcare industry. He sees participatory medicine, which he defines as "an approach to healthcare that requires active involvement by all stakeholders," as advantageous to all.

"The point isn't that patients know more than doctors," he says. "The point is that patients can help if they know what they're doing. This really is a new dance. There's knowledge on both sides now, so each needs to learn new steps."

—Tanya Lewis