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# Friends in Need

BY KAREN PATTERSON

*Online social media promote connection, education, and support.*

In the four years since she was diagnosed with stage 4 breast cancer, Lauren Groover has become a veteran of the medical battlefield.

Groover, 41, of Tupelo, Mississippi, has been tested for BRCA gene mutations, which greatly increase the risk of breast and ovarian cancers. She's participated in a study of Avastin (bevacizumab). She's had Taxotere (docetaxel), FEC (5-fluorouracil, epirubicin, and cyclophosphamide), Xeloda (capecitabine), Abraxane (albumin-bound paclitaxel), and now Gemzar (gemcitabine). She's used hormonal therapy, undergone tumor profiling to personalize her treatment, and suffered countless side effects. She's endured bone metastases and recently had multiple tumors found on her liver. "I'm always in treatment of some type," she says.

But Groover doesn't fight alone. Besides her husband and twin teenage sons, she has a battalion of "sister" (and fellow) cancer survivors in her Facebook network who give and receive support.

Online, she monitors the health of her Facebook friends and shares her experience with others—frequently earlier-stage survivors fearful about some aspect of their own care. "I'm very happy to answer their questions," Groover says.

The network, in turn, provides her support. When she recently posted news of her liver metastases, cards, e-mails, calls, and more streamed in. "It will make you cry," she says of such outpourings. "Someone I've never even met sends me pajamas in the mail."

In the realm of cancer support, social media websites like Facebook—which don't just convey information but rely on user submissions and often foster relationships and interaction—are no less revolutionary than, say, X-rays were for medical imaging: The new technology has changed everything.



Lauren Groover's Facebook friends include fellow cancer survivors.  
Photo by Ian Foster.

A survey last fall by Manhattan Research found about 35 percent of U.S. adults use online support sites and other health-related social media. In just two years, the American Cancer Society has developed followings of more than 16,000

people on Twitter, and nearly 170,000 on Facebook.

“Everybody agrees that social media and the Internet are becoming very important in terms of public health issues,” says John Mack, executive editor and publisher of *Pharma Marketing News* and *Pharma Marketing Blog*. “It’s where people now go to first when they’re trying to find out about medical conditions, even before they talk to their doctor.”

One key attraction is that any person, anywhere—whether they are a patient, survivor, caregiver, family member, or friend—can find someone else in similar circumstances.

“The Internet in general and, more recently, social media are really what led to the whole young adult movement,” says Heidi Adams, founder of Planet Cancer, a social and informational site for young adults with cancer, and director of grassroots engagement for the Lance Armstrong Foundation. “Prior to 2000 there really wasn’t any way for this fragmented patient population to find each other and connect. Planet Cancer was created as an online home to connect patients.”

Compared with less interactive Internet features, where information may be simply pushed out and comments perhaps pushed back, social media offer far more flexibility and depth, Adams notes. Advantages for patients include the ability to choose their level of interactivity, how and when they connect, with whom, and about what, she says. Users can send private messages—a discreet way to share medical information—or join a group, post a message on someone’s public space, share photos or video, or blog.

“The opportunity to share resources, advice, and encouragement is something that can be incredibly empowering for a cancer patient,” Adams says.

Similarly, social media can be an important outreach tool for individual health care providers. Anas Younes, MD, of M.D. Anderson Cancer Center in Houston, uses Facebook and Twitter, along with the video site YouTube, to communicate with anyone interested in receiving information about lymphoma or other cancers. For instance, his first YouTube piece for M.D. Anderson, on novel therapies for Hodgkin lymphoma, has had more than 12,000 views and led to an increase in referrals to the cancer center, Younes says. “You can reach people whom you don’t reach using standard communications tools,” he says.

On Facebook, Younes posts links to cancer-related or other medical news. There he has “fans” that follow him instead of “friends”—a setup that maintains the privacy of the followers, many of whom are patients or caregivers. Sometimes he adds his own insights, and others can comment as well.

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—Heidi Adams

Institutions like Dana-Farber Cancer Institute in Boston use social media to

extend their reach in the community—for instance, by highlighting news and features on the institute’s website, says Carolyn Grantham, editor for [dana-farber.org](http://dana-farber.org) and [espanol.dana-farber.org](http://espanol.dana-farber.org).

Besides followers or fans on Twitter and Facebook, Dana-Farber also has subscribers on YouTube, where spots range from vintage clips of celebrities touting its charity services to modern offerings, such as a top sarcoma physician explaining the disease and its treatment.

The institute also uses the interactive photography website Flickr to depict topics like a day in the life of the institute. “It’s another way of telling the story of what happens at Dana-Farber,” Grantham says.

She notes that restrictions like medical privacy laws can make it hard for health care institutions to connect via social media. “This is a way to do it that opens the door a little for people to connect with us.”

Drug companies, meanwhile, are cautiously exploring social media options, says Mack. But for them, too, legal considerations complicate the picture. For instance, are the companies required, when participating in a social media site, to report and investigate adverse events patients experience when using their drugs? “It’s unclear what their responsibility is,” Mack says.

At a recent Food and Drug Administration hearing, Mack says, the drug companies conveyed concerns that misinformation about what best can treat a particular medical condition were frequently promoted using social media. The companies have realized that without their participation, the online conversation about their products quickly becomes dominated by other voices. The trick, he says, is for the companies to master the online art of a give-and-take conversation, rather than a marketing-driven one.

For academic institutions like hers, Grantham agrees that preserving credibility and authority is key. “I have to maintain a level of gravity,” she says, adding: “We’re still discovering new ways to reach people, and that’s very exciting.”

*Editor’s note: Lauren Groover passed away on April 12, 2010, surrounded by friends and family. CURE is proud to honor her memory.*