A photograph of two people, a woman and a man, standing in an elevator. The woman, on the left, is wearing a red long-sleeved top and black pants, with her arms crossed. The man, on the right, is wearing a teal button-down shirt and black pants, with his right arm raised and hand on the elevator door. The elevator has a metallic interior with circular vents. The background is a dark, textured wall.

Patient Ambassadors
(L to R: Susan Nagy,
David Dafoe and Mary
Kelleher-Crabtree)
appear courtesy Snow
Companies. Location
courtesy Pfizer.

PATIENTS ON CALL

They're becoming the new key opinion leaders. Savvy, influential patients have pharma's attention and are growing relationships with industry, online and off. **Marc Iskowitz** on how firms have just begun to tap the potential of this emerging segment

While many pharma and device firms remain on the sidelines, understandably so, the lure of gaining a rapport with patients on social networks is reason enough for some to venture forth, despite the unknowns. Roche Diagnostics is one example. About four years ago, the Indianapolis maker of blood-glucose meters, insulin pumps and other diabetes-testing gear decided to jump into the digital sphere, but in a brick-and-mortar kind of way.

"The Accu-Chek brand was really early to the game, which has helped us tremendously," says Robert Müller, associate marketing manager of diabetes care for the firm. "Instead of dithering on whether we should or not, and how do we, we had some visionary people who thought, 'We really need to interface with the key opinion leaders,' who at the time were online diabetes bloggers."

And thus was born the Roche Diabetes Social Media Summit. The purpose in holding court with bloggers, explains Müller, was "to try and figure out a way to get involved that is helpful to people with diabetes, without offending them."

It invited the 30 most influential diabetes writers in North America—people like Kerri Sparling and Manny Hernandez—to its headquarters "just to meet with them and talk about how we work together." Today Roche is a sponsor of Sparling's blog and supports some of the online programming created by Hernandez's foundation.

Two years after the debut of its social media summit, Roche took another step, launching a Facebook page (facebook.com/AccuChekUS) and Twitter account (twitter.com/accucheck_us), as well as expanding its own blog (accu-chekdiabeteslink.com), launched in 2009, to cover both Canada and the US. It also started to maintain a presence on third-party sites tudiabetes.org, diabetesdaily.com and childrenwithdiabetes.com.

Roche says it uses the channels to listen to its audience and to promote diabetes education, awareness and advocacy. Patient conversations range from the cost of insulin to product reviews. Since 2009 the diabetes online community has swelled, and Roche is bent on tapping it for insight.

Like a physician KOL

"I don't think you can hope to serve your audience without knowing them," Müller tells *MM&M*. "The people who do that best—who truly understand the needs of their audience—are going to win. They're going to be the strongest companies."

Over the past year or so, the role of patients as an influence and information channel for pharma has blossomed. Experts on the trend say it's comparable to the rise of key opinion leaders (KOLs) in the physician world—doctors, typically from academic medicine, who reach out to other physicians likely to prescribe a product.

Two main groups of patient advocates have experience with products. The first receives training from boutique agencies like HealthTalker and Snow Companies, which specialize in word-of-mouth communications and use the real-life stories of patients to deliver marketing messages.

COVER & PHOTO LEFT: THADDEUS HARDEN



David Dafoe

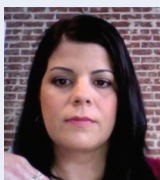
Three Patient Ambassadors were assembled by Snow Companies to represent the patient perspective, and asked for their opinions of the pharma industry, how they maintain credibility, and the challenges companies face in trying to engage audiences.



Mary Kelleher-Crabtree

Hoping that real people with real stories connect better than models, biopharma and device companies have been using patients in their outreach and education.

But as they develop relationships with companies marketing products, either directly or through agencies, patients must maintain their authenticity, or sacrifice trust. How do they prevent themselves from becoming compromised? Patients told *MM&M* they draw a line between sharing experiences and advocating for particular therapies.



Susan Nagy

"I look at myself as a voice for patients, always," says Susan Nagy, who has epilepsy. "If I am in a situation where I can't answer a question or feel

uncomfortable, I refer people to their doctor...My role is to share my story, not to recommend a treatment."

David Dafoe, who has multiple sclerosis, says he never preaches about his therapies, either. "We use our experience and guidance to show others ways to navigate their situation and issues," he says. "I listen to folks, and almost every time we quickly find common ground, and that is where we connect."

Brenda Snow, who founded boutique word-of-mouth marketing agency Snow Companies after her own experience being diagnosed and treated for MS, adds that the people that have a story to share understand that "building false hope in communities would be egregious and would undermine the good work that they do."

Let's not forget that this industry already suffers from a credibility problem, with hot-button issues like the cost of medicines only fueling suspicion. "Trust," says Mary Kelleher-Crabtree, a transplant recipient, "is probably the biggest challenge to engaging in substantive conversations between patients, care partners and pharma." For this reason, she says DTC messages need to be facilitated by members of the target population—patients—and that "This requirement will remain at least until the pharma industry is humanized and the trust level increases."

There's plenty of work to be done. "Like most people, I had been conditioned to think of pharma as cold, money-hungry corporations that care more about profits than people," continues Kelleher-Crabtree. "Now," she says, "I see pharma as a valued part of my healthcare team." Ditto for Dafoe and Nagy.

Online, a demand for disclosure is building. "The health activist community has been, in the last several months, saying, 'We're demanding transparency from each other and from the companies that work with us,'" notes Jack Barrette, founder and CEO of Wego Health.

Relationships between companies and patients must be stated as clearly as possible, he insists, where everyone can find it and understand it. Like a version of the drug brief summary, the disclosure should say, "This medical device company paid me to create this educational program," for example, "and it was subject to their regulatory review." That transparency is how someone can be an objective representative of a community and accept funding from a company."

The second and perhaps most visible segment of patient advocates are those, like Hernandez and Sparling in the diabetes realm or Dave deBronkart (aka e-Patient Dave) in cancer, who are especially adept at creating content. The foremost bloggers have become, effectively, small communications firms unto themselves, says Jack Barrette, founder and CEO of Wego Health, an online patient network that also acts as a liaison between its "health activists" and pharma to create educational programs.

"[The high-profile advocates and bloggers] want to communicate very valuable content and have created an agency structure—they're professionals, in a good way, and have managed to carve out areas where they can be seen as agency-like," Barrette says.

Beyond that top layer is a group who also blog but don't necessarily support themselves through their advocacy. It's that group, which Barrette calls the health activist middle class, that companies are now learning from: "They're so powerful because their numbers are so vast, and they're trusted because they're not semi-professionals."

There's a third tier online, "who don't even consider themselves patients," observes Wendy Blackburn, EVP, Intouch Solutions. Around a third of US adults use social media as a health resource,



In 2009 Roche Diagnostics invited 30 of the foremost diabetes bloggers in North America to its offices. The Roche Diagnostics Social Media Summit is now in its fifth year. Above, the 2012 group

according to a 2012 survey of 1,060 US adults by PricewaterhouseCoopers, and most probably fall into this third group.

"It's someone who maybe just got diagnosed and doesn't even realize there's this discussion we're having about pharma and social media," says Blackburn. "They just go online for information."

A stake in the ground

Belgian drugmaker UCB seems to target more of that rank-and-file set. UCB—whose brand portfolio spans Parkinson's disease patch Neupro, seizure therapy Vimpat, and Cimzia, a biologic for rheumatoid arthritis and Crohn's disease—started engaging patients online as another way to provide value. "We want to put a stake in the ground, to be an active part of the community," says Chemelle Evans, UCB associate product director, CNS.

The firm sponsors microsites, like the recently launched EverydayRAvictories, where patients can post stories; Facebook

pages, such as facebook.com/parkinsonsmorethanmotion; as well as YouTube channels, like YouTube.com/epilepsyadvocate. These efforts dovetail with consumer-facing commitments like educational magazines, scholarships, involvement with non-profits, and marketing campaigns.

The drugmaker mines user-generated content for insights. “It’s one thing to do traditional market research and get, at a point in time, what someone is thinking,” explains Patricia Choumitsky, senior manager, immunology for UCB. “It’s something very different to listen to them in an interactive way. By seeing their responses to everything you do, you can quickly and dynamically shift your focus.” One example was what she calls an “online social private research community,” the firm hosted with arthritis patients. “As a result of the community, we changed one of our direct-response offerings

to something that better met the patient need,” says Choumitsky. The offering is MY RA Fit Kit, a free exercise program.

The pitfalls of participation

Participation is not without its pitfalls. For instance, sources say patient-generated content is vulnerable to the same creative restrictions as most healthcare marketing.

“The FDA views patient ambassadors as testimonials,” says Brenda Snow, the founder and CEO of Snow Companies, “and if a patient says anything about a brand...the FDA views that as an extension of that company, so all the promotional, legal and regulatory [stipulations] have to be upheld.”

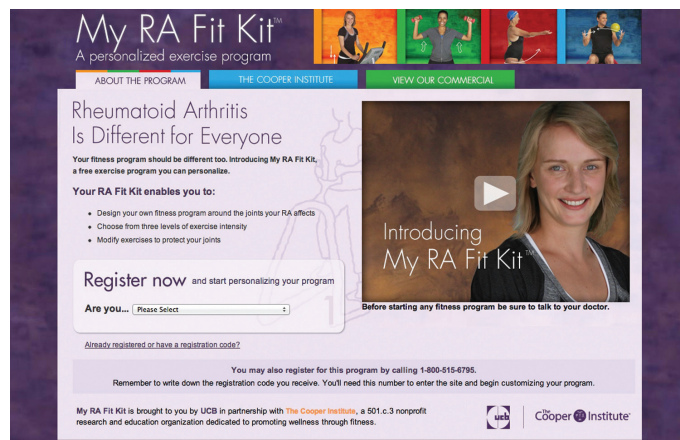
With patient blogs and testimonials thusly constrained, that

could mean the public will become as jaded toward them as they have become toward drug commercials on TV.

Marketers playing in social media also need to stay vigilant and ride the waves of the shifting digital landscape, such as when Facebook abruptly changed course in 2011 and forced pharma pages to open their walls to user comments, prompting several drugmakers to shutter theirs rather than commit to 24/7 monitoring of posts.

So far, that hasn’t scared Roche Diagnostics. About a year ago, it started using its Twitter channel for customer support, and its care staff monitors around the clock. A member of the staff will jump into a discussion when there’s a need to point those who are diagnosed toward credible online resources.

“If pharma can drive patients to accurate information, it furthers the goal of optimizing treatment experience and promoting adher-



UCB changed its direct-response offering, My RA Fit Kit (above), based on feedback from patients online; UCB's Facebook pages (left, one for the Crohn's community) dovetail with magazines (below).



ence,” says Tara Rice, manager of health education for the agency HealthEd. Rice points to a 2012 Wolters Kluwer survey that found 65% of people who turn to the internet with medical questions say they trust the information they find, “which is scary, because there’s a lot of inaccurate information online.”

ROI evidence is also scant. Roche’s Müller declines to quantify it, preferring instead to focus on soft indicators that responding to users on these platforms moves the trust meter. “The fruit of that is in a user pointing out during a conversation in a forum, ‘I know the guy from Accu-Chek is here,’ and I’m brought into the conversation. That shows rapport, that you’re doing something right.”

Asked for metrics, UCB’s Evans points to the firm’s epilepsy Facebook page, facebook.com/epilepsyadvocate, which has over 43,000 fans. She notes that some newly launched properties are steadily growing and increasing their fan base daily, but adds that it still “takes courage to get engaged in these emerging-media platforms.”

Daring though they may seem relative to industry peers, these companies say they haven’t sacrificed compliance for the chance to get closer to their key audience. Still, marketers say, doing so is more art than science.

The FDA has yet to issue an official guide book to social media. A little more than a year ago, it issued draft guidance on

“Responding to Unsolicited Requests for Off-Label Information About Prescription Drugs and Medical Devices,” which some interpreted as a sneak peek. But the agency has yet to clarify the situation.

Nevertheless, patient advocates and some pharma and device companies seem to be finding ways to work together.

“At the end of the day, it’s been a very rewarding experience to be able to engage [patients] in this way, and as an organization committed to making a difference in patients’ lives, we have to be willing to take that step,” urges Evans. “Weigh the pros and cons, like anything, but don’t shut the door on this amazing opportunity to help make a difference for patients’ lives.” ■

