

Up Front

Pharma Collaboration with Online Patient Opinion Leaders

The pharmaceutical industry has a long tradition of working with individual patients and patient organizations. Sometimes the goal is to promote a specific product, but more often the goal is to raise awareness about a disease or medical condition for which the company has a specific Rx treatment.

Pharma companies have hired patients as spokespersons (see "Behrman Wasn't the First Patient Spokesperson Paid Big Bucks By BMS"; <http://bit.ly/qc6ya>), given grants to patient advocacy groups (see "Pharma Dollars

(Pounds, Euros) are Grassroots Seeds"; <http://tinyurl.com/24vnfuc>), recruited individual patients to participate in market research focus groups (see "Levitra Market Research: The Interview"; <http://tinyurl.com/27fh68u>), and now may be hiring individual patients to monitor, moderate, or participate in online patient forums (see "J&J Agents Trolling for Adverse Events on the Internet"; <http://tinyurl.com/l4wqtf>).

Some patients welcome this collaboration with pharma and have been very vocal about the desire to be hired by pharmaceutical companies to help them moderate or manage online patient forums.

"Health Activists" like Allison Blass (Patient Blogger, Diabetes Activist, Lemonade Life) and Megan Oltman (Certified Migraine Coach, Patient Blogger, FreeMyBrain) have been attending conferences and visiting pharmaceutical companies. Their goal is to help pharma marketers understand the needs of "today's empowered" consumers and patients.

One of the needs of these health activists is the need to be paid for services rendered (see "Some Social Media Patient Opinion Leaders Want to be Paid Pharma Professionals"; <http://bit.ly/9X71WY>).



At a recent industry conference, Blass told the audience about attending a "Diabetes Social Media Summit" sponsored by Roche in Orlando, Florida. She came away from that Summit feeling much closer to Roche and now has a more personal relationship with "Todd," one of the Roche Summit organizers who was communicating via social media with Blass before the event.

The physicians' ears next door were probably burning with envy. They probably miss the good old days when pharma companies could invite THEM to outings at resort locations. But that's now verboten by PhRMA!

There are no PhRMA guidelines, however, about paying "patient self advocates" to attend "summits" at resort locations. Not that there's anything wrong with that! I'm just wondering if "Patient Opinion Leaders" (POLs) are replacing physician "KOLs" (Key Opinion Leaders) and where this will all lead.

In fact, I know where it may all lead: to Senator Grassley, who right now may be writing letters to pharma CEOs requesting information about such "summits."

When Blass and Oltman were asked to tell the audience what they want from pharmaceutical companies, Blass said "You need to pay someone's full time salary." She was referring to the desire of some pharma companies to interact with patients in online communities. "The only way to sustain growth and involvement in a [online] community," said Blass, "is to have someone who actually does it [manage social media interactions with patients] as their job... to become the person who is known and loved by the community."

Blass was talking about an online patient community set up and run by a pharmaceutical company as opposed to an independent online

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patient community that already exists. However, it is possible that pharma could also hire patients to become leaders on independent sites.

It makes perfect sense that pharma should have full-time employees managing their social media initiatives. However, it becomes problematic when pharma companies hire patient advocates to monitor other communities or to represent them in independent online communities.

The main issue is "transparency," which may be a new concept for eager patient advocates who wish to be hired as pharma POLs.

Congressional committees may investigate the relationships between the pharmaceutical industry and POLs just as they are now doing with KOL relationships. Once that happens, news media and the blogosphere are sure to publish stories and post items about the financial relationships between POLs and the pharmaceutical industry. Finally, government regulatory agencies may take notice. In fact, Jim Zuffoletti, president openQ, predicted in an industry conference presentation that "social media driven patient advocates or Patient Opinion Leaders will receive significant scrutiny" by the HHS's Office of Inspector General OIG as early as 2011.

I think it's appropriate to discuss the issues involving transparency and conflicts of interest that may arise if and when pharma companies pay individual POLs to help manage their engagement with patients online. What best practices should govern pharma's collaboration with POLs? Should the industry develop guidelines for their interactions with POLs via social networks (eg, develop a "Patient Collaboration Transparency Policy")?

To help me answer those and other questions, I hope you will respond to the following online survey: **Should Pharma Hire Online "Patient Opinion Leaders"?** (find it here: <http://bit.ly/c3Obcw>).

John Mack, Editor



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<http://bit.ly/c3Obcw>

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