

Patient advocacy groups are often not what they seem

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(Winnipeg Free Press Headline: Take pill ads with a grain of salt)

A newspaper article written by two doctors attacks screening for prostate cancer, saying that the evidence to support the practice is weak. A little later, a non-profit group called "Us too! International", which describes itself as the world's largest "grassroots, independent, patient-focused charitable organization" speaks out.

"Us too!" tells you that prostate cancer screening saves lives, and accuses the doctors who wrote the article of "journalist terrorist tactics".

A state government is considering new laws that will limit the prices that the government pays pharmaceutical companies for prescriptions in publicly supported programs. A television commercial paid for by an independent senior citizens group, "60 Plus", tells you that the laws will threaten your health by limiting your access to the best medicines.

You are sitting at a bus shelter and notice an ad that shows a dejected-looking man idly playing with a teacup. The ad asks you to "Imagine Being Allergic to People. You blush, sweat, shake – even find it hard to breathe. That's what social anxiety disorder feels like." The poster tells you the Social Anxiety Disorder Coalition, a non-profit organization, has sponsored the ad.

If non-profit consumers' group involvement made you more concerned about the criticisms of prostate screening, more worried about the drug restrictions, and more inclined to think of social anxiety disorder as a serious problem, you have lots of company. A 1999 investigation found that advocacy by independent groups influences consumers' perceptions. The investigation concluded that consumers "place a high level of trust in nonprofit organizations; prefer products marketed in association with a nonprofit organization; and believe that products marketed in association with a nonprofit organization carry an endorsement by the nonprofit organization."

As it turns out, the non-profit organizations associated with the three campaigns are neither independent nor objective. Tax documents show that the non-profit group in the first story, Us Too! International held \$799,012 in net assets at the end of 2000. Drug company contributions accounted for 95% of the group's tax deductible funding.

Another American Seniors group did not take kindly to "60 Plus", the non-profit group of the second story, attacking legislation to limit payments to drug companies. AARP, an organization with 35 million members aged over 50, was upset about the ad campaigns against legislation that would increase access to affordable medication. AARP found "60 Plus" had received \$575,000 from pharmaceutical-related firms in 2001.

In the third story, a pharmaceutical company created the non-profit group for a specific marketing campaign. In 1998, SmithKline, a multinational drug company, was about to obtain approval for one of their antidepressant drugs. The specific indication was treatment for "social anxiety disorder" (SAD). To boost sales, SmithKline decided they needed to promote the disease as well as the drug.

The company hired a public relations firm, Cohn and Wolfe, to help them. The PR firm dreamed up the "imagine being allergic to people" ad that never mentioned SmithKline or their drug. The coalition was no grassroots alliance of patients, but a creation of Cohn & Wolfe who handled all media inquiries on behalf of the group. Today, a recording that announces, "This program has successfully concluded," greets callers to the coalition's hot line.

The campaign worked well. In the two years preceding the drug's approval, fewer than 50 stories on SAD had appeared in the popular press. In May, 1999, the month when the drug gained approval, hundreds of stories about the illness appeared in publications and television news programs. SmithKline then launched ads showing how the drug could help SAD sufferers brave dinner parties and public speaking.

Using patient groups as a tool in campaigns to gain drug approval, funding, and popularization has become standard industry practice. The industry supports patient groups that range from less well-known psychiatric conditions like social anxiety disorder or generalized anxiety disorder, to common conditions such as irritable bowel syndrome,

osteoporosis, and diabetes. They rely on patient groups to supply quotes and compelling human stories for the media, and to pressure the regulators and politicians in charge of approval and funding decisions.

Some groups resist the temptation of drug money. Kathleen O'Grady, the Director of Communications for a non-profit public education group, the Canadian Women's Health Network, regularly refuses offers from PR firms representing the pharmaceutical industry. Her refusal preserves her organization's independence, but at the price of fewer dollars for public education.

Not many patient groups, however, can resist industry money and the influence that comes with that money. Pharmaceutical sponsorship has become so widespread that, unless non-profit organizations tell they that they are free of industry support, you should assume that the hidden hand of the industry is influencing their public campaigns. And judge the content with appropriate skepticism.