



HEALTH & SCIENCE

Disease of the moment: More care is the ultimate goal

Increasing public awareness of a medical condition makes it more likely that patients seek treatment, but creating name recognition is complicated.

By [Victoria Stagg Elliott](#), AMNews staff. July 2, 2007.

Many patients haven't heard of peripheral arterial disease, but the National Heart, Lung and Blood Institute wants to change that. This year, the agency's campaign, "Stay in Circulation: Take Steps to Learn about PAD," is partnering with the National Council on Aging to host educational seminars and screening events at senior centers. Public service announcements have been filmed. Multilingual fact sheets and posters created. An alliance called the PAD Coalition has been formed with 45 partners.

"Prevalence is high, but awareness of this disease is low," said Susan Shero, RN, NHLBI's project officer for this campaign.

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This undertaking is just one of numerous efforts to increase awareness about a disease. The goal: reduce stigma, get more patients treated, make it more likely that physicians know what they're facing and convince researchers to tackle the unanswered questions.

"If you can help one person have that conversation with their physician -- not feel alone, not feel out of control -- you've really benefited society," said Suzanne Goss, senior vice president at Y Brand, a health care branding firm in New York.

These initiatives come from patient advocacy groups that hope to improve therapeutic options for the conditions on which they focus as well as from pharmaceutical and medical device companies that expect to profit if disease awareness translates into more demand for their products. Government public health agencies also play a significant role, and these organizations form groups, such as the PAD Coalition, to strengthen the message.

Much of the work to increase disease awareness takes place in the most obvious vehicles: television and magazine advertising. Public service announcements are created. And most

refer to Web sites with even more information.

Public relations professionals look for opportunities to get a disease or medical condition mentioned and discussed accurately in the media. Surveys can be commissioned that outline the scope of the problem and provide another news opportunity.

For example, a few years ago officials at Centocor Inc., manufacturer of the monoclonal antibody Remicade (infliximab), realized that there was a great deal of confusion between irritable bowel syndrome and inflammatory bowel disease. They launched the "Voices of Crohn's" campaign featuring a survey of a thousand patients, asking detailed questions about how this disease impacted quality of life. The results were released to the media and posted to the campaign's Web site.

"In the news today, Crohn's disease is covered more accurately and more often than it had been prior to the launch of that campaign," said Michael Parks, the company's vice president of communications. "Even to this day we see a lot of the factoids that were included in that survey being published."

Many organizations also attempt to designate particular months, weeks or days for increased emphasis, and recruit celebrity spokesmen.

"Having a celebrity identify themselves with a particular disease can certainly increase awareness of it," said Debbie Durrer, executive director of the Foundation for Sarcoidosis Research. "It also helps to put a face on the disease."

But the nature of some illnesses demonstrates how not every strategy suits every medical condition and how marketing efforts have to be tailored. Case in point: Those working to increase awareness of spinal muscular atrophy are unlikely to find a high-profile spokesperson to bring more attention to this genetic disorder, because most people with it die very young. This also means that there is not a significant affected population to lobby for more attention.

"Nobody gets to that age where they can be famous and can become a spokesperson for us," said Kenneth Hobby, executive director of Families of SMA. "It's one of the challenges [we face]."

Their efforts are focused on enticing researchers, some are more subtle. Disease names can be tweaked to become more palatable. Urinary incontinence increasingly is called overactive bladder. Impotence has become erectile dysfunction. Manic depression is now bipolar disorder.

"This can be very powerful because it can create new urgency and new awareness, and it can start a dialogue," said Goss.

The mention of a disease name in a television program may even be a form of product placement designed to increase awareness. The industry weekly, *Brandweek*, reported earlier this year on the increased mentioning on television of prescription drug names, along with the diseases they treat.

Physicians: A prime target

While a significant chunk of disease-awareness efforts target potential patients, health care professionals are often the first wave approached. Drug companies, patient advocacy groups and professional organizations provide continuing medical education in varying venues as well as online. Nonprofit organizations, either professional or patient-focused, recruit experts to author guidelines or other scientific articles.

"It's a twofold approach. You can't ever do one successfully without the other," said Durrer.

But those who work in this area are constantly devising new strategies. Earlier this year, Centocor released "Innerstate," a nearly hour-long documentary about patients with the most common immune system problems that can be treated with infliximab. The film does not mention the drug, and the movie is believed to be the first disease-awareness campaign of its kind. The film toured the country, with each screening followed by a question-and-answer session with physicians and a health fair featuring advocacy groups.

"This is really about increasing awareness among patients as well as the general public and not about pushing a particular product or brand name," said Parks.

This approach is key because disease-awareness campaigns have far more supporters than do specific medical products. Plus awareness campaigns don't have the regulatory burden of direct-to-consumer advertising for prescription products.

"If you don't make a product claim then you don't have to balance the product claim with warnings," said Mel Sokotch, author of the advertising guidebook, *Shortcuts to the Obvious*. Adding claims and warnings "means that, instead of buying a 30-second commercial, you're often buying a 60-second commercial. That doubles the price."

Positive and negative images

Within the medical profession, disease-awareness efforts are often viewed positively -- but with caveats. The AMA supports advertisements that discuss a disease, disorder or condition and advise consumers to see their physicians, without mentioning a drug, device or other medical product. These types of campaigns, though, particularly those linked to drug and medical device companies that stand to make money from increased awareness, are not without critics.

Centocor's film elicited a complaint letter to the industry trade group, the Pharmaceutical Research and Manufacturers of America, and to the Food and Drug Administration, from several physicians and a service workers union in the Northeast suggesting the film was more direct-to-consumer advertising of Centocor's drug than disease awareness.

Meanwhile, both the *British Medical Journal* and *Public Library of Science Medicine* have devoted special issues to medicalization within the past few years, expressing concerns that some campaigns to increase disease awareness dangerously expand the definition of a medical condition to include the normal range of human behavior. This situation could lead to people receiving unnecessary treatment and put them at increased risk of adverse events.

"Where they're convincing people that aspects of ordinary life are really illnesses and identifying more people as sick, it's hard to see how that's helping," said Steven Woloshin, MD, who authored one of the *PLoS* papers and is a senior research associate and general internist at the VA Medical Center in White River Junction, Vt.

Questions have been raised about the legitimacy of some patient advocacy groups. The results of some of the surveys commissioned for public relations purposes sometimes end up published in peer-reviewed journals or presented at medical conferences. Many also challenge the objectivity of CME funded by companies that stand to make money from increased disease awareness.

In April, a Senate Finance Committee report on the subject of the use of educational grants by pharmaceutical manufacturers found that most companies had taken steps to separate this money from marketing efforts.

Guidelines have also been put in place by various industry groups and government agencies to further reduce the potential for abuse. Still, the report expressed concern because there was a "gray area" that existed between education and marketing. Also, although there were numerous citations from the Accreditation Council for Continuing Medical Education, no mechanism existed to review these programs before presentation.

Those who work in this industry counter, however, that the most effective campaigns give patients and professionals the information they need to make good decisions about appropriate treatment.

"You have to think about getting the right product in the right patient together with the right physician, and then you're going to get the best clinical outcomes," said Mark Summers, president of ThreeWire Inc., a direct-to-patient marketing services company in Eden Prairie, Minn. "But there are some valid criticisms of some campaigns."

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ADDITIONAL INFORMATION:

Name recognition

Restless legs syndrome has gone from an obscure condition that some physicians didn't believe existed to one that appears in daily parlance and is viewed with seriousness.

1945: Dr. Karl-Axel Ekbom of Sweden describes cases of RLS in *Acta Medica Scandinavica*. The condition is also referred to as leg jitters, irritable legs, Wittmaack-Ekbom syndrome, *anxietas tibiae* and *anxietas tibialis*.

1989: Eight patients form the Restless Legs Syndrome Foundation.

1995: The International Restless Legs Syndrome Study Group in September publishes a

paper in *Movement Disorders* outlining four defining characteristics.

1999: The American Academy of Sleep Medicine publishes the first RLS treatment guidelines in November.

2003:

- A National Institutes of Health working group in March publishes updated diagnostic criteria in *Sleep Medicine*.
- GlaxoSmithKline, the manufacturer of ropinirole, approved for treating Parkinson's, issues a March 31 news release about a study, presented at that year's American Academy of Neurology meeting, that found the medication can improve RLS symptoms.
- GSK issues another news release April 1 about a study, presented at the same meeting, that found RLS markedly decreased quality of life. Both studies were funded by the company.

2004: GSK takes out RLS-related ads in medical journals.

2005:

- RLS television ads appear in spring.
- The FDA approves ropinirole for treatment of RLS on May 5.

2006: The FDA approves pramipexole, the second drug available for this condition, on Nov. 10.

Source: News archives; *Public Library of Science Medicine*, April; RLS: UK

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Making people disease-aware

Patient advocates, pharmaceutical companies and government health agencies use an array of techniques to increase name recognition of particular medical conditions. Here are some methods:

- Create a palatable name for the condition.
- Host patient and physician educational events.
- Make fact sheets, posters and brochures.
- Film or write public service announcements for television, radio or print.
- Buy advertising space.
- Establish a Web site.
- Recruit a celebrity spokesperson.
- Enlist experts to write treatment guidelines or scientific articles.

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Weblink

Pharma Marketing Blog from the publisher of *Pharma Marketing News*
(pharmamkting.blogspot.com)

Disease mongering, *Public Library of Science Medicine*, April 2006
(medicine.plosjournals.org/perlserv/?request=get-toc&volume=3&issue=4)

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