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# Grass Roots Seeded by Drugmaker

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By [Robert O'Harrow Jr.](#)

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Showing all the signs of a thriving grass-roots movement, a host of new health-care groups are drawing attention to the perils of a contagious, sometimes lethal virus called hepatitis C.

Hundreds of doctors, community leaders and public-health officials have volunteered for the hepatitis C coalitions in 11 states. Members distribute thick information packets to educate the public about what they term the "silent killer" and the "millennium epidemic." Organizers have begun pressing state legislators to spend more to fight the disease, which attacks the liver and affects about 4 million Americans.

"Collectively we can have a powerful impact in providing education regarding Hepatitis C," said a recruitment letter from the group in New York.

But contrary to appearances, these coalitions are not spontaneous gatherings of concerned citizens. They are instead a key part of a carefully orchestrated marketing campaign funded by Schering-Plough Corp. to sell the primary therapy for hepatitis C, Rebetron, which costs \$18,000 a year.

The first coalition was started in Minnesota in late 1997 by a Schering-paid public relations executive, even as the drug was awaiting approval for sale.

The coalitions' toll-free phone numbers are paid for by the drugmaker.

Several coalition officials, including former senator Donald W. Riegle Jr. (D-Mich.), are on the payroll of Shandwick International, the public relations firm Schering hired to run the effort. And, in a practice that may violate Food and Drug Administration rules, Shandwick helped prepare scripts for the 800-number operators and educational materials sent out to patients.

The drugmaker's campaign offers a vivid look at a public relations tactic gaining currency in corporate America: The use of "AstroTurf," or "grass-tops," groups posing as authentic local organizations to promote a product or political aim.

"What they're doing is typical of the PR industry, but [something] we are never supposed to notice or see," said John Stauber of the Center for Media & Democracy, a nonprofit advocacy group that tracks the industry.

"What they want is credibility."

Medical ethics experts agree that more should be done to educate people about hepatitis C. But some say the Schering-funded coalitions raise troubling conflict-of-interest issues.

"It's ethically problematic when a company creates entities but then tries to pass them off as authentic and spontaneous grass-roots organizations," said Thomas Murray, president of the Hastings Center, a nonprofit group that examines medical ethics. "What bothers me is the deceptiveness."

It bothers Allan Rosenfield, too. The dean of Columbia University's Mailman School of Public Health, Rosenfield said he was under the impression when he joined the board of the New York coalition that Schering had provided only a small grant. But when told the extent of Schering's involvement, he said, "It just goes beyond what I think is appropriate."

He said he intends to resign from the group. "I don't like what I've learned," he said. "Sometimes marketing people in these companies don't use good sense."

Schering-Plough spokesman Robert Consalvo defends the company's actions. The aim, he said, is to educate people about an insidious and little-known blood-borne disease--as well as to boost sales of Rebetrone.

"There is a great need for more information about hepatitis C," he said. "Ultimately, our hope is those patients will use our product."

He acknowledged, however, that the coalition effort is funded by the company's marketing branch, not its charitable arm. He wouldn't say how much has been spent.

Sales of Rebetrone, a combination medicine containing both ribavirin and interferon, have increased more than 60 percent over the past two years, from \$363 million to \$586 million, according to IMS Health.

Consalvo denied that the company is being secretive, noting that some coalitions cite Schering, in small print and on some documents, as providing an "educational grant" or an "unrestricted educational grant." The company also is listed among scores of other groups as a member of the coalitions.

Late last month, however, in response to questions from The Washington Post, a Shandwick official acknowledged that the phrase "educational grant" was misleading. Shandwick issued a letter to all coalitions promising to better inform people of the company's role. It said that "all Hepatitis C Coalition communications such as invitation letters and press materials will contain the phrase 'Supported by seed funding from Schering-Plough Corporation' to alleviate any potential concerns about disclosure."

Thomas W. Abrams, director of the FDA's division of drug marketing, advertising and communications, said his agency generally does not interfere with "unrestricted educational grants" that companies make to promote good public health awareness.

"We would, however, become concerned if a drug company controlled or influenced the content of information disseminated by the seemingly independent organization," he said. He noted that he wasn't commenting directly on Schering's involvement in the coalitions.

Rebetron is not supposed to be named in educational materials, Consalvo said, and it did not appear to be. The company knows its product doesn't have to be mentioned because it is considered the "gold standard" treatment that the vast majority of doctors would prescribe, he acknowledged.

There's no question hepatitis C poses a major health education challenge. Many of those infected have had it for years and don't know it, according to the Centers for Disease Control and Prevention. The disease can lay dormant for years before damaging the liver.

People at risk include users of injection drugs, people who have had numerous unprotected sexual contacts and those who received blood transfusions before 1992. The number of new infections has dropped dramatically in recent years, according to the CDC, but the number of people expected to suffer liver damage or need transplants is expected to increase.

In July, to underscore the challenge ahead, U.S. Surgeon General David Satcher asked Congress to distribute a letter to constituents about the dangers of hepatitis C.

While Schering says it is attempting to meet that challenge with the coalitions, the groups are also part of a broader Schering effort to promote sales of Rebetron.

Shandwick works closely with the American Liver Foundation, a nonprofit group that has received about \$2.5 million over the past five years from Schering, according to federal tax records and ALF officials. That includes a pledge of \$50,000 to the ALF's New York chapter to pay for a full-time staff person to work with Shandwick.

Those donations helped the ALF to grow from two full-time staff members in one office to 30 full-time employees in 20 offices around the country, foundation officials said. Donations from Schering last year accounted for more than 12 percent of the group's budget, they added.

The company also has paid more than \$400,000 since 1997 to a Washington lobbying firm that has pressed Congress to ensure that veterans with hepatitis C are covered for treatment, according to a database of lobby records maintained by the Center for Responsive Politics.

That firm, Health Policy Analysts, has worked closely with Reps. Victor F. Snyder (D-Ark.) and Christopher Shays (R-Conn.), both of whom have held hearings about veterans infected with hepatitis C, according to aides. Snyder also sponsored a bill to ensure veterans are covered.

Schering also was a founding member of the Frontline Healthcare Workers Safety Foundation in Atlanta in 1998. The foundation sponsored a conference last month about the accidental exposure of health-care workers to hepatitis C.

The center of Schering's coalition effort is the Shandwick office in Minneapolis. Portraying themselves in letters and other documents as coalition insiders, public relations specialists there have built databases of

potential volunteers, trained patients how to discuss their ailment with the media and packaged educational materials for use across the country.

Patients and others seeking more information are told to call toll-free numbers assigned to the state coalitions. Operators who answer the calls identify themselves as part of the groups but are paid by Schering, according to officials at Convergys Corp., the telemarketing company that handles the calls in Utah.

Schering spokesman Consalvo said his company did not pay for the lines or write the scripts that operators used. Such an arrangement could run afoul of FDA rules, he said. So the Hep C Connection, a nonprofit group in Denver funded by Schering, pays the bills at Convergys, he said.

Not so, said Convergys spokesman John Pratt. "It belongs to Schering 100 percent," he said of the information collected by the operators. "Our contract is with Schering-Plough."

Nancy Longley, a Shandwick senior vice president, said her company and its consultants have worked hard to "go out and build the infrastructure" of an "information, education and awareness network."

Members listed on the coalitions' documents include government and private public-health officials, veterans groups, corrections workers, firefighters, unions and community groups.

The plan is to build the groups and then hand off control to others, she said, but that hasn't happened yet. Schering would remain a member, she said.

Coalitions are operating or under development in Arizona, California, Illinois, Massachusetts, Michigan, Minnesota, Nevada, New York, Ohio, Pennsylvania and Washington state, she said.

The hope, Longley said, is that the coalitions would have more impact on people than a costly advertising campaign. She denied intentionally deceiving anyone.

Some participants say it is rarely clear who is behind the efforts, however.

James Learned, a public-health educator in New York, said he was ready to volunteer after receiving a letter signed by "Diane Thompson, New York State Hepatitis C Coalition." As it happens, Thompson actually works for Shandwick.

"When I got these letters, I bought it," Learned said. He became suspicious when he noticed details, such as out-of-town telephone numbers for the organizers, that seemed inconsistent with a local grass-roots group. "I felt totally manipulated," he said. "It went against everything I work for as a health educator."

In Michigan, Riegle, the honorary co-chairman of the state coalition, showed up at the Detroit News last fall with a hepatitis C patient to press for a news story about the urgency of the problem.

But Riegle didn't mention to the News reporter that he is deputy chairman of Shandwick. He said in a recent

interview that he didn't think it was necessary because he was volunteering for the group and "this is a medical issue I happen to believe in."

"I don't see who's being harmed," he said. "I went along on a pro bono basis. . . . I was there on my own behalf."

In Massachusetts, a news release directed callers to "Kathy Keough of Massachusetts Hepatitis C Coalition." Keough is a drug industry consultant hired by Shandwick to run the group. She was not familiar with details of the press release, she said, because it was written by Shandwick officials in Minneapolis.

Robert Gish, a physician and member of the California coalition who said he has received grants from Schering, said the drugmaker should be praised for doing a job he contends the federal government has failed to do. "They're doing a service far in excess of questions a person might raise," said, Gish, a liver and hepatitis C specialist.

Marcia Angell, a physician who recently stepped down as editor of the New England Journal of Medicine, worries about the effect the coalitions could have on people's faith in public-health campaigns. "It looks balanced. But how do you know?" Angell said.

Schering's role "underscores for me the fact that drug companies cannot be in education," she said. "They can't because it's a conflict. Their primary mission is to increase the bottom line for shareholders."

Alfred DeMaria, director of communicable-disease control at the Massachusetts Department of Public Health, said the coalitions are raising public awareness of hepatitis C. But he said he's "somewhat concerned" about Schering's role.

"There's a fine line," said DeMaria, who was asked to join his state's coalition but declined. "It's an unusual way of marketing."

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