

T H E P A T I E N T

PATIENT ADVOCACY GROUPS are a force to be reckoned with.

These groups are invaluable partners to help pharmaceutical companies reach out to patients and physicians.

C O N N E C T I O N

By working with patient advocacy groups and professional organizations, pharmaceutical companies have the opportunity to inform thought leaders, prepare the marketplace for upcoming products, impact policy, gather market intelligence, and gain valuable feedback from patients, according to Best Practices LLC.

The public is becoming even more empowered when it comes to making healthcare decisions. This is all good news for the pharmaceutical industry, since an informed public is one of its best allies in the battle to take therapies from concept, to clinic, to market. The challenge for the industry is how to best tap into that informed patient base, as well as physicians and other healthcare professionals.

"Today more than ever, patients are educating themselves and are looking for information," says Mary McGovern, senior director of patient advocacy at Ortho Biotech. "Many times, they turn to advocacy organizations for help during the most traumatic times of their lives. Our goal is to partner with advocacy organizations and help them provide the answers patients are looking for."

According to research, advocacy groups often are the most trusted source for a patient.

"According to Gallup, the American Can-

cer Society is more trusted as a source of information about cancer than even the patient's own doctor," says Roger Sullivan, national director, strategic resources, with the American Cancer Society Foundation.

BUILDING PARTNERSHIPS

Leaders in the industry say pharma companies that fail to build and maintain relationships with patient groups do so at their own peril.

"When a company enters any therapeutic area it is essential, in terms of business strategy, to understand the per-

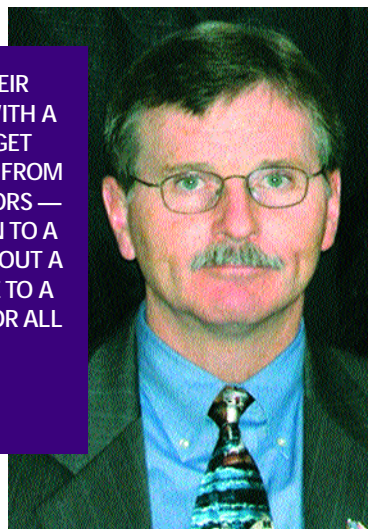
ceptions and needs of the marketplace," says Karen Carolonza, director of public relations and advocacy development at Pharmacia. "And patient groups bring those perceptions and needs to the table. Patients are more empowered; they're walking into doctors' offices and asking for certain drugs, asking about diseases. If we ignore that, we're not going to stay ahead of the curve. By investing in patient advocacy early and often, we put ourselves in a much better position to make educated business decisions overall."

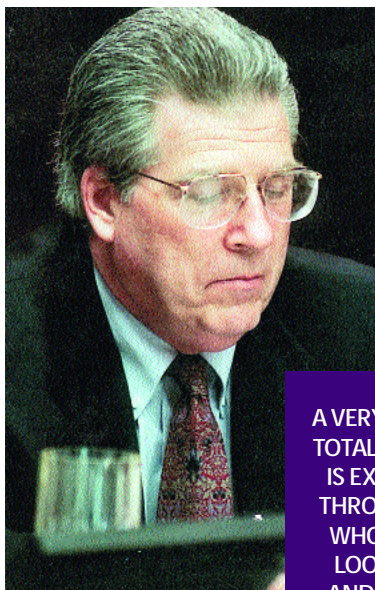
The value of an advocacy relationship is recognized by both corporate and nonprofit organizations, large and small.

"Without the distribution mechanisms, access to mass media, funding, knowledge, expertise, and in-kind contributions these corporations bring to the table, our ability to reach our goal to reduce disability and death from cardiovascular diseases and stroke would be significantly diminished," says Craig Beam, chairman of the board of the American Heart Association.

THE PATIENTS AND THEIR FAMILIES STRUGGLING WITH A PARTICULAR DISEASE GET INFORMATION AND HELP FROM THESE COMPANY SPONSORS — WHETHER IT'S DIRECTION TO A CLINICAL TRIAL, NEWS ABOUT A THERAPY, OR REFERENCE TO A PARTICULAR PHYSICIAN OR ALL OF THE ABOVE.

Jeff Hoyak





Over the past five years, the American Cancer Society has been working to forge deeper relations with the industry as it tries to meet its goals for 2015, which are to cut the death rate from cancer in half, reduce incidence by 25%, and measurably improve quality of patient life.

“Those goals transcend anything that an individual organization can achieve, so collaboration became a critical need,” Mr. Sullivan says.

Those in the industry agree. Pharmacia, for example, has found that by working with advocacy groups the company has been able to help create greater awareness about the need for either better treatments, or prevention, which often links up with products the company has on the market or in research.

“These programs offer a win-win because we get more awareness of our brands through these efforts, and the patient advocacy groups get more awareness of who they are as well as for the services that they provide to patients and patients’ families,” Ms. Carolonza says.

Smaller pharma companies also are starting to recognize the benefits of these relationships, partly because of the access to information such partnerships offer. Aderis Pharmaceuticals has spent the past year building outreach programs with advocacy groups in the Parkinson’s arena as the company continues research into therapies for the condition.

“These groups provide a number of services to the patients and to the physicians,” says Ken Rice, VP, chief commercial officer, and CFO at Aderis. “They provide education, they provide support for patients and families, and they very often act as lobbyists for funded research and scientific advances. As a small company, working with these advocacy groups gives us greater access to scientific thought leaders and to people who affect public policy. We are able to gain an improved awareness of what new products are being developed and what expanded indications there might be.”

The relationship works both ways. Robin Kornhaber, senior VP of patient services at The Leukemia & Lymphoma Society, says to provide information and support to patients, the organization depends on being kept abreast of what the industry is doing.

“We keep in touch with pharmaceutical companies that are conducting research in the area of cancers of the blood so we can provide information about where people might access

A VERY LARGE AMOUNT OF THE TOTAL MARKETING ENTERPRISE IS EXERCISED BY COMPANIES THROUGH BRAND MANAGERS WHO ARE NOT ALLOWED TO LOOK PAST THAT QUARTER, AND WE UNDERSTAND THAT, BUT IT’S NOT WHERE WE CAN BE — WE’RE NOT GOING TO DO ANYTHING TO SPIKE THEIR SALES IN THE NEAR TERM. IT’S THE LONGER-TERM PICTURE THAT CONCERNS US.

Roger Sullivan

clinical trials, and what products are in the pipeline,” she says. “It’s very important to maintain that relationship with the industry because the pharmaceutical companies are one source of cutting-edge research.”

Pharmaceutical companies with dedicated advocacy departments spend much of their time working to identify groups, both at the patient and professional level, that have goals in common with their corporate goals.

“The patient community and the pharma world are working hard for the same ends — relief of human suffering through biomedical advances and advances in treatments,” says Joan Samuelson, president of the Parkinson’s Action Network. “And we have many of the same challenges — a need for adequate research, and a need for quick government action where decision making is needed.”

There’s potential to further strengthen these relationships and make that teamwork even more effective for mutual goals.

“For example, if an advocacy group’s goal is to increase awareness about colorectal cancer and the importance of screening, and we have brands and products that are used to treat colorectal cancer, we look for the common ways in which we want to educate the public,” Ms. Carolonza says.

Pharma companies understand the value of working with advocacy groups to inform physicians about a disease state in an unbranded fashion.

“One of the things we consider to be our responsibility is to make sure that the professional organizations are as educated as possible, and advocacy groups help a great deal,” Mr. Rice says.

A well-developed, respectful relationship between corporate partners and nonprofit groups brings advantages to all groups involved, say those with experience in the field.

“Partnering with patient advocacy groups is a win-win-win situation,” says Jeff Hoyak, executive VP of MCS. “The patient advocacy groups win because they get to raise their profile and extend their reach and resources. The pharma companies win because they get the word out about research and therapies to their target audience, plus they demonstrate a commitment to patients and physicians beyond just marketing a new medication. And most importantly, the patients and their families struggling with a particular disease win, because they get information and help from these company sponsors — whether it’s direction to a clinical trial, news about a therapy, or reference to a particular physician or all of the above.”

Furthermore, working with advocacy groups helps companies put their medication in the context of the patient.

“The medications a company develops are for patients, and medicine isn’t taken in a vacuum,” says Stephanie Mazzeo-Caputo, VP of health education at HealthEd. “By working with the third-party advocacy groups, pharma companies can really better understand the environment in which the patient lives. They can better understand how their medication is being used and how they can help facilitate that process leading to greater patient understanding and improved health outcomes.”

Early formation of advocacy relationships also can help a company with product uptake when insurance is an issue. In that case, a pharmaceutical company might work



BY WORKING WITH THE ADVOCACY GROUPS, COMPANIES CAN REALLY UNDERSTAND THE ENVIRONMENT IN WHICH THE PATIENT LIVES.

Stephanie Mazzeo-Caputo

with a company such as HealthBridge to ensure that patients who are uninsured or under-insured are able to afford the medication that is prescribed by their general practitioner. HealthBridge then works with advocacy groups to try to get patients the coverage they need.

“Sometimes the cost of the medication involves a 20% co-pay,

which can be cost prohibitive for expensive drugs,” says John Seman, HealthBridge CEO. “These programs offer significant help in terms of product uptake because they provide financial resources to those patients that might not otherwise be able to take the product.”

BUILDING A CONNECTION

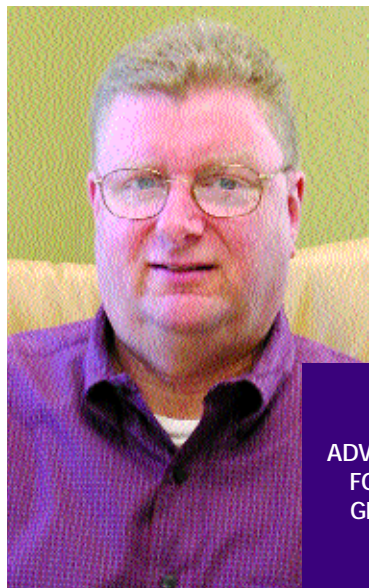
The question is not whether companies should build relationships with advocacy groups, but rather with which groups and how can the partnership be most effective.

In its study, Best Practices notes that benchmark companies look at the traits of certain professional and advocacy groups when making status decisions. For example, partners consider factors such as size of the group, its influence over its constituents, its level of organization, its reputation in the medical



WE BELIEVE IT'S MORE IMPORTANT TO GET INVOLVED WITH PATIENT ADVOCACY GROUPS ABOUT 6 TO 12 MONTHS BEFORE THE PRODUCT IS APPROVED AND AVAILABLE ON THE MARKETPLACE.

John Seman



WORKING WITH THESE ADVOCACY GROUPS GIVES US A FOCUSED AUDIENCE AND A GREAT DEAL OF INCREASED MARKET INTELLIGENCE.

Ken Rice

community, its influence with the media, and its previous track record. The number of products in a disease franchise also is a key factor.

“We’re not able to forge relationships with everyone; we focus on the groups that have a vested interest in a specific disease category, or groups that have common goals that fit with the goals of Pharmacia,” Ms. Carolonza says.

In deciding which groups to reach out to,

The Programs ... and the Results

Companies and advocacy groups cite examples of cooperative programs that have helped fill clinical trials, led to product uptake, and improved patient and physician knowledge about a disease state and how to prevent, test, and treat for it.

THE COMPANIES

Dermik — “We measure visits to the American Counseling Association Website, which has links to our site. The number of unique visits has been about 3,000 to 4,000 a month — exclusive of other programs. That led us to believe that our “Healthy Skins, Healthy Outlook” campaign was being seen and helping to drive more patients into physicians’ offices to talk about getting a prescription for a product to treat acne. We’re confident that through the work we are doing, our therapy BenzaClin will be at least one of the considerations the physician will offer.” — Rob Partridge

Genentech — “During Genentech’s early work on Herceptin we were facing many questions and concerns from breast-cancer

advocates. We learned that we needed to be very proactive about those concerns. We invited those advocates to share their concerns and their thoughts on drug development. Those advocates not only participated in clinical-trial design but also clinical-trial recruitment. These advocates were instrumental in getting Herceptin approved. After the product was approved, we also worked with those groups to encourage women to undergo a HER-2 test, which helped identify which patients should be treated as quickly as possible, and that had a direct impact on adoption of the product. It was through that early experience in breast cancer that Genentech decided to establish an advocacy relations division.” — Heather Schwartz

Ortho Biotech — “Strength for Caring is a program Ortho Biotech established to address the needs of a very valuable member of the healthcare team — the caregiver. We recognize that caregivers often find themselves isolated and overwhelmed. Strength for Caring provides education and access to community resources that help make the caregiving experience less stressful. Ortho Biotech trains nurses, social work-

ers, and members of advocacy groups to facilitate Strength for Caring seminars in their local areas. Our advocacy partners then offer the program as workshops and teleconferences for caregivers. Our partners for Strength for Caring include Lymphoma Research Foundation, Kimmel Cancer Center, the Leukemia and Lymphoma Society, The Siteman Cancer Center, CancerCare, and others. The education we provide through our programs creates more informed and empowered patients.” — Mary McGovern

Pharmacia — “We’ve been working with the Coalition of Cooperative Groups, which is an organization that helps accelerate the clinical-trial process for oncology patients. Through this coalition, with our sponsorship, we’ve been able to increase awareness of how oncology clinical trials are different from other clinical trials through nonbranded media campaigns and poll surveys. The way we benefit is that clinical trials gain more attention so patients may enroll quicker, which means we may get drugs to the market quicker.” — Karen Carolonza

Takeda — “We have been working with the American Heart Association on a program called

companies also need to consider the long-term value of that relationship. That, says Robert Partridge, director of communications for Dermik Laboratories, allows trust to be built between the corporate entity and the nonprofit as the relationship progresses. Dermik has been working with the American Counseling Association since 1997, through MCS, on a program to encourage teenagers with acne and their parents to speak to a physician.

"I've seen companies that do a program, and then a couple of years later they're off with another group depending on what is convenient to them that year," Mr. Partridge notes. "In our case, we searched and considered before we gave MCS the go-ahead to explore working with the American Counseling Association. We didn't want to be in a position where we did the program for a year or two and then the marketing message changed so we'd be off to something else. We wanted to build the best long-term relationship we could."

Ms. McGovern concurs. "Our philosophy in approaching relationships with advocacy organizations is a long-term commitment," she says. "This builds trust and credibility — advocacy organizations know that they can count on us. This philosophy and commit-

ment to patients is driven by our credo, which dictates that our first responsibility is to the physicians and patients we serve."

Building that relationship requires companies to keep advocacy groups informed about what they are doing, and also to be a sounding board for patient concerns.

"We maintain ongoing communications with groups to let them know what we're working on, the

status of our clinical developments, and the status of our marketed products," says Heather Schwartz, senior manager of advocacy relations at Genentech. "We also address concerns that the community may have about a disease or product."

For its part, advocacy groups can keep the flow of information going by bringing all affected parties together to discuss the challenges each faces.

"People with Parkinson's disease tend to be very isolated from their community because the disease is very stigmatizing," Ms. Samuelson says. "It has been a big job to bring people with Parkinson's together, and the connection with the industry is a big help."

"ACS is a guiding hand in trying to get government, industry, the research sector, patient organizations, clinicians, and the



THERE IS A TREMENDOUS NEED FOR GENERAL PATIENT-EDUCATION FORUMS, AND FROM OUR END, WE REALLY SEE A BENEFIT IN PARTNERING TO HELP WITH CLINICAL-TRIAL RECRUITMENT IN GENERAL.

Heather Schwartz

the Heart of Diabetes, Understanding Insulin Resistance, which is sponsored by both Takeda and Eli Lilly. The goal is to get patients to talk to their physicians about the link between diabetes and cardiovascular disease. In 2002, we had 7,000 people join the heart of diabetes program. I would say that's a relatively successful program." — Richard Daly

THE ADVOCACY GROUPS

American Cancer Society — "ACS recognized that colorectal cancer was a therapeutic area in which early detection would make a tremendous difference. We went to Pharmacia, recognizing that with its oncology product Camptosar, the company had strength. We are in a multi-year collaborative arrangement with Pharmacia that promotes colorectal cancer awareness and the need for timely screening. We also have worked with Amgen in a nonbranded fashion to inform patients and clinicians about neutropenia. That program has helped educate physicians about the extent to which an invasive infection can postpone and dilute chemotherapy. The advantage for Amgen is that by getting

physicians to understand the condition, the company possibly can get more physicians to prescribe its product." — Roger Sullivan

The American Diabetes Association — "Eli Lilly gave us a significant grant to host a series of training programs for staff and volunteers within the ADA on how to be good public policy advocates. The grant enabled us to have four major training sessions around the country and was a springboard for all the public policy initiatives that we've done since then. Johnson & Johnson came in with another major grant that enabled us to do even more in-depth work. We've passed bills in 43 states that require state-regulated insurance plans to cover diabetes supplies, equipment, and education. At the Federal level, we passed a law that required Medicare to cover diabetes meters, blood-glucose meters and strips, and education. None of that could have happened without the open-ended no-strings-attached support of industry. Lately, we've started working with Aventis, which has given the ADA a grant to help us reach out to minority communities, specifically the African-American community. We're very excited about

all of these initiatives, and we could not have done them without the support of the industry." — Michael Mawby

The Leukemia & Lymphoma Society — "For the past six years, Ortho Biotech has funded a program called Cancer Keys to Survivorship, which is designed to empower patients and provide them with the information they need to ask the right questions and get good information to make treatment decisions. Ortho Biotech has made an outstanding commitment, and we have reached more than 20,000 people since the program began." — Robin Kornhaber

Parkinson's Action Network — "We've had enormous help from the pharma industry in support of our annual public policy forum that takes place in Washington, D.C., where we teach people with Parkinson's disease and their loved ones about the disease, research, and potential for treatment. The companies' financial support is extremely important to help pay for the forum and provide scholarships to enable those with the disease to attend." — Joan Samuelson

media all at the same table," Mr. Sullivan says. "That way every group can learn to appreciate the barriers that others face."

The American Diabetes Association offers several outlets that help companies build a connection with patients and medical professionals, including meetings throughout the year, a post-graduate course each January, camps for kids during the summer, as well as through its magazine *Diabetes Forecast*.

"Those avenues offer a real opportunity for industry to have exchanges with the medical community involved in diabetes, as well as with the patient community," says Michael Mawby, VP for government relations at the American Diabetes Association.

TIMING IS EVERYTHING

For industry partners, there is some debate as to when a company should start talking to an advocacy group about upcoming products.

"We believe that the right time is in the later stages of clinical trials when the likely side-effect profile, the efficacy profile, and the timeline for likely approval is better known," Mr. Rice notes. "That translates into mid-Phase III."

But others point to the value of early relationship building, which not only can help a pharmaceutical company recruit patients for clinical trials, but can even give the company guidance on areas of importance for patients.

"Once a business group within the company has a sense of what area it's going to embark upon we consider it critical to reach out to groups that have expertise in that field, because it's important to understand the marketplace first," Ms. Carolonza says. "And sometimes working with the advocacy groups early not only helps us understand what patients want and need, but also helps us take things off the plate, to realize that an area we had considered isn't as important as we thought, and we should focus our energies and expertise in a different area."

One example, Ms. Carolonza notes, was when the company began research into the antibiotic Zyvox.

"By working with professional and patient organizations, and agencies such as the Centers for Disease Control, we found out that people were very concerned about antibiotic resistance," she says. "Because of that, we really took that as our platform, and asked: How could we go about improving the appropriate use of antibiotics through the development of this new drug? We worked with the CDC on



WE FEEL THAT A PUBLIC-RELATIONS GROUP CAN ACT AS A LIAISON BETWEEN THE COMPANY'S INTERESTS AND THE INTERESTS OF THE THIRD PARTY.

Robert Partridge

a program for beating antibiotic resistance, and through that we were able to pinpoint the marketing strategy for Zyvox."

Genentech, meanwhile, says it begins talking to advocacy groups about a potential product once it has entered the clinical stage.

"That's when we go out, find out who in the advocate community that particular product may affect, and let them know that Genentech is planning to work in that area, inform them of our clinical trials, and keep them apprised of the information and progress that we make," Ms. Schwartz says.

The point at which a company begins to reach out to an advocacy group with information about an upcoming product might also depend on the therapeutic area involved, says Richard Daly, senior VP of marketing at Takeda Pharmaceuticals North America.

"With HIV, being probably among the most sophisticated audiences out there, companies typically want to get HIV patients involved at the preclinical phases, because they can help design trials and the community is very tightly knit," he says.

MAINTAINING DISTANCE

Though companies and nonprofits do have the same end goal in common, there are huge differences, both real and perceived, that both groups must respect. Companies are required to turn a profit, and therefore must market products so that they will contribute to the bottom line. Advocacy groups exist to help patients, be that in fundraising, assistance, lobbying, or education. And

their very credibility hangs on the fact that what they provide is unbiased, unbranded information about a disease.

"A very large amount of the total marketing enterprise is exercised by companies through brand managers who are not allowed to look past that quarter, and we understand that, but it's not where we can be — we're not going to do anything to spike their sales in the near term," Mr. Sullivan says. "It's the longer-term picture that concerns us."

The experience for most groups, however, has been that companies are respectful of those relationships.

"We have found our relationship with pharmaceutical companies to be excellent," Ms. Kornhaber says. "I don't remember ever being asked to promote a company's drug, for example. They really understand that patients need information presented in an equitable way, so they can take the information and make their own decisions."

Mr. Mawby agrees. "Companies are extremely conscious of not doing anything that might compromise their standing with the public," he says. "They bend over backward not to cross the line where there may be perceptions of groups doing their bidding."

Dermik has found it helpful to work through an intermediary, in its case MCS, to ensure boundaries aren't crossed.

"In our view, a company approaching any third-party group might seem a little aggressive and even a little self-serving," Mr. Partridge says. "We feel that a public-relations group can act as a liaison between the company's interests and the interests of the third party."

Among the services advocacy groups offer are educational materials, often collating information from many sources. This is where a company such as HealthEd can help groups digest that information and create unbranded patient-centered information that can change behavior.

"When we work with advocacy groups, we're able to capture all the knowledge and expertise and hands-on experience that they have along with their needs and challenges, and then translate that into the development of



THE PATIENT COMMUNITY AND THE PHARMA WORLD ARE WORKING HARD FOR VERY MUCH THE SAME ENDS — RELIEF OF HUMAN SUFFERING THROUGH BIOMEDICAL ADVANCES AND ADVANCES IN TREATMENTS.

Joan Samuelson

well-designed educational materials and programs,” Ms. Mazzeo-Caputo says.

Those educational programs are, say individuals experienced in advocacy, critical to improve patient health.

“There’s a lot of criticism of pharmaceutical companies about the cost of drugs, and so forth, but there’s not an understanding of what

it takes to research and develop a drug and the amount of time, effort, and resources that go into that,” Ms. Kornhaber says. “Many pharmaceutical companies play a very good role in the patient community by providing drug-assistance programs and education programs. Many of the programs that we and other patient advocacy groups develop are made

possible by the support of the pharmaceutical companies. This partnership ensures that there’s support for education, so patients understand what their choices are.” ♦

PharmaVoice welcomes comments about this article. E-mail us at feedback@pharmavoice.com.

Experts on this topic

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BEST PRACTICES LLC, Chapel Hill, N.C.; Best Practices conducts work based on the principle that organizations can chart a course to superior economic performance by studying the best business practices, operating tactics, and winning strategies of world-class companies. For more information, visit best-in-class.com.

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voluntary health organization dedicated to funding blood cancer research, education, and patient services, with the mission to cure leukemia, lymphoma, Hodgkin’s disease, and myeloma, and to improve the quality of life of patients and their families. For more information, visit leukemia-lymphoma.org.

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JOHN SEMAN. CEO, HealthBridge Inc., Braintree, Mass.; HealthBridge is a reimbursement and product support company with a staff experienced in medical product support, patient advocacy, and customer service. For more information, visit healthbridgeinc.com.

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