

ADVOCACY RELATIONS

Finding **COMMON GROUND**

Where patient health
is concerned,

**THE GOALS OF
PHARMACEUTICAL
COMPANIES
AND ADVOCACY
GROUPS INTERSECT.**



TERI COX

COX COMMUNICATIONS PARTNERS

People know about Breast Cancer Awareness Month and Prostate Cancer Awareness Month, the ribbons, the races, and so on. **But the general public isn't aware that the pharmaceutical industry, and particular companies within the industry, launched those initiatives that have likely saved millions of lives.**

Everyone is familiar with the famous looped ribbons associated with the various disease awareness campaigns, such as Breast Cancer Awareness Month and the yellow "Livestrong" wristbands of the Lance Armstrong Foundation to generate cancer awareness. But the public may not be aware that these programs originated through, or were made possible by, the support of pharmaceutical companies. Many of the industry's other nonbranded advocacy efforts also are less well known, such as health literacy programs and outreach programs to caregivers.

Through partnerships with advocacy groups and the development of their own outreach programs, pharmaceutical companies are going beyond solely developing medicines. By finding common ground with the advocacy groups that represent specific patient populations, the pharmaceutical industry can move beyond being seen as just a manufacturer and marketer of medicines to being viewed as an ally and partner in a patient's health and well-being.

Pharma Outreach

Outreach efforts and activities come in many shapes and sizes. Company executives interviewed for this Forum stress the importance of going beyond just writing a check to reaching out to advocacy groups as partners to improving patient health.

LACEY. Our commitment at MedImmune is to provide more than just financial support; it is to seek active engagement with advocacy groups and community-based organizations. We like to have true relationships with these groups. We even provide volunteer opportunities for our employees. Part of this mission is our desire to contribute meaningfully to the communities in which we live and work.

DEBUONO. When we initially formed the Partnership for Clear Health Communication (PCHC), we saw this as an important vehicle to improve compliance and adherence with medication. We believed that if people understood how to take their medicines and why they were taking them, then they would take them properly, which would be good for their health and good for our organization. As we began to think more and more about the role that Pfizer plays in healthcare and healthcare delivery, we began to expand the way the program is implemented. We now view PCHC as an opportunity to improve patients' understanding of their chronic illnesses. The more patients know about what their illnesses are, why they have to change certain behaviors, and about the medicines they have to take, the better they will understand how to self-manage their chronic illness, allowing them to lead longer and healthier lives. As a company that is committed to improving the health status across the population, we feel that one key vehicle is improving health literacy and patients' ability to read, understand, and act on health information.

WOMBLE. Bristol-Myers Squibb has a very long history of partnerships with patient and professional organizations. We have been a leader in the field of oncology for more than 40 years, and it has always been important to us to address issues that are of concern to the cancer community as a whole and that look across not just patient advocacy but the community in total.

POLLINI. We do a lot of work with various groups from different perspectives. For example, we do some work through a donations

THOUGHT LEADERS

SCOTT D. BERNIS, M.D., MPH, FAAP. VP of Chapter Programs, March of Dimes, White Plains, N.Y.; the mission of the March of Dimes is to improve the health of babies by preventing birth defects, premature birth, and infant mortality. For more information, visit marchofdimes.com.

DIANE S. BLUM, MSW. Executive Director CancerCare Inc., New York; CancerCare is a national nonprofit organization that provides free professional support services to anyone affected by cancer: people with cancer, caregivers, children, loved ones, and the bereaved. For more information, visit cancercare.org.

TERI P. COX. Senior Managing Partner, Cox Communications Partners, Lawrenceville, N.J.; Cox Communications Partners combines clear vision, fresh thinking, and entrepreneurial energy with decades of leadership in corporate and healthcare communications and advocacy. For more information, e-mail coxcomptnr@aol.com.

BARBARA DEBUONO, M.D., MPH. Group Leader Public Health, Pfizer Health Literacy Initiative, Pfizer Inc., New York; Pfizer discovers, develops, manufactures, and markets leading prescription medicines for humans and animals and many of the world's best-known consumer brands. For more information, visit pfizer.com.

BOB FRANKS. President, HealthCare Institute of New Jersey, Hillside, N.J.; The HealthCare Institute of New Jersey serves as a unified voice for the state's research-based pharmaceutical and medical technology industry. For more information, visit hinj.org.

JAMIE LACEY. Director, Media and Public Relations, MedImmune Inc., Gaithersburg, Md.; MedImmune, which is dedicated to advancing science to develop better medicines to help people have healthier, longer, and more satisfying lives, focuses on the areas of infectious diseases, cancer, and

inflammatory diseases. For more information, visit medimmune.com.

SUZANNE MINTZ. President and Cofounder, The National Family Caregivers Association, Kensington, Md.; NFCA supports, empowers, educates, and speaks for the more than 50 million Americans who care for a chronically ill, aged, or disabled loved one. For more information, visit thefamilycaregiver.org.

CATHY POLLINI. Senior Director, Corporate Planning and Communications, Eisai Inc., Teaneck, N.J.; Eisai is a U.S. pharmaceutical subsidiary of Tokyo-based Eisai Co. Ltd., a research-based human healthcare company that discovers, develops, and markets products in more than 30 countries. For more information, visit eisai.com.

ROGER SULLIVAN. Director, Resources and Alliances, C-Change, Washington, D.C.; C-Change is comprised of the nation's key cancer leaders from government, business, and nonprofit sectors and aims to share the vision of a future where cancer is prevented, detected early, and cured or is managed successfully as a chronic illness. For more information, visit c-changetogether.com.

MIKE TRINGALE, M.S.M. Director of Marketing and Communications, Asthma and Allergy Foundation of America (AAFA), Washington, D.C.; AAFA is a nonprofit patient organization dedicated to improving the quality of life for people with asthma and allergies. For more information, visit aafa.org.

REBECCA WOMBLE. Director of Business and R&D Communications, Bristol-Myers Squibb Co., New York; Bristol-Myers Squibb's mission is to extend and enhance human life by providing the highest-quality pharmaceuticals and healthcare products. For more information, visit bms.com.

BUILDING STRONG PHARMA-ADVOCACY PARTNERSHIPS



MARK KRUEGER
MARK KRUEGER & ASSOCIATES INC.

Initially, patient groups may view pharma interests as self-serving. But relationships will build gradually into strong alliances as goals and interests are shared, commitments are demonstrated, and an open and honest dialogue addressing strengths, as well as weaknesses, takes place.

WHEN APPROACHING PARTNERSHIP

possibilities with a patient group, pharma companies need to emphasize ally development. A pharma company shouldn't expect a patient group to think like it does; pharma companies need to learn to respect the scientific and medical knowledge of the patient groups and expect to be challenged on controversial issues. Companies need to make a good first impression with honest dialogue and let the patient groups know there is a long-term commitment.

Developing relationships should be the responsibility of a designated person whose office is under the corporate operational structure and budget. Ideally, he or she should report to a senior executive. The office should be separate from product marketing and other operations yet have the freedom to draw dollars, manpower, etc. from those functional areas.

Realistically, this person is an interpreter for both the company and the patient group. While developing this position and responsibility is an

emerging practice by many pharma companies, too many still place the effort as a contributions line item. The existence of such a designated function with its own decision-making power and budgets rightfully implies a genuine long-term commitment to patient groups.

While patient groups welcome cash contributions, they often also profit from technical or professional advice. Their interest might be in obtaining information about a company's experimental compounds and marketed products to share with their constituencies. They may gain a great deal from consultation with a company's IT, compensation, or strategic planning staff. In return, patient groups can help with marketing goals, such as publicizing information about new drugs in their newsletters and on their Websites, as well as assisting with clinical-trial recruitment.

Once the partnership is established, make the commitment in dollars, time, and duration, and expect accountability. Have a clear plan and budget from the patient group with joint accountability built into an agreement. An effective strategy is to start small and build the program as it goes. Choose one project to partner on first, and then fine-tune the logistics and relationship.

Often, developing effective programs requires the expertise of outside healthcare public-relations and marketing professionals. Assistance involves understanding regulatory and policy issues of patient groups in cardiology, diabetes, HIV/AIDS, immunology, infectious diseases, mental health, oncology, respiratory, etc. This expertise can be invaluable in accelerating regulatory approval and for increasing public awareness and appropriate use of products.

DOs AND DON'Ts OF PATIENT GROUP RELATIONS

DO

- DO** treat patient advocacy groups as customers, not vendors
- DO** consider having patient advocacy groups develop education materials; they can say things a company can't
- DO** ask them to review patient-education materials
- DO** ask them to help with disease-awareness programs
- DO** understand that their leadership and volunteers have varying levels of sophistication and influence
- DO** provide patient advocacy groups with timely, accurate, and honest information
- DO** give patient groups a voice in decisions that affect goals
- DO** negotiate
- DO** collaborate

DON'T

- DON'T** think only in terms of product promotion; patient advocacy groups can do much more; it's all about the relationship
- DON'T** assume patients don't understand medical language; they are often very sophisticated consumers
- DON'T** assume that just because advocacy groups don't think in terms of ROI, they can't offer value; they are the patient experts and their perspective is very valuable
- DON'T** sell a product to advocacy groups; they don't care about a company's sales or profits, they care about meeting patient needs
- DON'T** let an agency establish the relationship on the company's behalf; advocacy groups don't like giving agencies their expertise; they'd rather work directly with the company
- DON'T** start too big; start small and let the relationship evolve
- DON'T** make decisions in a vacuum; patient advocacy groups are well connected and rely on long-term funding to survive; they value stability and long-term relationships

THE FIVE Ds OF WORKING WITH PATIENT GROUPS

- 1 DUE DILIGENCE** — Do the homework
- 2 DEDICATION** — Have direct contact with company employees
- 3 DIPLOMACY** — Expect to address confrontations over issues, rival groups, and unrealistic financial requests
- 4 DISCLOSURE** — Treat patient groups as scientific partners, give them the facts, address weaknesses as well as strengths
- 5 DOLLARS** — Include the price for admission and for staying there

Source: Diane S. Blum, MSW, Executive Director of CancerCare Inc., New York. For more information, visit cancercares.org. Mark Krueger, MPH, President of Mark Krueger & Associates Inc., New York. For more information, visit kruegerandassociates.com.

DR. SCOTT BERNIS

MARCH OF DIMES



Nonprofit corporate relationships can be more than a pharmaceutical company writing a check. Our relationship with MedImmune is an example of this; **our initial one-year partnership has blossomed into a multiyear relationship.**

committee, where we might focus more on town, county, or state efforts, versus other national efforts. Our corporate group focuses on meeting resource needs and what we believe are altruistic efforts, such as our work for caregivers. In the product arena or the brand area, we look to partner with nonprofit associations or advocacy groups. Newer to Eisai, for example, is the epilepsy arena (Zonegran), and so we work with the Epilepsy Foundation to award grants.

FRANKS. All of us connected with the pharmaceutical industry have heard from patient advocacy organizations and other healthcare stakeholders about the fact that the high cost of medicine is a barrier for too many patients. In an effort to make sure that medicines are made available to those who need them but can't afford them, the HealthCare Institute of New Jersey, which includes 20 worldwide pharmaceutical and medical technology companies based in New Jersey, developed Rx4NJ. At every stage of the program, we have worked hand-in-hand with patient advocacy organizations and other stakeholders to ensure that the program is organized and implemented in a way that is as user-friendly as possible.

LACEY. We look to develop partnerships with organizations that are appropriately related with our strategic corporate priorities. One of our areas of focus includes patient groups in disease areas aligned with our therapeutic areas of focus. For example, pediatric healthcare is very important to us. Our lead product, Synagis, is for high-risk or premature infants, and we have done a lot of work in the pediatric area. We have a multiyear partnership program with the March of Dimes at the national level. We work with the organization to provide information, resources, and comfort to families with premature babies. This is done through a program that the March of Dimes calls NICU (neonatal intensive care unit) Family Support.

WOMBLE. Many advocacy groups are small organizations that started at the kitchen table because a loved one may have died of, or is suffering, from a disease. These groups don't always necessarily have the expertise in-house

to develop the programs, so we bring to the table knowledge and experience in terms of how to get organized. We can provide support and guidance by tapping into our company resources. For example, we worked with a children's advocacy organization that needed help with the design of its Website, so we reached into our organization and provided someone who could offer guidance.

POLLINI. We particularly look to bring value and provide support to the community through our outreach activities. For example, we support a program run by the Whitney Museum of American Art in Manhattan that brings in elderly people from assisted living communities. They are given personalized tours to expose those seniors who may have a more limited environment to art. We also have programs and support that come out of the marketing area that address the needs of patients who use our products. For example, we have a product for acid reflux, Aciphex, and there was effort applied last year to an education program called Gut and Gurgle U. Our efforts aim to provide education and resources to patients in need.

Advocacy Needs

Advocacy groups are a conduit for important information to patients regarding their disease or condition. By understanding the needs of these groups and their patient communities, pharma companies can be partners and provide the appropriate support.

BERNIS. Relationships with pharmaceutical companies can be about more than financial support, but certainly to implement our initiatives we have to raise money. We can't achieve our mission without money, and to attract sponsors and donors, we have to have a very strong mission.

MINTZ. Because NFCA is an organization that supports family caregivers across the life span of patients and across all diagnoses, we look to partner with companies that understand the vital role that family caregivers play

**REBECCA WOMBLE**

BRISTOL-MYERS SQUIBB

We have long-term relationships with advocacy organizations. **We don't work our advocacy efforts around product launches and marketing programs.**

in healthcare and in providing medications and addressing patient safety issues. These companies need to recognize that family caregivers significantly influence their loved ones' actions, for example, going to the doctor, willingness to try a new medication, and following prescribed regimens. If a company doesn't get that, it is hard to build a relationship.

COX. Before industry players approach advocacy organizations, they should have a clear understanding of their own business mission, product marketing objectives, and their management's willingness to commit a long-term investment of time and resources. Then they are ready to have an in-depth dialogue with the decision makers of the advocacy organization to find common ground. The advocacy group's CEO or executive director, as well as the key leadership of its board of directors, all must feel comfortable partnering with the pharma company for it to work. When the key leaders are together, those from the pharma company need to be able to say, "Here is what we bring to the table, and here are our ideas about how we might work with your organization. What are your thoughts about this, and what would be of value to your organization and constituents?" Then those from the pharma company should listen, ask questions to gain an understanding, and allow the organization to react and present its agenda. Then they can all work together to define the common ground for forming a trusted partnership.



BOB FRANKS

HEALTHCARE INSTITUTE OF NEW JERSEY

The largest patient-assistance programs in the world are those that are operated or supported by the pharmaceutical companies that develop the various drugs that these patients need.



JAMIE LACEY

MedImmune

In just about every disease area there are patients who need clear, valid information and support systems. When we work with advocacy groups, we hope to broaden that support system and work together to help provide accurate information about treatment options.

TRINGALE. The ideal relationship works when there is true equality among all parties. One-sided, funder-driven relationships are transparent — not just to the partners, but to consumers and others, as well. And partnerships controlled and inhibited by stuck-in-the-mud nonprofit organizations never reach their full potential or even get off the ground. True equality is achieved when each party recognizes and protects the unique value that each partner brings to the table; pharma brings resources — funding, products, and marketplace expertise — and nonprofits bring public trust — independent credibility, critical consumer insights, and an unbiased voice for the project.

MINTZ. In an ideal world, we look for relationships similar to the one we have with Eisai, which is corporate focused as opposed to tied to a single brand. On the other hand, we have had wonderful brand-related relationships, such as with the Novartis Exelon team. Ideally, though, because we are not a disease-specific organization and because caregiving affects every chronic degenerative illness there is, we prefer to engage in broader cross-brand relationships. We think companies can benefit the most that way too, but they need to understand how hard it is internally to make that happen.

BERNS. Our best partnerships are with organizations that recognize the leveraging opportunity, have a strategic interest in our mission, and understand that the March of Dimes never endorses a product. There is never a misunderstanding about that; we discuss that right up front, and that helps to foster a strong relationship.

BLUM. There have been occasions when I have worked with a product manager who wants to know how his or her company can quantify the impact of the advocacy program

the company is supporting and quantify whether more prescriptions will be written. That is not what our mission is, and that is not how we work with pharma companies.

COX. Pharmaceutical company executives have a difficult time moving away from the ROI mindset integral to managing a business. Expectations in terms of ROI can be better defined by evaluating the “soft ROI” that comes from partnering with third-party organizations. These efforts and returns are measurable in terms of share of voice and creating a more positive reputation for a company and the industry at a time when it is constantly under fire.

SULLIVAN. Collaborating with patient organizations or any group outside the company’s direct business channels is not easily measured on a strict ROI basis. But if a company has a leading therapy in an area, then it wants the same things that patient organizations want. Both the company and the organization want patients to know they don’t have to endure a particular condition, side effect, or disease. There doesn’t have to be a brand name on the campaign; it’s about helping patients understand that there are therapies available, and that they should ask their doctor what the best medication is for them.

TRINGALE. The most important factor the Asthma and Allergy Foundation of America looks for when selecting a corporate partner is a like-minded objective. Companies that agree to measure objectives in terms of increased public awareness, consumer education, or disease prevention — in addition to sales, reach, and media impressions — are priority partners for us. This should also be a critical factor for pharma companies when evaluating relationships with nonprofit asso-

ciations. If a nonprofit organization isn’t willing to recognize the importance of helping a partner’s bottom line — which, in the case of pharma, means more medicines in the hands of patients who need them — then it’s really not a true partnership. Finding common ground on a few like-minded objectives at the onset is important to determine if the fit is right for both parties.

Best Practices

Industry and advocacy executives with many successful partnerships to their credit cite communication, an understanding of the patient community’s needs, and leading by example as best practices when forming partnerships.

MINTZ. Companies need to understand that the funds that they are providing have to not just cover program costs, but support the infrastructure of the nonprofit organization to help it grow so that it can be an even better partner in the future and reach larger patient audiences. From our perspective, that is important.

WOMBLE. The first thing to do when working with an advocacy group is to address the issues that are facing the community at a given time. Bringing the right parties to the table is important.

SULLIVAN. Looking for common ground is a best practice when working with an advocacy group, and it usually isn’t that difficult to find as long as the companies take a broader view.

DEBUONO. We have found that it is important that we “walk the talk.” We evaluate the patient-education materials that we create as a company and make sure that the information is readable, understandable, and actionable by

GOOD WILL FOR GOOD RETURNS

“A poorly executed cause-related marketing program can backfire, damaging the reputation of all parties, harming the company’s bottom line, and distracting the patient advocacy group from its mission. It is important for communications professionals from all groups to stay ahead of the curve and create or adopt best practices to ensure successful programs in the future,” says Mike Tringale, M.S.M., Director of Marketing and Communications for the Asthma and Allergy Foundation of America.

Since its advent in the early 1980s, cause-related marketing has evolved and it is no longer a simple charity handout that is sufficient to support or add value to a commercial brand. Today, it’s called many things — cause marketing, societal marketing, charity cobranding — and it’s all about linking commercial brands to nonprofit brands for goodwill and good returns. Cause-related marketing has become a common practice in every industry, from financial services to healthcare, and it is enthusiastically embraced by nonprofit associations and foundations.

In the past 20 years, cause-related marketing isn’t the only thing that has evolved. The pharma industry has changed along with the awareness, perceptions, and opinions of consumers, key public opinion leaders, policymakers, and others. If not quite a full-blown crisis (although some have called it such), the current lack of trust among these stakeholders does threaten the future landscape for the industry.

Yet, the public’s hysteria about “big pharma” may be fueled by a lack of information as much as misinformation. The pharma industry has been a leader in cause-related programs. The industry spends almost \$1 billion a year on restricted and unrestricted educational grants, sponsorships, disease-awareness campaigns, and more. In fact, the very nature of pharmaceuticals is to alleviate suffering and cure disease. But today, pharma’s good intentions alone do not win consumer goodwill or improve the public’s trust. To accomplish that, there must be more strategic and sustained cause-related action — at both the corporate and brand levels. It’s not a crisis; it’s an opportunity.

EVERYTHING OLD IS NEW AGAIN

Although programs, methods, and

implementation models vary, a well-implemented cause-related partnership can increase sales, generate visibility, strengthen customer loyalty, enhance the brand, bring positive media coverage, and more. Cause-related strategies are appealing to pharma companies and nonprofit patient advocacy groups alike for the simple reason that each partner brings a unique critical value to the team: pharmaceutical companies bring resources (products that meet consumer needs and funding for projects); and patient advocacy groups bring public trust (the independent voice of patients and an objective perspective on the issues).

Cause-related marketing and PR began as the simple exchange of money from a corporation to a charity with permission to promote that donation to consumers. It has evolved into a more complex partnership between corporations and the charities requiring a greater level of communication and cooperation between them. This was a natural shift as more companies began using cause-related strategies in more creative ways and charities began to leverage their value and demand more financial support of their own brands. Today, the stakes are higher than ever, but so are the rewards.

The concept of linking corporations or brands with nonprofits remains the same, but the methods have evolved. New challenges require another shift in the existing cause-related model. For modern cause-related efforts to be successful, a third partner — the PR agency — needs to be included in the mix with the pharma and the patient advocacy group to bring the final critical value to the team: communications skills, tactics, and creativity to help the corporation and patient advocacy group break through the overwhelming clutter of consumer messages.

Together, all three team members are

equally involved in strategy, planning, message and material development, timing, implementation, management, and measurement of the cause-related project. Each member’s unique value influences its role on the team, but decisions are mutual and agreeable.

A WIN-WIN-WIN-WIN MODEL

Consumers of, and partners in, cause-related programs can easily distinguish between true long-term corporate nonprofit partnerships and one-sided short-term relationships. Successful models require balance between all entities. A true third-party partnership is centered around consumer and patient needs, and it creates a total value that is greater than the sum of its parts. As a result, pharma’s brand messages get woven seamlessly into nonprofit public-education messages, resulting in increased consumer attention, goodwill, and sales. Nonprofits get needed funding for educational outreach and awareness programs and support for direct patient services. PR agencies get happy clients and award-winning campaigns. Most importantly, consumers and patients get exposure to the information and resources they want and need. It’s a win-win-win-win.

GETTING IT RIGHT

The success of partnerships depends on equality among all partners. Third-party partnerships work because every side of the “value pyramid” is covered, and programs and messages remain centered around consumer wants and needs. These partnerships require an honest assessment of the strengths and weaknesses of all partners, and success requires mutual respect among the entire team.

Source: Mike Tringale, M.S.M., Director of Marketing and Communications for the Asthma and Allergy Foundation of America (AAFA). For more information, visit aafa.org.

ROGER SULLIVAN

C-CHANGE



I can't think of a disease that can be solved by just the pharmaceutical industry, the government, or the volunteer sector. No one entity has the solution, and we won't get there separately; we all have to work together.

patients and consumers who look at the materials and take our medications. We have a goal that all of the patient-education materials that we create are written at a 6th grade reading level. All of our patient-education materials are reviewed by a committee of experts who are trained to assess materials for health literacy. If the materials don't pass that review, we send them back to be revised to meet all of the principles of Clear Health Communications, which is a Pfizer initiative.

COX. Many companies do not have a culture or mechanism for internally sharing information throughout the company about what they are doing with third-party groups. This is not a good practice. Often, there is overlap in a company's third-party group relationships and financial contributions given to these organizations across various functional areas and divisions. Sometimes, these relationships are even considered proprietary. This information shouldn't be a secret kept within a functional area. It should be shared and available to others in the company on a global basis. It is important for people within a company to know that a colleague in another department also is working with a particular advocacy group. It is important for employees to know about and support these relationships and programs embraced by their company. Creating and maintaining a central database that contains this information would certainly be a best practice.

SULLIVAN. Companies don't have to pass the tin cup for a patient organization, and the organization, in turn, isn't obliged to shout the brand name of the company's medication from the rooftops. Credibility disappears if this happens. A good partnership is a simple matter of understanding who is out there and which groups are after the same goal.

COX. Third-party groups have to be able to maintain their independence and shouldn't be seen as, or feel they are being used as, a front for a given company or the industry.

MINTZ. It is important that the pharmaceutical companies we work with understand that there is an ethical and moral line that we won't cross. Most companies do understand this, but sometimes PR agencies have a more difficult time recognizing where to stop.

A Dedicated Position

Advocacy efforts often fall under the domain of the communications and marketing teams, but some pharmaceutical companies are beginning to assign a dedicated advocacy role to facilitate communications with advocacy groups.

COX. The pharmaceutical companies that "get it," and are more sophisticated and experienced in appropriate advocacy relations, have a dedicated person or team for this function. Public relations and communications staff also serve this function well when they understand the need to integrate a communications plan with advocacy strategies and also are aware of, and sensitive to, the mission, mindset, politics, limitations, and internal procedural requirements of the third-party organizations. Companies that are less sophisticated don't devote the resources necessary to advocacy and expect their marketing teams to know what to do. This is where I think they make a big mistake. Unless the marketing director or product manager understands how to define, build, and navigate successful relationships with key third-party advocacy organizations, the marketing plan can be headed for trouble.

DEBUONO. We have an Alliance Development Group within Pfizer that works with national health organizations that are part of the National Health Council to help organizations achieve their goals, which are in line with our goals. We have a group that works in Washington, D.C., and at the state levels with organizations such as the American Heart Association, the American Cancer Society, and a variety of different nonprofit health organizations to help support the achievement of their goals, to build awareness about



CATHY POLLINI

EISAI

Advocacy groups have always had a need for resources, and these groups tend to rely on grants and partnerships for their initiatives and programs, which is where we come in and help.

conditions, to provide access to health coverage, and to provide information to those organizations.

TRINGALE. Some companies have a dedicated advocacy relations director; others manage partnerships through brand teams. Still other companies prefer partnerships to be supervised by PR and communications staff, while others handle relationships through their advocacy, policy, or government relations professionals. And, believe it or not, some pharma companies do all of the above, depending on the therapeutic area or the complexity, nature, and objectives of the partnership. All of these models work successfully, but companies need to know whether the nonprofit partner is flexible enough to handle any or all of these different models.

MINTZ. More and more companies are developing advocacy positions at the corporate level, and this is a good thing because it provides continuity. Brand teams change so often. In one relationship we have, there have been four or five brand managers. Building relationships is hard when there is a lot of turnover.

LACEY. At MedImmune, advocacy outreach and relationships are handled cross-functionally with communications serving as part of each team working with an advocacy organization. Other departments are brought in and may lead the relations, depending on the type of advocacy organization we are working with, as well as whether the relationship is tied more closely to the corporation as a whole, a disease area in which the company has a long-term history, or



DIANE BLUM

CANCERCARE

If a company's actions are benefiting patients, eventually these initiatives will benefit the company. It may not be a direct cause and effect, but there is a bigger picture that is the societal responsibility of pharma companies.



SUZANNE MINTZ

THE NATIONAL FAMILY CAREGIVERS ASSOCIATION

We like working with pharma companies because they understand the significant role of family caregivers in healthcare. **Pharmaceutical companies have such a broad reach that working with them gives us a wider platform for getting our messages out.**

a new therapeutic area. In this way, we can provide support to advocacy organizations at various stages of the development cycle in a consistent and strategic fashion.

BLUM. Partnerships often work more effectively when there is someone in the company whose job it is to work with advocacy groups. This person then understands the concept of finding common ground and can evaluate what the two groups share and how the program benefits the company in terms of being a patient-health-focused organization.

COX. If marketing approaches an advocacy organization for the first time three to six months before a product launch and just expects the group to "do something" in support of a product campaign, that just won't work. All too often, that is how the marketing team approaches initial outreach to patient advocacy groups, and this is when problems occur.

BERNS. The best relationships are based on good communications and have good point people. Our partnership with MedImmune is based on this model. Assigning a specific person to work on the relationship moves the partnership beyond just financial support and allows a company to discover and take advantage of other opportunities.

WOMBLE. Each of the therapeutic areas within Bristol-Myers Squibb has an advocacy relations person. The advocacy role is not a part of the marketing division; it resides separately and in most cases does not focus on any brand-specific programs.

Public Perception and Skepticism

Although the industry's current negative perception by the public is not a news flash, the impact of this perception on the industry's progress in the fight against diseases is an area of growing con-

cern. Experts believe pharma companies need to move beyond words to action to begin to overcome negative perceptions.

SULLIVAN. The public's current perception of the pharmaceutical industry is simply an enormous obstacle to the medical progress that is needed. Because people have lost their trust in the industry, words and rebuttals are no longer an adequate defense. Pharmaceutical companies need to start being associated with groups or circumstances the public trusts. The typical approach of big companies is to have their communications agencies on retainer, and these groups create and plan the company's communications. Often the last chapter of the plan involves signing up a patient organization that will give sanction to what the company is doing; that is not a genuine collaboration.

COX. The industry's image could be greatly improved if more stories about its good works were being told. There are many outstanding examples of model advocacy programs and partnerships in which pharmaceutical companies go way beyond just meeting short-term marketing needs to serve the higher good. These examples must be shared. Additionally, more companies should use these as models to help shape better advocacy relationships for the long term. (For more information, see related box following the Forum.)

DEBUONO. More than ever, it is important that all companies recognize that they are not going to be able to get as much done individually as we can collectively. In an increasingly complicated healthcare arena, it is critical that we, as an industry, begin to draw attention to the important role that education and awareness building can play in motivating people to take care of themselves. One entity cannot do that alone. Many advo-

cacy organizations recognize that they need partners, whether those are other nonprofits or corporate partners, and I am seeing a willingness on the part of many nonprofits and advocacy organizations to work with corporations to help advance their goals.

FRANKS. Programs such as Rx4NJ are essential for the industry to improve its reputation. All pharmaceutical companies exist to develop and market medicines that address human health issues and in particular to make sure that patients don't experience barriers when they seek to access prescription medicines. Rx4NJ allows the pharmaceutical industry to stand behind its commitment to make medicines available to those who are in need and are unable to afford these medicines.

LACEY. We are living in the information age, where there is a bombardment of communications from the Internet, television, news sources, word of mouth, and so on. There is a need to work together to ensure that accurate information reaches patients and their support systems so that they can make good choices along with their physicians about healthcare treatment options. Advocacy groups often deal with patients directly and can give feedback to the industry so that we can understand what patients are most concerned about and how we can work to help address those needs.

COX. Some companies have done the industry a great disservice through the years by just writing checks and thinking this is an effective relationship. It isn't always about the big checks; small contributions with a lot of in-kind support can make all the difference. ♦

PharmaVOICE welcomes comments about this article. E-mail us at feedback@pharmavoices.com.

COLLABORATIONS AT WORK

There are many examples of successful partnerships between drug manufacturers and patient advocacy groups. The executives interviewed for this Forum have provided the following experiences as examples of particularly successful efforts.

BRISTOL-MYERS SQUIBB AND THE CANCER COMMUNITY

WOMBLE. About five years ago when we began working very closely with CancerCare, one of the oldest patient organizations in the country, we sat down to address what its concerns were as a patient-care organization, and at that time lung cancer was on the top of the list. CancerCare believed this was a very underserved and underrecognized population in terms of providing communications about what patients needed to do, not only in terms of reaching that patient population and providing social services and counseling, but also guidance in terms of treatment.

BLUM. We worked collaboratively with the Oncology Nursing Society (ONS) and the Chest Foundation on a program that was funded by Bristol-Myers Squibb for six years, focusing on lung cancer awareness. We entered this partnership to bring attention to how common a disease lung cancer is. The first goal of this program was to bring attention to the incidence and mortality of lung cancer. The second focus of the program was to encourage people with lung cancer to seek out options and take a role in their care. Traditionally, people with lung cancer are often told there is nothing that can be done for them, when in fact there are advances in lung cancer treatments, and there are more treatment options and much better supportive care available now. The third goal of the campaign was to create educational support resources for people with lung cancer, because people with lung cancer are often stigmatized and blamed for their disease. This was not a branded program in any way; no products were ever mentioned, but Bristol-Myers Squibb generously supported this collaboration with the ONS, the Chest Foundation, and CancerCare. We reached out to the media, consumers,

patients, and to medical professionals. Bristol-Myers Squibb's participation in the program was primarily through funding, and several company representatives also attended our meetings. The goal of Bristol-Myers Squibb's involvement in the program was to try to enhance the quality of life for people with lung cancer, which has always been a primary corporate objective. The company was one of the first to reach out to patient groups, recognizing that what benefits patients will also benefit the company.

WOMBLE. During the last three years, our relationship with Lance Armstrong has evolved into a major initiative called Tour of Hope, and this is very broad in terms of its reach into the cancer community. We have had participation on the part of the National Cancer Institute, and we have eight other cancer-focused groups as partners, whose missions are to raise awareness of cancer-related clinical trials. The low rate of participation is recognized as a major issue within the cancer community. Currently, fewer than 5% of adult patients participate in cancer clinical trials. It is a very broad campaign and is very specifically focused on getting the word out as to why it is important to participate in cancer clinical trials.

SULLIVAN. The close collaboration between Bristol-Myers Squibb and Lance Armstrong is a wonderful story, since Lance is arguably the most famous cancer survivor. The focus on increasing awareness of, and understanding of, clinical trials doesn't just impact or benefit Bristol-Myers Squibb; it affects everyone. These are the kinds of programs that companies need to do on a much more consistent basis. These actions are the trust-building measures the industry needs now.

EISAI AND CAREGIVERS

POLLINI. A very early program for Eisai's U.S. operations, which were established in 1995, was Caring to Help Others. We initiated this as an extension of our corporate approach of a "global human health care mission of satisfying

unmet medical needs and increasing benefits to patients and their families." Frankly, the latter part of that mission is to go above and beyond the introduction of new or valuable treatments, and Caring to Help Others was born out of this mission. Because we were involved with our product, Aricept for Alzheimer's disease, we observed that caregivers have tremendous needs. The need to train caregivers and volunteers was one of the issues that arose from the research we conducted with seven nonprofit groups, including AARP, The National Council on the Aging, as well as groups such as the National Family Caregivers Association and the National Alliance for Caregiving, which are the two partners that we continue to work with.

MINTZ. What has been so remarkable about the National Family Caregivers Association's relationship with Eisai is senior management's involvement. When we started our first project with Eisai — Caring to Help Others — Bill Sheldon, who was then CEO, would actually come to the meetings and get into the weeds with us. For a CEO to make that type of a commitment to a social project blew me away. Because of the senior-level involvement, we really believed that Eisai practices its mission. Our current project, a public-education campaign called "Family Caregiving — It's Not All Up To You," has a high level of senior corporate involvement, and there is a strong sense that everyone in the company knows about the project.

COX. I was project manager and editor for the development of the Caring To Help Others volunteer training program. This was a corporate program for Eisai at a time when the company was not well known and was close to receiving FDA approval for Aricept. Eisai wanted to identify and sponsor a project that would make a difference and that would establish the company as a leader in recognizing and supporting the needs of caregivers of chronically ill older adults, including, but not limited to, those with

Alzheimer's disease. The company conducted focus groups with various stakeholders — patients, caregivers, nurses, and physicians — to get a greater understanding of what the challenges are for these caregivers. We also reached out to the key national advocacy organizations focused on aging, healthcare, caregiving, and volunteerism. Eisai asked these groups what important needs were not being addressed. We heard repeatedly that there was a great need for a comprehensive, user-friendly training program to enable community organizations to train volunteers to effectively support primary caregivers of chronically ill older adults. This need was embraced by Eisai at the highest levels. Representatives from the advocacy groups were recruited as Eisai's advisory council, and, together, we worked on this project for more than four years.

POLLINI. When we began work on Caring to Help Others, we brought together different groups and asked what was needed. We wanted to go above and beyond the treatment approach. The group found that training manuals did not exist for caregivers. Caring to Help Others was designed as a training manual or a "train-the-trainers" program. We worked with organizations throughout the country and provided the manual to help them train volunteers so they might be better prepared to assist patients, particularly in a volunteer role. Our latest initiative is the support of the Family Caregiving program (familycaregiving101.org), which is directed to family caregivers and builds upon the foundation of Caring to Help Others.

COX. Caring To Help Others is a modular train-the-trainer program now being used by more than 12,000 organizations across the country to prepare volunteers to assist caregivers of seriously ill older adults. It was published in 2000. The manual is free of charge to community organizations and is now featured on the caringtohelpothers.com Website, where sections can be downloaded. As a result of this program, Eisai and its nine advisory council partners have received the

American Society on Aging's Brookdale Award for best practices in training related to the needs of older adults. This was an enormous commitment by a small company. The 500-plus-page manual went through two or three iterations and was field tested. This program helped to put Eisai on the map. The company established excellent relationships with important advocacy organizations tied to its corporate mission. Eisai's ongoing relationships with some of these groups have spurred new caregiver support initiatives.

MINTZ. Eisai wants to be a partner with us, as opposed to just funding programs. At the same time, the company recognizes where we draw the line so it doesn't impose its goals. The project that we are working on now began a few years ago when the NFCA, and the National Alliance for Caregiving received a grant from a foundation to do research on why family caregivers don't self-identify and what we can do to break through that barrier. The goal was to use the research to craft a public-education campaign. We knew what we wanted to do, and we went looking for support. I approached Eisai to see if the company wanted to put some money toward this program. The company offered us 25% of the estimated cost of the entire program, which was phenomenal. This gave us the money to get started as we continued to seek the rest of the needed funding. When we were having difficulty locating funding we went back to Eisai, not to ask for additional funds, but rather their assistance in helping us find it from others. To our surprise, senior management came back and asked us to demonstrate the benefit to Eisai becoming the sole sponsor of the project. We put together a package, and Eisai accepted it. Thus Eisai became more than a company that provided funding; it became a collaborator with us. For instance, it was Eisai that came up with the idea of having its salesforce take the campaign messages directly into doctors' offices. Since they had already been approved, getting legal's buy-in hasn't been an issue. The actual outreach effort hasn't been implemented yet,

but will be shortly. This partnership has been really wonderful.

MEDIMMUNE AND PREMATUREITY

BERNS. A case study of a strong relationship between a nonprofit health organization and a pharmaceutical company is our relationship with MedImmune. In 2003, the marketing director from MedImmune who was responsible for the drug Synagis, which is indicated for the prevention of serious lower respiratory tract disease caused by respiratory syncytial virus (RSV) in certain pediatric patients at high risk of RSV disease, called to explore the message about RSV and whether we had that in our print and online materials. We discussed the ways in which we might be able to work together, and the educational message about RSV was a key overlap with our mission and our prematurity campaign. MedImmune came on board, and, through its one-year sponsorship, we launched the Website for our NICU (Neonatal Intensive Care Unit) Family Support program. In addition to being able to create a Website filled with information for families experiencing the NICU, we also were able to include information in line with the American Academy of Pediatrics guidelines about RSV infection. That was the beginning of our relationship, which has blossomed from there and still continues to grow.

LACEY. We try to take our partnerships beyond just a specific project. We now have a multiyear commitment to the NICU Family Support program with the March of Dimes, and we are in frequent communication with the organization — always considering other ways we can help. For the Prematurity Awareness Month that they hold in November, we partnered with the March of Dimes on some of the ads to help them have more breadth and depth in their reach. And when they mentioned to ►

COLLABORATIONS AT WORK (continued)

us that their leaders were having a Prematurity Awareness Day event at Freedom Plaza in Washington, D.C., we saw the opportunity to not only be a sponsor but have our local employees participate as well. We had about 50 employees who were there to help cheer the speakers and be part of the rally. And one of our physicians, who is a pediatrician and a pediatric pulmonologist, spoke to the crowd as well. So it was a nice way to share the event with the March of Dimes and go beyond our initial commitment of supporting the NICU Family Support program.

BERNS. With MedImmune, there is an embodiment of the partnership from the employees as well. The company sent a busload of its employees to a prematurity awareness event that we held in Washington, D.C. Light blue MedImmune sweatshirts could be seen all over the place. It is great to have this type of relationship where the employees feel very engaged with a mission of a nonprofit. This partnership is more than a corporation writing a check. This relationship with MedImmune is an example of how an initial one-year relationship has blossomed into a multiyear relationship.

PFIZER AND HEALTH LITERACY

COX. Pfizer is well known for its leadership in health literacy. The company has done a great deal of work in this area. Pfizer has a program that provides grants to community organizations that apply. These groups have to demonstrate measurable results as they implement their funded programs and mobilize their communities around improving health literacy, often working with the local healthcare systems or at the church or community group level.

DEBUONO. We have been committed to Clear Health Communication activities for seven years. Our goal was to first identify more about the epidemiology of health literacy and then move toward finding

solutions. We realized that we can't both identify and then implement solutions without partners. To form Clear Health Communication, we partnered with groups such as America's Health Insurance Plans, The National Council on the Aging, and the National Health Council, along with a variety of literacy organizations. The group became a 501 c3 nonprofit organization last July and is now working very closely with the Center for Medicaid and Medicare to make a difference in developing educational materials and messages for seniors around Medicare programs. We are very fortunate to be working in such a positive alliance with advocacy organizations that are very interested in some of the same issues as Pfizer.

COX. Often, companies develop materials that are visually impactful but are written at a higher level than many people can understand. Then, important messages about products and diseases fail to reach much of the population. Being aware of this problem and working to change it is an enormous contribution to improving health awareness and patient education in this country. Pfizer has gone way beyond the typical approach to patient education to address a very serious national need. This is advocacy at its best.

DEBUONO. Through the Clear Health Communication initiative, we have helped a number of different advocacy organizations think about the way in which they communicate regarding a particular issue. We have heard from heart, lung, and legacy organizations that the Clear Health Communication initiative has helped them think about the way they produce and develop education materials because they want to build awareness and education for their constituencies. We also have a whole range of things that we can offer to these organizations to help support their infrastructure, their needs, and their goals. It is important for pharma companies, and certainly a company such as Pfizer, to have long-term sustainable relationships beyond their products.

THE PHARMACEUTICAL INDUSTRY AND PRESCRIPTION ACCESS

FRANKS. The pharmaceutical companies involved in Rx4NJ have organized the program and have fully underwritten all costs related to it, which is an expenditure of almost \$5 million to promote awareness of the availability of the Rx4NJ program. The costs of the program are more than just the support of the promotional activities around Rx4NJ, but the extraordinary costs of all the medicines that are provided to patients through the mechanism of Rx4NJ. And the program is paying off; since it was launched in January, more than 70,000 New Jersey residents have contacted either the Website or the toll-free number; and, of that group, 74% have been matched to one or more patient-assistance program.

POLLINI. The industry is looking for creative ways to lend support and reach more people, and Rx4NJ is a good example of that. The HealthCare Institute of New Jersey (HINJ) and its membership lobbied around the fact that New Jersey is the home of the pharmaceutical industry, so it was important to show people in our home state how we can help. HINJ took the call to action and the job of working with PhRMA, and the program has been a success.

FRANKS. We met one-on-one with 30 patient organizations in New Jersey, laid out our vision for Rx4NJ, and asked them to lend their name and their organizational support to the program. In what was one of the most remarkable exercises that we have ever engaged in, we had unanimous support from every one of the organizations that we visited. Each one, in turn, agreed to lend its name as an Rx4NJ partner and to help communicate the availability of this new resource to clients and various support networks.