

made on their behalf by physicians and regulatory agencies. PET/CT is proving on a daily basis to be the diagnostic tool that can make a real difference for many patients. We all know that molecular imaging and molecular medicine procedures, if administered appropriately, can change diagnosis and disease progression in cancer, but we are faced with the challenge of conveying this information to those it can most benefit.

At the same time we must find creative but evidence-based ways to convey the message to referring physicians that molecular imaging provides personalized and predictive advantages not facilitated by other approaches. Among these advantages are the ability to distinguish responders from nonresponders, predict and quantify responses to therapy, rapidly assess treatment effects, verify therapeutic targeting, identify appropriate patients for alternative therapies, delineate personalized target volumes for radiotherapy, and assist pharmaceutical companies in accelerating the bench-to-bedside development of beneficial agents.

Elias Zerhouni, MD, the director of the National Institutes of Health, believes in this message. He said, “If

we are going to take advantage of the current explosion of knowledge in genomics and proteomics on a clinical basis, then nuclear imaging with radiopharmaceuticals is the way to go. Although a lot of research has been undertaken in MRI, ultrasound, and even novel optical imaging approaches, none of these have the potential of nuclear imaging.” The surroundings are rather positive—many people out there believe in molecular imaging and molecular medicine. We just have to find the right methodologies to reach out.

In addressing the underutilization of molecular imaging in daily clinical practice we must focus on informing all interested individuals about both the clinical and the economic benefits, a task that will be easier if we are willing to invest in outcomes studies. Collaborative effort is clearly needed as we move together along this promising road to personalized medicine.

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Strategies in Education and Outreach

Reaching out to patient and professional audiences requires careful consideration of the message, the needs of the audience, and the method of delivery. When reaching out to patients, for example, organizations often aim to influence knowledge, attitudes, and behaviors. The relevance of the message, coupled with an understanding of the unique needs of individuals in varying subgroups to learn more about their disease and treatment options, leads to successful educational initiatives and outreach. Delivery vehicles such as in-person programs, print publications, Web-based communications, and innovations in education, such as teleconferences, are among current strategies, and each is enhanced by a clear perspective on what does and does not work with specific groups. In addition, evaluation efforts are critical in measuring the success of these efforts.

Implementing Effective Outreach

At the Lymphoma Research Foundation (LRF), we work, among numerous other missions, to translate increasingly complex medical information for a range of patients and their families and to devise innovative methods for getting important messages out to these and other groups. One advantage is that it is easier to educate patients than to change the health care system itself, so this is an area in which substantial inroads can be made by careful planning and targeting.

Several key constructs structure our work in patient education and outreach. The first of these is the need to

appreciate that the ability of any single adult or group of adults to take in information varies, depending on a number of factors. Moreover, this variance can occur within the same individual at different times. A person’s ability to process complex medical facts about non-Hodgkin’s lymphoma (NHL), for example, may be quite compromised immediately after his or her diagnosis with the disease, whereas at another time this information may be welcome. Second, patient outreach efforts must be disease-centric. Individuals are interested in their (or their family members’ or friends’) specific type of disease. Therefore, at LRF and other disease advocacy groups, the emphasis in recent years has been to make sure that useful information is available on each disease rather than on umbrella disease groupings. The third construct is the need for information on treatment. Simply providing background information on a disease does not go to the central question every patient has: what is the best option for my treatment? It is important to offer appropriate information on treatment options and clinical trials. Finally, patients and their families and friends need additional avenues of support. All of these constructs provide important criteria by which information can be more accurately and helpfully targeted at those who need it most—patients, survivors, and loved ones.

Three Strategies for Outreach

At LRF, we have identified 3 strategies for effective outreach to patients: refining the applicability of the message,

creating and nurturing strategic partnerships, and choosing appropriate vehicles for delivery of the message. It is important to emphasize that these are not standalone strategies; our work is most effective when all of these approaches work in tandem to yield the greatest impact.

In refining the applicability question, we always begin with the “so what” questions. We target our messages at patients with a disease or health concern and provide significant, disease-specific information from the many scientific studies that are published and presented each year. We translate these scientific data into news that has meaning for those with the disease or health concern. To refine the message, we look at that message from the patient’s perspective, asking “What does this mean to me? How does this affect my treatment?” These questions often help us to hone the message and clearly serve to enhance its utility and impact.

Many groups, agencies, organizations, and individuals have significant stakes in the ways in which public outreach efforts on specific diseases are characterized and implemented. Partnering among groups with similar interests and goals is a valuable way to leverage diverse strengths and talents. The synergy among professional societies, patient advocacy organizations, corporations, and media can have far-reaching effects. It is important to remember that such efforts must involve both “worker bees” and leaders—regardless of the quality of boardroom planning on an outreach effort, it will have to be implemented by dedicated individuals elsewhere in these organizations. Moreover, strategic partnerships should be carefully planned, with roles and expectations made clear at the beginning and spelled out in contracts and specifications.

The strategy of carefully choosing a vehicle for delivery is becoming more and more complex as the numbers of ways to reach patients increase. At LRF, through many such efforts, we have found that the most significant variable in delivering an effective message (as well as in recruiting individuals to participate in outreach) is the degree of expertise perceived by the patient—the extent to which the patient trusts that the information is expert-based and has value. Because of this, we have found that in teleconference and in-person outreach settings, it is important to have area-specific experts available to address topics of immediate interest. It is more helpful, for example, to have a recognized expert in NHL radioimmunotherapy (RIT) speak to a group considering this treatment than to have the director of a major cancer center whose own research interests lie elsewhere. The chosen expert must also have the ability to translate his or her own extensive knowledge of a complex topic into information patients can understand. A willingness to answer questions with frankness and sensitivity is also required. Other elements to consider in choosing methods of delivering messages are the appropriateness of messages for specific groups. Pediatric populations, for example, require different kinds of information targeted at parents and children.

A Multitiered Model

At LRF we also emphasize the importance of a multitiered approach that recognizes the different types of information that patients may need during the course of their disease. The first tier is that of basic information. These are the initial resources that can serve as a reference, explaining what the disease is and where to obtain additional information. The second tier provides disease- and treatment-specific information that is tailored to subsets of patients and their needs. The final and most complex tier involves regular updates on research and includes the ability to reach out and provide the most relevant and up-to-date information from basic and clinical investigations in a specific disease setting.

Basic information should be available to patients as soon as possible after diagnosis. At LRF we produced a 130-page booklet titled *Understanding NHL: A Guide for Patients*. We provide a variety of disease-specific information and resources on our Web site that address the second tier of the approach, and we also offer teleconferences, webcasts, and in-person programs.

Some of the most challenging and rewarding opportunities over the past few years have been in the third tier of translating the latest relevant data from professional meetings to the patient level. After a recent American Society of Hematology (ASH) meeting, LRF held a teleconference at which an expert translated scientific abstract results for an audience of 1,200 patients. This is an example, too, of the possibilities of strategic partnerships. We are focusing on building bridges with professional organizations like ASH and looking at what they can bring to patients. Many ASH scientist members, for example, are actively involved in clinical trials. We look cooperatively at practical ways to drive home to patients the importance of considering participation in a clinical trial as a treatment option.

We also look at developing information and reaching out to communities that might be underserved. Although LRF is lymphoma specific in its outlook, we realized in 2003 that we did not have much information available to patients with mantle cell lymphoma (MCL), nor was a great deal of such information available elsewhere on this relatively rare form of NHL. We worked to build up multiple layers of outreach on MCL, including comprehensive Web-based information featuring the latest in clinical trials and up-to-date research news delivered at a patient-friendly level. We also began in 2004 to offer in-person sessions on the disease. At the first round of these sessions only 5–10 people attended. By 2007 we were averaging 60 people at each session—a significant number given the relatively low incidence of the disease.

The experience with MCL outreach has taught a number of valuable lessons. First, reliable and consistent provision of information over time leads to the ability to reach more people. Such efforts often have a snowball effect, with the result that perseverance, together with testing and improving the model based on experience, leads to success. Second, we have been reminded of the power of old-fashioned marketing (placement of ads in local papers, sending out postcards, and

forming community partnerships) in reaching individuals who may not be regular Internet users. We also found it most helpful to engage physicians, nurses, and other health care workers in distributing the information. Particularly for a disease entity like MCL, where little collateral information is available, health care professionals value this support in communicating effectively with patients and families. Finally, our experience with MCL confirmed the importance of targeting outreach to specific groups of patients whose interest in the message is strong.

Another example of the multitiered approach can be found in LRF outreach efforts on RIT. LRF educates individuals about many types of treatment options. We are not advocating RIT over other methods but are invested in increasing awareness of it as 1 of numerous types of available treatments. Recognizing the underutilization of RIT and that a number of clinical trials had opened in the past year, we asked: How do we increase awareness of RIT as a treatment option for patients? We first aligned our relationships with relevant health care and nonprofit organizations to assist in getting information out to their patients. We decided to focus our efforts on the development of a portfolio of information that could link patients more closely to research and clinical trial opportunities, provide the latest updates, and work to dispel myths. Our initial work indicated that many patient questions about RIT centered on toxicity and subsequent treatment regimens, and we knew it would be important to create settings in which patients could interact directly with experts who could address these questions. Although we looked at a number of vehicles for outreach, we ultimately settled on teleconferences, which have proven an effective strategy for getting the message out. People who participate in these conferences only need a phone and can participate from any place at any time.

Suggestions for Delivering the Molecular Imaging Message

At LRF, strategic partnerships that agree on a highly targeted message and appropriate ways to deliver that

message have proven successful at reaching thousands of patient throughout the United States and beyond. The multitiered approach can be applied to the current challenge to the SNM and molecular imaging community to educate patients and influence physicians and regulatory agencies on the importance of this rapidly developing field. Among the recommendations to implement such an approach are:

- (1) At the basic information level, prepare fact sheets and booklets with explanatory information, background, and definitions. One strategy would be to assess basic information for patients already available through SNM and consider turning this into a primer that can increase their awareness of molecular imaging options from diagnosis through long-term care.
- (2) At the disease-specific level, consider addressing individual areas in which molecular imaging is now having beneficial impacts and in which it is likely to do so in the future. At this summit we have heard lung cancer and lymphoma cited as areas in which molecular imaging and therapy have the potential to influence diagnosis, management, and treatment. SNM might consider developing lung cancer- and lymphoma-specific information for patients.
- (3) At the scientific/research outreach level, SNM could provide regular updates on research from professional meetings, trends in technology, and new approvals targeted at patients.

These resources, incorporated into a larger strategic plan identifying the most appropriate vehicles for getting this information to the right patients at the right times, should ensure wide exposure and high impact for the molecular imaging message.

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Making the Case for Molecular Imaging

Despite many extraordinary advances, molecular imaging remains among the best-kept secrets in health care. Many physicians and many more patients are not convinced of the value of newer molecular imaging procedures over more familiar diagnostic approaches. Part of the problem is a lack of understanding about precisely what constitutes molecular imaging and molecular medicine and what the benefits are on a scientific and human level. The evidence of

this value, particularly in terms of clinical outcomes data, must be organized in a way that can be understood and then widely promoted. The challenge is to identify ways in which this important information can be disseminated. In short, how can members of the molecular imaging community serve as emissaries to the public? This presentation offers background information and suggestions, focusing in part on strategies for venturing into the blogosphere.