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Their Role in the New Health Care Environment

Jamie Young

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# State Medical Oncology Societies

Their Role in the New Health Care Environment

by Jamie Young

Over the past several years, as new challenges have confronted oncology care providers, the organizations that represent cancer care have radically altered their missions to refocus their attention and some of their resources on financial and reimbursement problems that threaten the quality of cancer care and the livelihood of cancer care providers.

While national organizations such as the American Society of Clinical Oncology (ASCO) and the Association of Community Cancer Centers (ACCC) are helpful in dealing with federal authorities (such as Congress and the Health Care Financing Administration), an increasing number of problems can be attributed to state insurers' and state governments' reticence and/or lack of understanding of these issues.

As a result, many medical oncologists have recognized the need to organize state societies that can serve as a mechanism to bring together oncologists and organize efforts to deal with local problems. A recent ACCC survey found developing or existing societies in more than 40 states.

In 1992 ACCC began accepting state chapter members, underwriting some state meetings, providing them with delegate

status, and assisting with policy work in local legislatures. ASCO followed in 1994 with its state affiliate program.

Information on the purposes of state oncology societies is instructive and demonstrates the diverse ways that medical oncologists in particular have come together. Some state oncology societies have existed for a number of years, formed as "outreach" efforts of comprehensive cancer centers or specialized cancer centers. Some oncology societies in local areas are "journal clubs," providing for exchange of information on scientific matters. The primary purpose of these two types of organizations has included the development and promotion of educational objectives. More recently, state organizations have developed that focus on practice issues, i.e., problems in the delivery of quality cancer care that are a byproduct of reimbursement policies of government agencies and insurers.

Regardless of the genesis of these state organizations, it appears that most have increasingly turned their attention to practice issues, such as the costs of practice and the complexities of adequate reimbursement, and to efforts aimed at influencing legislative policies.

Following are articles that examine important initiatives at two state oncology societies and review ACCC's growing relationship with state organizations.

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*Jamie Young is ACCC director for state societies and government relations.*

## The Illinois Medical Oncology Society: Focusing on Guidelines

by James L. Wade III,  
M.D., F.A.C.P.

The Illinois Medical Oncology Society (IMOS) was formed six years ago to *prevent* a guideline from becoming state law. In 1989 the state legislature passed a bill requiring an informed consent and Investigational Review Board approval for any medical treatment in Illinois not approved by the Food and Drug Administration (FDA). Fortunately for all patients in our state, the first action of IMOS was to educate the legislature and the governor's office about the detrimental impact of such a law. The bill was vetoed, and it has never been reintroduced.

Over the past two years, our society has taken on a supportive role in the development of cancer care guidelines in conjunction with Blue Cross/Blue Shield of Illinois. In 1992 IMOS recommended that any cancer treatment guidelines include a provision for NCI- or FDA-approved investigational studies. In 1993 IMOS completed the first study measuring how often participation in an investigational study is denied by a third-party

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*James L. Wade III, M.D., F.A.C.P., is a medical oncologist at the Decatur Memorial Hospital Cancer Institute in Decatur, Ill., and president of the Illinois Medical Oncology Society.*

insurance carrier. In 1994 IMOS helped Blue Cross/Blue Shield draft guidelines for the follow-up care of cancer patients after completion of the initial diagnosis and adjuvant therapy.

The process of cooperation did not occur overnight. The first step was for IMOS to provide documentation that it represents the broad interests of all oncologists throughout the state, from both the private practice and academic settings. We next enlisted the help of the Illinois State Medical Society and its acknowledgement that we indeed represent oncology practice. The third phase involved meeting with Blue Cross/Blue Shield leadership to present our own proposed set of guidelines, based on a consensus statement from our guidelines committee. Once the guideline project was completed, Blue Cross/Blue Shield asked that an oncology advisory committee be formed, made up of representatives of our membership. The committee is now charged with determining if and how bone marrow transplant centers should be credentialed and approved.

The major issue now is: Where do we go from here? How can these follow-up guidelines, or any guidelines for that matter, be implemented in a way that teaches us something about patient outcomes and treatment cost?

This topic is harder than it may seem at first glance. For example, let us ask, "What should the end points be for follow-up guidelines for cancer patients?" The most important end point, of course, is overall survival. The guidelines are not set up to compare follow-up strategies and their impact, if any, on survival. Only a large national randomized trial comparing different follow-up schedules could test that question.

Another question that must be asked is, "Can the guidelines help detect new cancers for which the patient may be at higher risk for developing?" The current Blue Cross/Blue Shield data system can track the intensity of diagnostic testing done after the first diagnosis of a malignancy, but it does not have the ability to record the results, i.e., if the patient subsequently developed a complication of adjuvant therapy or a new second malignancy. The Blue Cross/Blue Shield system can track costs of follow-up care, but it may have a difficult time distin-

guishing routine follow-ups from the evaluation of new symptoms.

The Mayo Clinic is also exploring the issue of the follow-up care of oncology patients. It intends to use a set of standard follow-up schedules that are similar to those developed by IMOS and Blue Cross/Blue Shield. The Clinic will then tabulate the results of the testing by using a reporting system similar to that used in a cancer registry. The goal is to learn how often the follow-up schedules detect new events—not how often the patient presents with a new symptom in between routine follow-up visits.

Our long-term goal is to better understand and justify the care that we provide. Each time we see a patient, even for a routine visit, we expend resources. We must be able to show the health care payers what value rests in follow-up care.

### **The Indiana Medical Oncology Society: Raising Awareness and Changing Policy**

by Robert T. Woodburn,  
M.D.

The Indiana Medical Oncology Society (IMOS) represents Indiana medical cancer specialists (hematologists and medical oncologists). Membership consists of 67 hematology/oncology specialists, including the faculty at Indiana University. The Society's mission is to provide advocacy for Indiana cancer patients and to promote standards of excellence for high-quality cancer care. Having a credible society with a strong membership positions us to respond to new challenges.

In 1994 health care reform captured the attention of the nation. IMOS members recognized the need for certain changes in the health care delivery system. We were concerned, however, that the political urgency of the reform movement stood a chance of destroying the more favorable aspects of U.S. health care.

Last year, the Society articulated

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*Robert T. Woodburn, M.D., is a medical oncologist and Indiana Medical Oncology Society president.*

its views on health care reform in a position paper and sought to raise public awareness of what we believed was the restrictive, bureaucratic nature of President Clinton's reforms.

In March 1994, as IMOS president, I attended an American Medical Association conference in Washington, D.C. On the first day of the meeting, all the major congressional leaders spoke on health care reform. On the second day, physicians in attendance were bussed to Capitol Hill for a lobbying effort. A group of us from Indiana set up appointments and visited our senators and seven out of ten Indiana representatives. We solicited their views on health care reform and, in turn, gave them ours.

On return, we created a complete mailing list of senators and congressmen. Then, we made sublists of the members of key Senate and House health care committees and started a letter writing and phone campaign. Patients and employees and their relatives and friends were invited to participate. Thousands of letters and hundreds of phone calls to Congress resulted.

I made diskettes of the congressional mailing lists available to IMOS members, encouraged them to write legislators, and planned to include one member from each of the 10 Indiana congressional districts on another visit to Washington, D.C., on June 30, 1994. We encouraged feedback to the IMOS executive office regarding letters written and legislative contacts made. Our executive board approved a position paper on health care reform, which we mailed to members of Indiana's congressional delegation and key congressional committee members nationwide.

Although our visit to Washington was sparsely attended, we met with all but one of Indiana's legislators or their health care legislative assistants. We hand-delivered the IMOS position paper, and, again, were well received.

Our final trip to Washington was on August 17, 1994, the date the House was set to vote on the Clinton-Gephardt Bill. This time we recruited 225 people from north-west Indiana and the Chicago area. We raised funds through phone solicitations to other physicians, small businesses, and concerned individuals. Some participants paid

their own way, while others were sponsored by supporters.

Senators Lugar (R-Ind.) and Coats (R-Ind.) arranged a Senate Committee room where they spoke to our group, answered questions, and sincerely thanked us for our support. Our efforts were not easy. It took a great deal of time and dedication by many concerned people. However, as a grass roots action, our people learned how government works. Participants were profoundly enlightened and comforted with the knowledge that we fought hard and helped to influence a critical policy issue.

## ACCC and State Societies

by Jamie Young

Over the last several years, the Association of Community Cancer Centers has played a major role in assisting the development of state societies. In the last three years, ACCC has worked hand in hand with nearly 20 state societies to enact state-level, off-label and clinical trials legislation.

There are several reasons for ACCC's interest:

- Insurers are organized at the state level, as are most Medicare carriers, and this is where idiosyncratic problems often arise and need to be addressed.
- Physicians at the state level often have the power of law behind their decisions, since many insurance policies guarantee patients that they will receive care that is state of the art, and this is often legally determined by the expert opinion of local physicians.
- Today, health care reform is focused at the state level, with many states already seeing passage of health care reform packages.
- State reform can often create a "bandwagon" effect, which leads to federal reform or the adoption of similar legislation in multiple states.

The multidisciplinary leadership of ACCC has made it clear that the entire health care team must continue to succeed or community cancer

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care is in trouble. It is already clear that the supply of oncologists is going to decline, while the number of patients is going to skyrocket over the next several decades. If oncologists cannot make a living, this will further exacerbate the problem. Hospital administrators within ACCC have been strong champions of assuring that medical oncologists are adequately compensated, stating openly that what is first done to physicians will later be done to hospitals.

As ACCC has sought ways to combat the trends that are sharply limiting cancer care, the Association has recognized the potential power of locally organized medical oncologists as part of the team. However, ACCC's leadership acknowledges that local oncologists will require significant resources to be effective and will need to be exceedingly prudent in their use of existing resources.

As ACCC has surveyed existing organizations and investigated ways to assist in the development of new organizations, a number of concerns have emerged. Among them:

- How can state organizations be most effectively organized, mini-

mizing legal costs, paperwork, the creation of separate corporations, and annual IRS and regulatory filing requirements?

- How can the logistics of the organization be easily managed (i.e., membership recruitment, membership communications, annual billing, bookkeeping, financial statements, meeting logistics, speaker selection, etc.)?
- How can the extraordinary financial and legal resources be obtained to analyze existing regulations, laws, and coding, and determine the appropriate mechanisms for altering reimbursement policies?
- How can resources be obtained to work with state legislatures, state regulators, third-party intermediaries, local media, and the medical oncology profession necessary to change existing policies and promulgate favorable new reimbursement policies?

The answers to these questions are by no means simple. ACCC, working with legal counsel that specializes in association law, has provided a number of answers. For example, state oncology organizations that form as ACCC state chapters need not separately incorporate.

ACCC can provide at the society's request a series of services at costs below those typically obtained elsewhere. For example, society officers can be added to the Association's master directors' and officers' liability insurance at nominal rates.

Working with national Association funds and grant funds of other concerned organizations, ACCC can supplement local/state oncology society resources...and using its contacts at the national and state levels, the Association's staff can get rapid access to the decision makers at state organizations and at national affiliates.

ACCC can assist the state oncology societies in their organizational activities, providing assistance with both logistical and strategic planning issues. This assistance goes beyond merely meeting management and other logistical activities; it provides senior staff support for state oncology societies, as well as access to other significant resources useful in dealing with the myriad of issues that are now affecting oncologists. ■