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Patient Advocacy in an Information Age

On January 30, 1997, the Association of Community Cancer Centers hosted a one-day meeting on "Patient Advocacy Issues: Information, Choice, Availability, and Access," to explore the challenges facing today's cancer patients. In attendance were patient advocates and leaders from eight oncology-related organizations, including the American Cancer Society, the Association of Oncology Social Work, Cancer Care, Inc., the Candlelighters Childhood Cancer Foundation, the National Alliance of Breast Cancer Organizations, the National Cancer Institute, the National Coalition for Cancer Survivorship, and the Oncology Nursing Society.

"The role of advocate can no longer be performed in isolation," stated ACCC President John E. Feldmann, M.D. "As advocates for quality cancer care, ACCC must collaborate with patients and fellow advocates whose collective voice is growing louder in the public health care policy arena."

ACCC is committed to advocacy on behalf of cancer patients, their families and the community. In 1995 the Board of Trustees established a special Presidential Grant to fund the retreat. Ortho Biotech Inc., was this year's sponsor of the ACCC Presidential Grant.

THREATS TO QUALITY CARE

In today's cost-driven health care system, cancer patients may face barriers to essential elements of quality care that can include limited access to oncologists and oncology supportive care services.

With many hospitals eliminating oncology-specific units, there is a trend toward a decreased emphasis on the specialization of nurses in

cancer care, said Kathi Mooney, R.N., Ph.D., A.O.C.N., F.A.A.N., Oncology Nursing Society president. Some hospitals may be losing their interest in seeing that a certain percentage of nurses receive oncology certification. Mooney also cited as a threat to quality care the increased use of unlicensed care givers in providing bedside care to patients.

Many oncologists, limited by time and other managed care constraints, must strike a balance between fully informing their patients and providing an overwhelming amount of information about options that their plans may discourage or deny. ACCC Executive Director Lee E. Mortenson, D.P.A., cited a recent ACCC survey in which 47 percent of oncologists reported that they had hesitated to recommend a treatment option to a patient because of a previous denial from the insurance company. Susan Stewart, editor of the *Blood and Marrow Transplant Newsletter* responded: "Discovering that a treatment or reimbursement option had been available but was never introduced as a possibility can be devastating to a patient."

Fortunately patient advocacy organizations are ready to help guide patients through a maze of difficult choices. The majority of groups represented at the retreat operate web sites that link to each other and to a variety of other organizations. Patient advocates credit the Internet with increasing their ability to reach the ever-growing number of people with access to on-line information.

The National Cancer Institute is becoming more involved in patient advocacy efforts. Within the past year, NCI Director Richard Klausner, M.D., created the Office of Liaison Activities to strengthen NCI's relationship with advocacy and voluntary organizations. Led by Director Eleanor

Nealon, the office will create a two-way communication channel between NCI and community organizations. "Part of advocacy is telling patients they have a right to the best information," Nealon said. However, the information must be accessible in easy-to-understand formats. NCI's 1-800-4-CANCER information service helps navigate patients through their various options. NCI also distributes information through its web site, CancerNet, which includes global resource listings of national and local patient advocacy groups as well as NCI's PDQ database. NCI is currently developing a patient partnership with the PDQ database, where PDQ protocols will be translated into patient-friendly summaries and made available on the Web.

FINDING SOLUTIONS

"In a cost-driven system where standards of care are driven by the bottom line, we need to compile a body of evidence to demonstrate to third-party payers and the general public that the involvement of cancer specialists in delivering quality cancer care results in improved patient outcomes," stated Ellen Stovall, executive director for the National Coalition for Cancer Survivorship, and facilitator for the event. To that end, the Oncology Nursing Society is presently developing outcomes data to justify the existence of an oncology nursing specialty threatened by cost containment measures.

Patient advocates agreed that public opinion will be the driving force in directing change in health care. "Our job is to take what we know about quality cancer care and market it to the general population," said Nealon of NCI. "We have to trust that public opinion will drive legislation and influence the managed care companies to do what is right." ■