



Partnerships in Patient Advocacy

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Partnerships in Patient Advocacy

Since its founding in 1974, the Association of Community Cancer Centers has considered advocacy on behalf of its members and cancer patients as one of its most important functions. To that end, ACCC hosted a one-day meeting on "Partnerships in Patient Advocacy," held October 6, 1997, in Arlington, Va. The goal was to foster communication and collaboration among patient advocacy groups, as well as to seek common ground on which advocates and ACCC can work together. In attendance were patient advocates and leaders from ten 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 Coalition for Cancer Survivorship (NCCS), the Oncology Nursing Society, the Susan G. Komen Breast Cancer Foundation, the *Blood and Marrow Transplant Newsletter*, and the National Cancer Institute. Ortho Biotech Inc. sponsored this year's meeting.

"There is strength in numbers," stated James R. Zabora, M.S.W., chairman of ACCC's Ad Hoc Committee for Advocacy. "If we can link together, we can move forward to help assure quality cancer care and to help patients in the community." Those links include partnerships in patient education/dissemination of patient information, provider education, business and payer education, advocacy research, and political and legislative issues.

CONCERNS ABOUT ACCESS TO CARE AND CLINICAL TRIALS

High on advocates' list of concerns is the need to assess the extent of the problem with payer denial of appropriate treatment. Patient advocates agreed that research and hard data are lacking, although anecdotal accounts about denials abound.



Representatives from leading patient advocacy organizations met for discussions at ACCC's 3rd annual Patient Advocacy Meeting. Among the participants were (left to right) ACCC President James L. Wade III, M.D., ACCC Executive Director Lee E. Mortenson, D.P.A., Susan Stewart of the *Blood and Marrow Transplant Newsletter*, Pamela J. Haylock, R.N., Oncology Nursing Society President, and NCCS President Betsy Clark.

"We need information from patients on their experiences in accessing appropriate care," said ACCC President James L. Wade III, M.D. "Whether the barrier to care is the physician, the insurance company, the hospital, the geography, the patient himself—they're all possibilities."

Furthermore, said Wade, it is important to "mine information from patient advocacy groups to sort out those patients who could not get on clinical trials because their insurance companies would not let them."

According to NCCS President Betsy Clark, NCCS conducted an informal survey of patients around the country regarding clinical trials. "Of those on clinical trials, some said, 'I am on a clinical trial, but I had to do it myself.'... Most troubling were those who responded, 'My doctor said that clinical trials are just a passing fad.'" Few people noted that their experiences with clinical trials went well, said Clark. Moreover, "the average person with cancer doesn't know what a clinical

trial is, let alone how to get on one."

During the many hours of discussion, meeting participants voiced a number of other concerns, including the need for:

- research on long-term follow-up care of cancer survivors
- patient and provider education about the special needs of minority populations
- dissemination of a cancer care resource guide that helps patients assess if they are receiving the best care possible
- increasing awareness of providers about the value of pain management and psychosocial programs
- helping businesses evaluate the quality and completeness of their own insurance plans
- developing joint data collection about patient concerns and insurance denials on web sites
- continuing advocacy efforts at the state and national legislative levels.

A summary statement of recommendations and possible partnership projects will be published in a future *Oncology Issues*. ❧