



Cancer and AIDS Advocacy: Are Two Bands a Parade?

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FROM THE EDITOR



Cancer and AIDS Advocacy: Are Two Bands A Parade?

by Lee E. Mortenson, D.P.A.

If you didn't read *And the Band Played On*, you have certainly heard of it by now—the first book about the gay community and the discovery of the AIDS virus. I believe that it is time for the cancer and AIDS communities to join together in seeking relief for their constituencies, which are so different in some ways, but overlapping in others, with the same fundamental challenges ahead.

As health care reform unfolds, these two communities share many common causes:

- 1) Both represent the high cost diseases of the future.
- 2) Both depend on evolving technologies, requiring significant investment from government and private sources.
- 3) Many of both constituencies are on Medicare, or are spending down their assets to become Medicaid eligible.
- 4) Both are going to continue to have critical portions of their care managed in hospital and outpatient settings.
- 5) Both deal with life-threatening conditions.
- 6) Both are at high risk of being stopped in their tracks by managed care organizations that are unwilling to spend on research, new technology, specialists, or specialized care.

At the recent Presidents' Retreat, leadership came together from thirty-five state medical oncology societies, eight national oncology societies, and two AIDS advocacy groups. After two days of dialogue and presentations, most, if not all of us, were exhausted and concerned about the implications of reform for our patients and the providers who treat them.

There is no segment of oncology or AIDS care that is not being affected. Some physicians are reporting rapidly declining incomes, while

others attempt to band together to strengthen their position or join with hospitals. Some oncology nurses are being laid off or replaced by nurse practitioners with little or no experience in oncology. Some nurses are not having the opportunity to work and train in a hospital and are directly joining the staffs of home care organizations treating cancer patients. Hospitals are consolidating and closing. The pharmaceutical and biotechnology industries are reporting that more than 40 percent of their companies are already cutting back on cancer research.

AIDS providers are reporting that they are having difficulties with off-label indications. And some AIDS patients are worried about getting anyone to treat them, not having a choice of physicians, and not having anyone in their managed care plan or alliance who specializes in HIV-patient management.

The NCI staff are deeply concerned about slowing accrual, and the national cooperative groups (like the National Surgical Adjuvant Breast and Bowel Project, which presented at the Retreat) are bracing for increasing denials. Our ACCC survey of oncologists indicated that more than 3,000 patients were denied participation in clinical trials by their insurance companies last year.

As if this wasn't bad enough, in Florida, the draft legislation says insurance will pay for only what is on the label.

Clearly, there are a half-dozen key issues that many state societies, the eight national cancer organizations, and the AIDS organizations all have as common concerns. Our immediate challenge will be to bring many of these organizations together and, in effective ways, tell our state and national legislators what they are really doing to the people they hope to serve. ■