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Patient Advocacy Issues in a Changing Health Care Environment

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to become more involved in the state legislative process and to mobilize their constituencies to lobby state legislators.

The avalanche of paperwork required by managed care companies is also impeding physician efforts to place their patients on clinical trials. But that is only part of the problem, contended Susan Stewart, editor of the BMT Newsletter. She is concerned about physician hesitation to inform a patient about a clinical trial for which reimbursement will very likely be denied. "Patients should have the right to know about treatments that they may in fact be able to receive or at least try to receive," Stewart argued.

A REPORT CARD ON SERVICE

To make educated decisions when choosing a managed care plan, employers and health care consumers require more information. To that end, meeting participants proposed creating a report card that would rate the priorities and level of care of managed care organizations. Patients would report on their experiences with, for example, ease of access, reimbursement delays, or even the number of phone calls required to have questions answered. The report card would serve as a measure of patient satisfaction with managed care plans.

Amy Langer, M.B.A., executive director of the National Alliance of Breast Cancer Organizations and facilitator for the discussion, defined the changing health care environment as one in which care is constrained, physicians are controlled, the needs of cancer patients are not paramount, and quality of life interventions are viewed as dispensable.

"Patient advocates must fight to raise awareness of quality of life issues through information and education, regulatory change, and legislative lobbying," said Langer. "But perhaps most importantly they must enlist patients to become advocates for their own care."

Treatment of HIV-Positive Patients

by John S. Hoff

here is an interesting new case concerning the obligation of health care providers to treat HIV-positive patients. The Americans with Disabilities Act (ADA) prohibits a place of public accommodation from preventing a person from enjoying the full and equal enjoyment of services because of disability, unless the patient would pose a direct threat to the health and safety of others. A person is disabled and falls under the protection of the ADA if he or she has a physical or mental impairment that substantially limits one or more of his or her major life activities.

A recent case dealt with an HIVpositive but asymptomatic woman who visited a dentist to have a cavity filled. During her visit she revealed her condition. The dentist stated that, pursuant to his infectious disease policy, he would not fill the cavity at his office but would do so at a hospital, which would require an extra charge for the use of hospital facilities. The woman sued the dentist for violation of the ADA. The court concluded that the dentist had violated the ADA.

Providers everywhere need to understand the reasoning behind which the court based its decision. The court found that asymptomatic HIV constitutes a physical impairment under the ADA. However, physical impairment itself is not enough to invoke the ADA. The impairment must substantially limit a major activity of life. The court determined that this test was met

John S. Hoff is ACCC legal counsel with Swidler & Berlin, Washington, D.C. because the patient said that her asymptomatic HIV status limited her reproductive activities. The risk that pregnancy would present to her own immune system, the risk of transmitting HIV to a child, and the fear that she would die and thus leave a child without a mother deterred her from bearing children. The court found that conceiving and raising one's own children are basic civil liberties and major life activities under the ADA. Thus, even though the HIV did not render the patient sterile, it limited a major activity of her life. She was therefore protected by the ADA.

The next question was whether treating the patient would harm others. The dentist argued that performing "invasive" dental procedures in his office presented a significant health risk to himself and his staff. A witness from the Centers for Disease Control and Prevention testified that if the CDC guidelines were followed, treatment in the dentist's office would not present a direct threat to the health of others.

Courts in a number of cases have found that treatment by HIV-positive health care providers presented a threat to the health of patients. The court distinguished those cases. stating that, in such instances, the infected providers presented a risk to patients, which the patients could not control. In contrast, the dentist treating a patient with HIV could guard against personal risk by taking the protective measures suggested by the CDC. Consequently, the court found that the patient's HIV status did not present a direct threat to the health of others. The dentist was found to have violated the ADA. 🖀