



States Acting on Off-Label Legislation

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To enhance communications between ACCC leadership and membership, this column presents excerpts from ACCC board meetings as they occur.

■ **Cancer/Health Policy Boards.** The Board received requests from various organizations for qualified individuals to be considered to serve on advisory boards. The following individuals have been submitted for consideration:

Agency for Health Care Policy and Research, National Advisory Council—Robert T. Clarke, MHA; National Cancer Institute, Office of Cancer Communications, Cancer Survivors Advisory Group—Nancy A. Nowak, MA; Oncology Nursing Society/ Oncology Nursing Certification Corporation, Chemotherapy Consensus Conference—Connie Henke Yarbrow, RN, BSN.

■ **Governmental Affairs Committee.** James L. Wade, III, MD, announced the Committee's plans to develop and distribute a survey to gather data on the reimbursement patterns for patients on clinical trials. The initial survey will be distributed to member Community Clinical Oncology Program Principal Investigators and Data Managers. The committee plans to use the data to document reports from members of increasing incidence of denials by insurance companies for the patient care costs of patients on a clinical study.

■ **ACCC/ONS.** The Board approved recommendations presented by the ACCC/ONS Joint Working Group. See related story in "Association News," p. 5.

■ **Strategic Planning.** The Strategic Planning Committee, under the direction of Chairman, Albert B. Einstein, Jr., MD, presented a revised mission, goals and objectives document to the Board for review. The Board made one addition and approved the document for distribution to the membership for comments.

■ **Standards.** Connie Henke Yarbrow, RN, BSN, Chairman of the Committee, reported on progress of the standards review. The Committee has conducted a thorough review and will present their draft document to the Board and an additional interdisciplinary, sampling of the membership for comments. The Committee expects to present a final, updated document to the Board for approval in March. 📄



States acting on off-label legislation

By Jamie Young

ACCC and others were working on the introduction of off-label legislation in a number of other states for 1993.

House Bill 1270 was introduced in Indiana by State Representative Charlie Brown and was approved by the House of Representatives 98-0. Testimony provided by Indiana Medical Oncology Society President Dr. Robert Woodburn was essential in the House Insurance Committee. It is now awaiting consideration by the Senate Insurance and Financial Institutions Committee. Negotiations have led to the insurance industry removing their opposition to the bill which should clear the way to its eventually becoming law in Indiana.

House Bill 741 was introduced in Georgia by State Representative Butch Parrish. Through the efforts of ACCC, the Georgia Division of the American Cancer Society and the Georgia Society of Clinical Oncology, the bill has already passed the House by a vote of 165-1. The Georgia General Assembly will be completing its 1993 session by the end of March and passage of this bill will be an ACCC priority.

House File 90 was reintroduced on behalf of ACCC and the Minnesota Society of Clinical Oncology by State Representative Alice Hausman. A companion bill has been introduced in the Senate by State Senator Pat Piper. Hearings have been scheduled for this bill and numerous supporters are on board.

In Nebraska, Legislative Bill 415 was introduced by State Senator DiAnna Schimek in late January. It was recently heard by the Banking, Commerce and Insurance committee where ACCC testified in favor of the bill while the insurance industry spoke in opposition. Its outlook is unclear but the sponsor is hopeful that a compromise can be reached.

Finally, State Representative Nancy Benoit of Rhode Island introduced House Bill 6642 on February 24th dealing with off-label drug reimbursement. 📄

You may have heard the old saying that there are two things you don't want to watch being made: sausage and laws. ACCC has developed model legislation that can be introduced in any state, however, the end product rarely mirrors the pure idea from which it was inspired. The legislative process is one that requires flexibility, pragmatism, negotiation and, yes, even a strong stomach sometimes. Such was the case in Massachusetts, which recently joined the states of California and Illinois in the passage of off-label drug legislation. (See the news story on page 5.)

Prior to the introduction of the bill, the decision was made to narrow its focus from all drugs used in an off-label manner to those used off-label in the treatment of cancer. This is often the call of the legislative sponsor who may decide that the best chance of passage is predicated on a streamlined bill. The majority of off-label uses occur in oncology, but off-label denial also affect AIDS patients and, to a lesser degree, cardiac patients.

Senator Nancy Achin Sullivan, the Massachusetts sponsor, is a two-time cancer survivor. Those of us who were privileged enough to work with her can understand this feat. It was her tenacity that led to the passage of the off-label bill. Senator Sullivan is no longer a member of the State Senate, having decided not to run for re-election because of her health. However, I am glad to report that on the one year anniversary of the discovery of her breast cancer, she received a clean bill of health. What she went through the past year, both with her personal battle against cancer and her professional battle for the off-label bill, cannot be adequately described in this column, but it would make a heck of a movie.

At the same time our efforts were coming to fruition in Massachusetts,