

## Taking Our Message to Capitol Hill: ACCC/ONS Host Second Annual Policy Institute

**O**ncology nurses, cancer program administrators and patient advocates visited the offices of their respective members of Congress on Capitol Hill March 9 to make their voices heard. Their message to the nation's lawmakers in the 107<sup>th</sup> Congress: monitor the ambulatory payment classification (APC) system to ensure Medicare beneficiaries' access to the latest cancer therapies, implement solutions to resolve the serious nursing shortage on patient care, and provide coverage of clinical trials for non-Medicare patients.

"Let your senator and representatives know what's on your mind. They want to listen to your expertise," said Shalla Ross, legislative assistant to Rep. Philip M. Crane (R-Ill.). Crane is vice chairman of the House Ways and Means Committee and a member of the Ways and Means Health Subcommittee that has jurisdiction over many health issues.

Ross indicated that the priority health care issues on the agenda of the 107<sup>th</sup> Congress include:

- Modernization of Medicare (possibly incorporating prescription drug coverage, new medical technologies, and anti-cancer oral therapies)
- A patients' bill of rights (possibly including access to health care for the uninsured)
- Implementation of the Health Insurance Portability and Accountability Act (HIPAA), whose controversial medical privacy regulations are not yet finalized.

The congressional visits were part of a two-day Annual Policy Institute, held March 7 to 9 in Arlington, Va., hosted by ACCC and the Oncology Nursing Society, and sponsored by ALZA

Pharmaceuticals and Ortho Biotech, L.P. This is the second year a policy institute has been offered. About 40 oncology nurses, cancer center administrators, patient advocates, and others heard lobbyists and Capitol Hill staffers present insight often laced with humor on the complex legislative, regulatory, and budgetary processes in Washington, D.C. Attendees were taught practical, hands-on methods to reach legislators and Hill staffers and how best to educate them about current legislation and regulation affecting cancer care.

"It's a new Congress and Administration and therefore a good time to communicate with your legislators," said Bob McLean, president of REM Legislative Services, Inc., of Arlington, Va., who spoke about the need for oncology care professionals to take their message to the new Capitol Hill.

"Grassroots lobbying is very effective because voting constituents have power," McLean said. He suggested that any visit to Congress include an invitation to the Representative, Senator, or staff member to tour the constituent's cancer facility. "A site visit is the most effective tool to educate members of Congress about issues that are important to you," he said.

McLean advised following up a visit to Capitol Hill with a written thank-you letter instead of e-mail, although he noted that congressional offices receive a total of 350 letters, phone calls, visits, faxes, and e-mails—on a slow day!

McLean also noted the lack of institutional memory of many Hill staff. In 1997 Senate staff had 5.6 years experience, and 62 percent of Senate legislative assistants were in their current jobs two years or

less. In 1998 House staff had just 4.9 years of experience, and 78 percent of House legislative assistants were in their current jobs two years or less.

### QUESTIONS AND ANSWERS

"What is the best route for an organization to get sponsors for a bill?" asked Paula T. Rieger, R.N., M.S.N., C.S., AOCN®, FAAN, president of the Oncology Nursing Society (ONS).

"Find the champions on the Hill who are interested in your idea and are willing to advocate it throughout the lawmaking process," replied speaker Walter Oleszek, Ph.D. "The advantage is on defense, not offense. Those who want to block or modify your idea have the advantage over those who want to get their own ideas through unscathed." Oleszek is senior specialist in American national government with the Congressional Research Service of the Library of Congress in Washington, D.C.

"How long does it take for an idea to become law?" asked another attendee.

"Sometimes ideas can take years or even decades before conditions are right in the country for action to occur," Oleszek said. "This was true for the evolving process required to implement Medicare in 1965 during the Johnson administration."

However, Oleszek noted, "technically the lawmaking process takes two years from the time of introduction in Congress to its delivery to the White House for the president's signature. Otherwise, the legislation dies in the 107<sup>th</sup> Congress. The bill would then need to be reintroduced in the 108<sup>th</sup> Congress."

"Still," he concluded, "members of Congress most often want to be reelected and will therefore move on legislation that reflects well on

them and will help them get reelected.”

How can cancer program administrators and oncology nurses affect the regulatory process? Bruce M. Fried, J.D., advised attendees to:

- Develop a personal relationship with legislators to establish trust and convey their message
- Know the evolution of the law that affects their issue and how underlying policies were set
- Develop comments in a timely fashion that advance their position
- Meet with appropriate policy makers
- Build coalitions to help change any regulations that threaten quality cancer care, care delivery, or reimbursement.

“If you’re not proactive,” said Fried, “you’re going to get the policy decision that is given to you.” He also maintained that great opportunities exist for coalition building and collaboration because health care organizations share similar policy concerns in the delivery of health and cancer care services and know how effective it is to speak with a unified voice. Fried is a partner with the Health Law Group of Shaw Pittman in Washington, D.C., and a former director at the Health Care Financing Administration.

Throughout the meeting presenters emphasized that nurses have the power to influence policy decisions. “Nurses have power in knowledge and in numbers. And nursing has the power of the profession to shape health care,” said ONS President Rieger. According to Rieger, nurses helped educate Congress about the “Pain Relief Promotion Act,” or the Hyde-Nickles bill, which actually hindered the ability to provide adequate pain control or home services.



Above, Allen Schick, Ph.D., (left) professor in the School of Public Affairs at the University of Maryland in College Park, answers questions after his presentation on congressional budgeting.



Above, Sen. Ted Stevens (R-Alaska) meets with Carole S. Edwards, R.N., O.C.N.®, of Juneau, in the senator’s Capitol Hill office.



The bill did not pass the 106<sup>th</sup> Congress.

Rieger urged nurses to meet with and write to members of House and Senate committees, providing input on policy positions and how a bill will impact the care of patients. When visiting Capitol Hill, “...introduce yourself and explain how you can help the legislator. Offer to witness or supply information. Most of all, tell legislators your stories.”

Conveying a “Hill” message to David Sherlin, legislative correspondent in Sen. John Edwards’ (D-N.C.) office, is Cathy A. Glennon, R.N., M.H.S., O.C.N.®, C.N.A., health center administrator of oncology services at Duke University Medical Center in Durham. Not shown but also attending the meeting was Jeff Heffelfinger, M.H.A., administrative director of Alamance Cancer Center in Burlington.