Highlights of ACCC's 27th Annual National Meeting

by Marion Dinitz and Astara March

Close to 500 cancer care professionals gathered in Washington, D.C., for ACCC's 27th Annual National Meeting March 28-31, 2001. Entitled "Surviving the Changing Economics of Cancer Care," the meeting provided attendees with timely information to help hospitals and practices adjust to the rapid pace of change in the year 2001 and beyond.

ACCC's conference brought together a diverse group of thinkers and doers who provided innovative ideas and concrete solutions to the problems cancer programs and practices must confront. These topics ranged from oral chemotherapy drugs to forthcoming medical privacy regulations that impact the delivery of cancer care services.

ACTOR ROBERT URICH INSPIRES ATTENDEES

"We can't control what happens in life, but we can control how we react to what happens to us," said Robert Urich, world-famous TV and stage actor. Urich was diagnosed with synovial cell sarcoma in 1996 and had one recurrence, but is now cancer free. Soft-tissue sarcomas comprise about one-half of 1 percent of all cancers.

"I've always played characters who have been capable and up to a challenge. I thought, well, maybe it's time for me to see if I can display some of that toughness," said Urich when asked about his first 48 hours after diagnosis. He has gone through treatment and continues to work while speaking openly about his disease. Since his diagnosis, he has spoken before groups of cancer survivors around the country and has raised tens of millions of dollars for cancer research.

"There comes a moment in life where you define the moment... or the moment defines you," said Urich, pointing out that he has moved past the anger and fear of death and dying and gone on to hope and living.

Urich said he has much to be thankful for: the oncology nurse who showed compassion and understanding and inspired him to continue with his treatment...the physicians who diagnosed and treated him and with whom he has developed "a partnership"...the chemotherapy drugs that have been developed through scientific and medical research...strong religious beliefs that have guided him on his road to recovery.

When asked what he would like to see changed about the cancer care system, Urich replied: better communication among providers regarding the latest breakthroughs in cancer research, and reduction in the number of questions that clinicians repeatedly ask their patients as they proceed through the treatment process.

FEDERAL SECTOR ACTIVITY

ACCC plans to work with the General Accounting Office (GAO) to help compile data on the costs of provider services and drugs in the outpatient hospital setting. According to Lee E. Mortenson, D.P.A., ACCC executive director, the data will help resolve the controversial conclusions of an earlier Department of Justice study that determined that Medicare providers in the office setting receive higher margins on the acquisition of chemotherapy drugs.

TV actor and cancer survivor Robert Urich was the keynote speaker at ACCC's 27th Annual National Meeting.

PHOTOGRAPH BY JAMES THATCH

"Under Medicare, approximately 60 percent of chemotherapy is administered in the office practice setting, while 30 percent is given on a hospital outpatient basis," Mortenson told GAO staff. "If Medicare lowers drug reimbursement much below the current average wholesale price (AWP) of minus 5 percent, medical oncology practices will not be able to cover their expenses. They may have to close their offices, shifting substantially more cancer care services to outpatient hospital departments," he said. Hospitals might have to

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triple the number of cancer patients they see, and may not have the extra capacity to handle this influx.

Fortunately, GAO staff and legislators on Capitol Hill seem willing to work with provider groups to help avoid such drastic problems, according to Mortenson. The GAO study is expected to be completed this year, perhaps as early as September.

SEN. BROWNBACK FOCUSES ON THE WAR AGAINST CANCER

"I am delighted to be part of this great cause to eliminate cancer," said Sen. Sam Brownback (R-Kans.), a speaker at the conference and a member of the Senate Committee on Health, Education, Labor and Pensions. Sen. Brownback himself is a cancer survivor, having been successfully treated for melanoma. He described his cancer experience as "very rewarding because it caused me to personally examine my life and make it richer and fuller." Sen. Brownback is co-chairman of the Cancer Caucus on Capitol Hill as well as a new member of the National Dialogue on Cancer.

"This nation is best when it is challenged and focused," said the senator, referring to historic landmark events such as putting a man into space in 1961 and landing a man on the moon in 1969. He maintained that now is the time for America to be resolute and determined to win the 30-year-old war against cancer.

"Perhaps some day cancer will no longer be a major public health concern as a result of the efforts being made to eradicate this disease," Sen. Brownback said.

The senator also urged attendees who planned to visit their legislators on Capitol Hill to tell their stories of hope and personal experiences of cancer care delivery.

"Stare them in the eye, and show them your heart. That's what touches members," Sen. Brownback said.

WHAT'S HAPPENING WITH HIPAA?

The controversial and delayed medical privacy regulations authorized under the Health Insurance Portability and Accountability Act of 1996 (HIPAA) were issued in final form in December 2000. The effective date was extended to April 14, 2001, and the Bush Administration has reopened the regulations for comment.

At this juncture, health care providers would have two years (until April 14, 2003) to comply with the final regulations, said Robert Falk, an attorney with Powell, Goldstein, Frazer & Murphy, LLP in Washington, D.C. However, he indicated that the new Administration may make additional changes and possibly extend the compliance date.

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The regulations, which have generated more than 52,000 comments, are described as very costly to implement and complicated for health care providers, health plans, and clearinghouses to follow. Nevertheless, the regulations are not likely to go away because lawmakers don't want to be portrayed as being "anti-privacy" or "anti-patient," Falk said.

Under the privacy rules, patient health information—whether transmitted in electronic, paper-based, or conversational form—would be protected from disclosure.

"Conversations between physicians and nurses in the hallways, facsimiles, and e-mails (if the patient can be personally identified) are covered," Falk said. He pointed out that an option exists under the rule allowing providers to de-identify patient health information on, for example, quality assurance reports and clinical research, which would then be exempt from the rule.

The disclosure of patient health information would be limited to the patient and the Office of Civil Rights. All other uses and disclosures of patient health information would be prohibited unless the patient gave written consent, according to Falk, who described this as the game of "Mother May I."

Patients would have the right to inspect and copy protected health information and the right to amend their medical record, which is a new concept, Falk said. Providers who violate any standard under the regulation could receive a civil penalty of $100 per standard per incidence up to $25,000 per year per standard.

Since the regulations are complex and detailed, many questions still exist and will require answers from the Department of Health and Human Services. However, noted Falk, health care providers will need to invest in privacy infrastructures and security mechanisms, and train their workforce to comply with the new rules.

RECRUITING AND KEEPING QUALITY ONCOLOGY STAFF

One of the most critical issues in oncology today is the recruitment and retention of quality staff members at all levels of the cancer care organization. Chris A. Roederer, M.A., vice president of human resources at the H. Lee Moffitt Cancer Center and Research Institute in Tampa, Fla., shared both his experiences and projections on how to recruit through the first years of the 21st century.

"First, stop depending on newspapers," he told attendees. "Advertise positions on web sites such as Monster.com, in professional journals, and through recruitment/search firms." He estimated that each recruiter handles around 40 open positions, and insisted that an adequate recruiting staff is critical to success. Because retaining employees requires a dedicated allocation of funds, Roederer also suggested that recruitment and retention goals be integrated into the organization's strategic plan, and that employees be considered one of the organization's most important "strategic assets."

"The first step in recruiting good health care employees is to make sure that they are offered compensation and benefits that are competitive within the field, and are as close as possible to those enjoyed by workers in the commercial sector," said Roederer. Placing staff education, training, and development high on the institution's priority list is essential, as

ACCC Honors Patient Advocate

Nancy Davenport-Ennis, president and founding executive director of the National Patient Advocate Foundation, was honored in a special award ceremony in Washington, D.C., at the Association of Community Cancer Centers' 27th Annual National Meeting on March 30, 2001. Davenport-Ennis received ACCC's Annual Achievement Award for Outstanding Contributions to Cancer Care, and was honored for her tireless efforts on behalf of cancer patients and providers across the country.

Davenport-Ennis has worked with hundreds of insurers and helped thousands of cancer patients secure coverage for cancer care. Along with ACCC and other key national organizations, she has helped make the case to Congress that advances in cancer technologies must be adequately reimbursed to assure quality patient care. Furthermore, she has helped advance legislative and policy reform measures designed to improve access to health care through state and federal initiatives, including health insurance portability issues and genetic privacy.

"Every single day we pound the streets of Washington, D.C., to effect reform, we gain the potential to help those who are perhaps not in a financial position to help themselves," she noted. "This award simply marks the very beginning of a very long journey for the National Patient Advocate Foundation...and probably for each of you. Although we have had success resolving some concerns over the last year, we still have many issues confronting us today."

Among the policy issues that continue to be of concern are reimbursement problems with Medicare's new ambulatory payment classifications (APCs), which may threaten patient access to quality cancer care. At the same time, hospitals and oncology practices may be forced to radically alter their services in the face of challenges from the Health Care Financing Administration (HCFA) on drug margins. Although new drugs and devices with the potential to turn cancer from a fatal to a chronic disease are on the horizon, hospital cancer programs and oncology practices are both facing some of the most significant challenges to organizational viability that cancer care providers have ever seen.

Davenport-Ennis has been involved in health care issues since 1993. She initiated the development of a National Legal Recourse Network and a National Case Managers Network, which were created to serve patients referred to the organization for assistance in resolving debt crisis, job discrimination, and insurance matters.

Davenport-Ennis graciously accepted the award on behalf of the many dedicated individuals active in the national coalition, comprised of the Association of Community Cancer Centers, the American Society of Clinical Oncology, US Oncology, the Oncology Nursing Society, members of the Cancer Leadership Council, pharmaceutical industry representatives, and, of course, the patients themselves.

ACCC Immediate Past President David H. Regan, M.D., presents patient advocate Nancy Davenport-Ennis with ACCC's Annual Achievement Award for Outstanding Contributions to Cancer Care.

"Nothing that is extremely significant in life can be accomplished in the unit of one," said Davenport-Ennis. "All of us in the health care delivery field and the world of advocacy must join together to address the policy issues that can make a difference in access for millions of men, women, and children in this country."

Speaking directly to the many cancer care professionals in the room, Davenport-Ennis expressed her gratitude for their work in encouraging patients to write letters to their legislators. "Go back and tell them that their hard work makes a huge difference, and we are very grateful."

is making sure employees are supported by adequate technology. According to Roederer, it is also important to maintain traditional benefits (such as retirement programs; medical, dental, and life insurance; tuition reimbursement; and employee recognition/reward programs); but the newer, nontraditional compensation strategies will make the most difference. Sign-on and referral bonuses, retention bonuses, gain-sharing bonuses, weekend bonuses, and rewards for career advancement are all important.

This last concept was perhaps the most far-reaching. Roederer suggested that, if a certain type of worker is needed and not available in the workforce, an organization can "grow its own" by taking an employee with potential in a lower-level position and paying for the schooling necessary for each to perform in the higher-level job. Employees supported in this way sign contracts agreeing to serve the sponsoring institution for a certain number of years in return for their education. Roederer said this strategy has worked for a variety of positions, from medical records

clerk (drawing from the environmental services staff) to histologist (with candidates from more general clinical lab personnel). He also suggested getting qualified seniors to return to the workforce part-time to staff hard-to-find positions.

Since cancer centers are so stressful, Roederer thought adding on-site massage therapy, a meditation area, casual dress days, holiday parties, and employee social events would boost morale. And with employees being asked to work 10- and 12-hour shifts, Roederer said a "concierge service" to run errands for workers was a fringe benefit likely to produce excellent results. Employers hire organizations to do things as diverse as dry cleaning, shoe repair, changing the oil in employees' cars, setting medical and other appointments, and preparing meals, all for discounted group rates. Employees pay for these services themselves, but the convenience of arranging them at the workplace, plus the discount, is seen as a tremendous bonus in this era of diminished quality and family time.

Roederer firmly emphasized that no benefits can replace or compensate for meaningful, challenging work and a pleasant work environment.

While some of these measures may seem extreme, Roederer cautioned that nothing less would serve in a future where the majority of today's workforce would retire by 2010. In addition, fewer and fewer people are entering the nursing profession, and a 33 percent increase in the number of pharmacists needed over the next five years will be met by no more than a 6 percent increase in trained pharmacy personnel. Significant staffing shortages already exist in research support, general laboratory support, radiology and radiation therapy, information technology, and general employment areas such as administrative assistance, environmental services, and medical records. Roederer thinks only aggressive retention measures will keep medical institutions from closing their doors due to the lack of trained personnel.

"Feedback from employees is crucial to institutional self-monitoring," said Roederer. He suggested that departing employees be asked to evaluate their work experience, and regular suggestion and complaint processes be set up within the organization.

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THE FUTURE OF ORAL AGENTS

"Between 25 and 30 percent of the oncology medications currently being developed are oral formulations," said John F. Akscin, director of business development at Oncology Therapeutics Network in San Francisco, Calif. According to Akscin, while most of these drugs may eventually replace their IV counterparts, some are new compounds that will only be administered by mouth. These products are designed to attack different disease mechanisms, and can potentially be used across a broad array of tumor types. Likely benefits could include the absence of drug resistance, a reduction in toxicity and side effects (such as bone marrow suppression, gastrointestinal problems, or hair loss), and the potential to provide maintenance treatment. Examples of oral anti-cancer therapies include cytotoxic agents, anti-angiogenesis products, products that impact the cell-cycle mechanism, inhibitors of signal transduction, and hormone-suppression agents.

Oral cancer agents offer a variety of patient benefits. Generally, patients like oral chemotherapy because they can lead more normal lives and experience fewer side effects. There is no need for needle sticks or ports, and fewer office visits are required. On the down side, compliance is a problem. Akscin quoted a study that showed that oral medications were taken on time and in full dosage only 30 percent of the time. While nurses can show patients how to deal with side effects and instruct them in proper drug handling, getting patients and their caregivers to stick to a drug schedule is difficult. "It is a challenge to voluntarily take a pill that will make you feel worse than you already do, even if there are desirable benefits in the long term," Akscin said.

Medicare covers oral anticancer drugs only when there is a non-self-administrable equivalent. Congressionally mandated coverage extensions for select self-administered products (such as immunosuppressive agents, erythropoietin, hemophilia clotting factors, certain oral anti-cancer drugs, and certain oral anti-emetics) do not include a number of existing oral cancer products and are too limited to ensure patient access to new novel oral cancer therapies. As a result, this policy essentially denies Medicare beneficiaries access to the majority of oral anti-cancer therapies that do not have an intravenous equivalent.

"Oncology leaders will have to convince carriers to cover oral agents in the same way they have covered parenteral therapy. Doing so will save lives, improve quality of life and longevity, and result in cost-effective, better outcomes," Akscin said.

Although Medicare reimbursement remains a stumbling block to increased use of oral chemotherapy drugs and supportive treatments, Akscin challenged the cancer care community to change this situation by lobbying the Health Care Financing Administration and intervening in the DMERC licensing and claims process at the local level. He noted that commercial insurance agents may pay for oral chemotherapy, although plans and formulary restrictions vary. While the drugs may be dispensed in the physician's office, regulations differ considerably from state to state, and procedures for storage, labeling, and recordkeeping are stringent.

"Management of these new agents will be very complex, particularly since there is a dearth of data regarding long-term side effects of the newer oral agents. Monitoring treatments will require the development of a whole new technology to measure endpoints. In the end, the success of oral agents will depend on how well they work and who will pay for them," Akscin said.