# A National Voice for Quality Cancer Care in Our Nation's Communities

by Lee E. Mortenson, DPA

The year 2004 marks the 30th anniversary of the Association of Community Cancer Centers (ACCC). Throughout the past three decades, ACCC has served its constituencies always with the same goal—to help ensure that the oncology community has the resources to provide the best in cancer care to people with cancer.

Mission and relevance often slip off the radar of an organization as it matures. How easy it is to fall into the dormancy of continuing to do what you did last year and the year before.

Recently, we learned that the National Association of Breast Cancer Organizations (NABCO), one of the pioneering cancer advocacy organizations, was closing. Amy Langer and her staff made breast cancer a national issue, despite formidable obstacles; now, NABCO was going away. Yet, its rationale for closing also made sense: other organizations had picked up the mantle and were doing the job NABCO had first set out to do.

Three cheers for Amy and NABCO. Once again, they have stayed alert and acted courageously.

ACCC remains wide awake. Our vision and dynamism have allowed the Association to change and meet the evolving needs of the oncology community.

ACCC's approach to its mission also remains clear: Do *whatever it takes* to assure that patients with cancer and their families have access to quality cancer care now, while contributing to the search for better solutions for the future. "Whatever it takes" includes many activities unconventional for any organization.

## The First Years

ACCC has never been the "standard" professional organization. ACCC's membership includes both academic and practical components. It doesn't have classes of membership where physicians are empow-

*(Bottom left) At ACCC's Annual National Meeting in spring 1987, then ACCC President Paul N. Anderson, MD, presents The Edward L. Moorhead Award of Special Merit to ACCC Executive Director Lee Mortenson (at left).*

*(Center) David K. King, MD, FACP, of Phoenix, Ariz., who served as chair of ACCC's Presidents' Retreat for 10 years, received a special 10th Anniversary Award at the 2002 Presidents' Retreat.*

*(Bottom right) Then ACCC President-elect John E. Feldmann, MD, FACP, presented Rodger J. Winn, MD, with ACCC's Annual Award for Outstanding Achievement in Clinical Research in fall 1995.*

ered and the rest of the group views their activities through the looking glass. The Association takes some controversial policy positions when appropriate and has a history of taking on big opponents and not letting go. When working with Congress and the federal bureaucracy, ACCC does its homework and focuses on doing quality studies, finding solutions, and making them work.

ACCC comes by this attitude "honestly." The Association's founding fathers and mothers were determined to build something new, a mechanism that would involve the whole multidisciplinary cancer team: physicians, administrators, nurses, social workers, data managers, pharmacists, and advocates.

In 1974, when we first came together, medical oncology was not yet a formalized medical specialty. Congress and President Nixon had declared war on cancer in 1971 and provided funding for a group of university-based comprehensive cancer centers. Some graduates of those university-based programs went into research, and some went into private practice.

Many who went into private practice immediately realized that cancer care was on the verge of a radical shift, a whole new paradigm. Those who once worked separately had to work together in the patient's management, especially since the multiple drug regimens available at the time were toxic and complicated to administer. J. Gale Katterhagen, MD, an oncologist from Tacoma, Wash., came up with the groundbreaking idea of establishing an oncology unit in his community hospital.

Katterhagen with a few other pioneers founded ACCC. The Association's initial purpose was to spread the gospel of multidisciplinary care and teach other hospitals how to establish an oncology unit.

Clinicians involved with ACCC also recognized the need for specialty-trained nurses who understood oncology care. Fortunately, at the same time a pioneering group of nurses was founding another organization, the Oncology Nursing Society (ONS).

These nurses were peers in every sense of the word.

The idea of a multidisciplinary approach to cancer care is old hat now, but it was revolutionary three decades ago when surgeons dominated cancer care and medical oncologists and radiation oncologists were viewed as interlopers with much to prove. Integrating the cancer care team would take more than a decade.

## An Influx of New Ideas

As medical oncology became a recognized medical specialty in the 1970s, new ideas emerged almost immediately: the need for palliative care, the need to model what a multidisciplinary community cancer center might look like, and the need for community cancer programs to be able to access clinical research.

Answering the need for palliative care came hard on the heels of developing the Association itself. Elisabeth Kubler-Ross, MD, was advocating hospice care in England, but we didn't have anything like it in the United States. ACCC decided to launch a series of U.S. regional meetings with key speakers on hospice from England and Canada. From this spark, an interest in hospice grew in community hospitals and in the voluntary sector.

In the early years, ACCC and its staff stayed involved with hospice and palliative care, but once the National Hospice Organization was fired up and on its own, our involvement ended (temporarily). Later, after hospices developed throughout the nation, some of the stalwarts of the movement appeared to be resisting the idea of Medicare funding, believing that hospice should be an all-volunteer effort. ACCC's Board, being both idealistic and practical, thought that position was shortsighted. After all, without Medicare coverage, far fewer hospices would be viable. So, ACCC partnered with the National Association for Home Care (NAHC) and co-founded the Hospice Association of America—a national association that today represents more than 2,800 hospices and thousands of caregivers and volunteers who serve terminally ill patients and their families.

One of the group's first actions was to secure Medicare funding for hospice.

While the hospice movement was taking root, another critical challenge emerged—creating a model of the essential elements of a community cancer center. Many early models were based on university-based cancer centers, which had distinctly different missions. Under the leadership of ACCC President Bob Enck, MD, a multidisciplinary group of Association members put together standards for each component of a cancer program, building on the foundation of a multidisciplinary cancer program established by the American College of Surgeons (ACoS). Our manual has served as a guidebook for generations of program developers. Eventually, many of ACCC's recommendations were adopted and adapted by ACoS.

At the same time, the National Cancer Institute's Division of Cancer Control began funding some community demonstration programs. The first program, the Clinical Oncology Program (COP) and its successor program, the Community Hospital Oncology Program (CHOP), attempted to determine whether quality cancer care could be delivered in a community setting. Yes, even in the mid-1980s this question was still being debated.

Physicians, nurses, and administrative staff involved in both COP and CHOP were adamant about doing a solid evaluation of quality care as a program component. When the National Cancer Institute (NCI) appeared to be reneging on a promise to do a full evaluation, a number of the programs banded together to do their own, using ACCC as a


*(Top left) National Cancer Institute's Leslie G. Ford, MD, (at left) receives ACCC's Clinical Research Award in fall 1999 from then ACCC President Margaret A. Riley, MN, RN, CNAA.*

*During ACCC's National Annual Meeting, attendees are encouraged to visit the Capitol Hill offices of their respective congressmen. Shown here (center), some ACCC members meet in the congressional office of Sen. Olympia J. Snowe (R-Maine) in 2003.*

*Key congressional legislators and policymakers are invited speakers at ACCC meetings where they provide insight into pressing public policy initiatives. Congressman E. Clay Shaw, Jr. (R-Fla.) (second from right) was a featured speaker at ACCC's 29th Annual National Meeting in Washington, D.C., in March 2002.*

*ACCC hosts two national meetings each year. Far right, "Spenser for Hire" and "Vega$" TV star Robert Ulrich, who was diagnosed with synovial cell sarcoma, was the keynote speaker at ACCC's 27th Annual National meeting in March 2001. ACCC also hosts an annual National Oncology Economics Conference that is held each fall.*

forum to bring the data together. Eventually, NCI followed through with its own evaluation. Both evaluations demonstrated similar results: quality cancer care was a reality in communities across the nation.

As you can imagine, given questions about the ability of the community to deliver quality cancer care, the idea that community oncologists should participate in clinical research was at first controversial. Over the years, ACCC presidents, including Katterhagen, Enck, and Paul Anderson of Colorado Springs, Colo., along with Bill Dugan, MD, from Indianapolis and Bob Frelick, MD, from Delaware, all championed clinical trials in a community setting. Still, it took more than a decade to develop and demonstrate that there was an infrastructure that could support the development of clinical research in the community.

The key catalyst in bringing research to community cancer programs was another ACCC president, Edward L. Moorhead, II, MD, from Grand Rapids, Mich. Together, Moorhead and Dugan campaigned for clinical trials in the community. They argued that not only could it be done, it *had* to be done. Where else were the large cooperative clinical trials groups going to have access to cancer patients who no longer traveled to university-based cancer centers?

Vince DeVita, Jr., MD, the director of NCI at the time, was skeptical. Where was the infrastructure to support trials? The data managers? The fiscal intermediaries? Moorhead rose to the challenge and barnstormed the country, developing an ACCC manual on what was needed to conduct clinical trials in a community setting. He and Dugan testified before Congress on the need and value of clinical trials in the community.

DeVita, to his credit, decided to give the idea a chance.

Then, a number of arguments developed about how to shape an actual NCI-funded program. Katterhagen, at this point a member of the National Cancer Advisory Board (NCAB), used his considerable talents of persuasion to quarterback the ideas through NCI's maze. David Johnson, a hospital CEO and one of ACCC's first administrator presidents, worked with Katterhagen and NCI staff to put together a program that everyone believed was workable. Community clinical oncology programs (CCOPs) and Cooperative Group Outreach Programs (CGOPs) became a reality.

For a time, clinical trials data from the community were segregated from university data, at least until Charles Coltman, Jr., MD, and Charles Moertel, MD, said that their analyses showed community contributors had higher quality data and were more likely to stick with the protocols than their university counterparts!

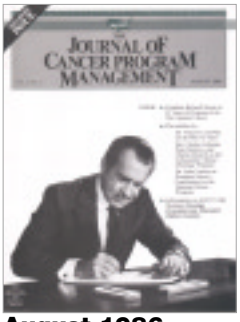
Moorhead and company were lucky to have Jennifer L. Guy, RN, as a successor ACCC president. Guy had a reputation as the best data manager in the country and taught many of the initial programs how to do the data collection and do it well. Her own program in Columbus, Ohio, was held up as the most exceptional quality clinical trials contributor to several groups for a number of years.

As time went on, ACCC Presidents Carl Kardinal, MD, and John Feldmann, MD, helped expand opportunities for community oncologists to participate in clinical trials from NCI and industry sources. Kardinal continues to head up ACCC's CCOP and Community Clinical Research

Committee, a common meeting ground for CCOPs with different primary research bases.

## Economics Takes a Bite

More than a few ACCC presidents received battle scars. Paul Anderson, MD, was one of those who received his share. He had a "whatever it takes" attitude in his fight for quality CHOP evaluation and then proceeded to take on an even bigger hot potato—the need to look at the impact of reimbursement on quality of care. Anderson and his ACCC Board held the first ACCC National Oncology Economics Conference (now our fall meeting) in 1983. He received hate mail from a number of academics and more than a couple of community practitioners. How dare ACCC bring money discussions into a world where only quality of care mattered? We did not disagree—quality of care was foremost—but the world of medicine was changing, and fast.



**August 1986 (Premier issue of ACCC's Journal)**

**Winter 1989 (With the new journal name)**

**May/June 1994**

No sooner were community clinical trials a reality, then diagnosis-related groups (DRGs) surfaced. ACCC's first forays into the economics of cancer care prepared us for some of the realities of prospective payment, but others were surprises. For example, the DRG for chemotherapy was the lowest paid of all DRGs and set well below any hospital's ability to keep a cancer patient as an inpatient. Suddenly patients were moved from inpatient status to physician offices (now a common location for chemotherapy and supportive care). We had the good fortune of the first supportive care drugs becoming available just as this shift was happening, making the idea of providing chemotherapy for many patients on an outpatient basis more of a possibility.

Nonetheless we could see the conflict between Medicare's payment policies and clinical research.

In 1983 ACCC President John Yarbro, MD, PhD, and I wrote an article about this conflict that was published in *The Journal of the American Medical Association* (*JAMA*). The head of HCFA responded and said that clinical trials were covered…all the way up to the payment for the DRG. This long-running debate involved NCI and HCFA in lengthy and unproductive discussions and increased our concerns. Not until the Clinton Administration did we finally see action on our concerns, and the answers are still often ambivalent.

Yarbro, by the way, had a lasting impact on the Association. He was at NCI and head of the Cancer Centers Program when ACCC was first founded. His prodding (backed by a small seed grant) resulted in the name change from the Association of Community Cancer Programs to the Association of Community Cancer Centers. His guidance was essential in the clinical research debates and also in the early reimbursement discussions.

## Money, Cancer Care, and State Oncology Societies

The 1980s was the decade when community cancer centers began struggling with rapidly escalating healthcare costs. Economics and financial issues began to dictate how an oncology patient would be treated, and many hospitals and physicians held that too often these cost-savings attempts were coming at the expense of patient care.

DRGs, managed care organizations, and then—by an oversight—some changes in medical oncology coding caused several key codes to be eliminated at the suggestion of the American Society of Clinical Oncology (ASCO). It was a sad mistake; a comedy of errors really. By the time the mistakes were uncovered, the Current Procedural Terminology (CPT) book was already at the press and the damage was done.

Many practitioners were angry, and a number of state oncology associations were formed in part as a protest. Nonetheless, the ACCC Board saw the real potential for state-level cancer organizations: local insurance policies were affected by local practitioners who, under law, set the local standards of care. State societies could be a key foundation for national political action; they could be important in affecting state legislation that might be necessary (and soon they were).

ACCC decided to champion the idea of state oncology societies in the mid-1980s. By that time David King, MD, of Phoenix, Ariz., was involved, and a great many of ACCC's innovative ideas can be traced to King's leadership. ACCC established a new category of state chapters and began to support the development of state societies by co-sponsoring regional ACCC meetings, and eventually serving as a management organization (today we serve 14 state organizations).

The value of state societies was apparent when the off-label issue emerged in the 1990s. At a meeting between the National Blue Cross and ACCC in Chicago, we learned that insurers were considering declaring everything not on the FDA label (i.e., off-label) "experimental" and ending coverage. We realized this change would have been a huge blow to oncology. A formal ACCC study (the first of many) was validated by a General Accounting Office analy-

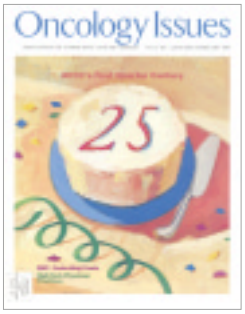
sis. Both studies found that 50 percent or more of cancer care is given off-label, confirming our worst fears.

King and his ACCC Board decided that "whatever it takes" included getting legislation passed in states around the country that defined off-label and that also provided legitimate sources for off-label recommendations. That campaign eventually led to 39 states adopting ACCC's model legislation along with Medicare and Medicaid. State societies were crucial in making off-label legislation happen.

And then ACCC needed to develop a way to make certain that everyone was kept current with new off-label recommendations. On the back of a napkin in a bar in Columbus, Ohio, King developed the *Compendia Bulletin* format. ACCC launched its *Compendia-Based Drug Bulletin*, a quarterly compilation of all cancer-related drugs and indications listed in the major compendia. The goal of ACCC's new publication was twofold—to educate insurers and third-party payers about the information contained in the compendia and to close the time gap between when a new indication or drug is recognized by the compendia and when it is recognized (reimbursed) by payers.

That led to a number of other initiatives, including a great deal of work with the U.S. Pharmacopeia (USP) on its off-label review process. Yarbro initially, and more recently, ACCC President Ed Braud, MD, of Springfield, Ill., both served on the USP oncology committee and assisted in streamlining the review process.


**March/April 1997**




**January/February 1999 (At 25 years)**


**March/April 2002 (After the 2002 redesign)**


**November/ December 2003 (What it looks like today)**

## A History of Successful Advocacy

Off-label legislation, state oncology societies, and DRGs led inexorably to ACCC's greater involvement in national politics and another generation of Association leaders. Ensuring adequate reimbursement for cancer care became a top priority and ACCC's Ad Hoc Committee for Reimbursement was set up. Until recently, when the committee finally lost its "ad hoc" prefix, King was fond of saying that he was chairman of the longest standing ad hoc committee. "We set up the committee," he says, "as 'ad hoc' because we expected the issue to be 'fixed' pretty quickly. The joke was on all of us."

Two ACCC presidents with some political horse sense, Jim Wade, III, MD, of Decatur, Ill., and Al Einstein, Jr., MD, now of Seattle, Wash., worked with King and ACCC staff to see what we could do to stem a tide of reimbursement policies that threatened (and still threaten) to reverse the progress of our basic mission: to assure that cancer care is readily accessible to patients and their families in their home communities.

HCFA, now called the Centers for Medicare & Medicaid Services (CMS), presented a series of challenges to payment in both hospital and practice arenas throughout the late 1990s. Several times, without congressional permission, the agency arbitrarily lowered payments for drugs in both settings. Working with a coalition of other organizations, ACCC mobilized its membership to seek congressional support. And in two cases, we succeeded.

Congress joined in the criticism of the current payment system in the late 1990s, launching GAO and CMS investigations. Pointing to the potentials for abuse and profits in the drug mark-ups, Congress began developing legislation to change the payment systems for drugs.

The first major initiative was the proposed Ambulatory Payment Classification (APC) System. The original version of this payment system deeply underpaid oncology drugs, which ACCC was able to prove to Congress and GAO using data obtained from HCFA and analyzed for ACCC by several outside consulting firms. Two years of hard work with Congress produced APC "fix" language that was largely crafted by ACCC, resulting in payment of chemotherapy and supportive care drugs at average wholesale price (AWP) minus 5 percent. This major victory for cancer care providers was short lived. By 2002, CMS was once again under-reimbursing oncology drugs in the hospital setting. Collaborating with other oncology organizations, ACCC worked to stop similar actions on the office practice level.

In 2002 and 2003 ACCC undertook to convince Congress that underpayment to hospitals was a mistake. Once again, we used a data-driven approach, leading to a legislative proposal drafted by ACCC and introduced by Representative Clay Shaw of Florida. The bill (H.R. 5450) was largely ignored by CMS in its final rule released in October 2002, leading to a second year of drug underpayments. Some sole-source drugs were now being paid as low as 50 to 60 percent of AWP.

Work by ACCC throughout 2003 culminated in the incorporation of Shaw's legislation in the Medicare Prescription Drug, Improvement and Modernization Act (DIMA) signed into law in Dec. 2003. Our language did more than bring hospital outpatient drug prices to breakeven. The new law also lowered the bundled drug amount to $50 and insisted that drugs without a C-code be reimbursed at AWP minus 5 percent. While ACCC supported efforts by a coalition of medical oncology

organizations to alter office payment, it took sole responsibility for fixing the hospital outpatient funding, and our data-driven approach prevailed.

### United in the Fight

To meet the ever-changing challenges facing both hospital-based and office-based cancer programs, ACCC leadership believed there was a need to mobilize its own resources and to work on collaborative activities with other organizations, such as ASCO, ONS, the American Society of Hematology (ASH), and the state societies, to develop joint policy initiatives on both fronts.

Fostering collaboration among organizations is a natural extension of ACCC's fundamental multidisciplinary orientation and led to ACCC's Presidents' Retreat. This annual meeting brings together all the oncology state society presidents and the leadership of the other major oncology organizations to exchange views on national and state policy issues. Throughout the 1990s and into the new millennium, ACCC has encouraged the major provider groups to coordinate their legislative activities, and, with ONS, has trained a cadre of physicians, administrators, and nurses who are savvy about affecting policy issues on the state and national levels. Four ACCC presidents have had profound effects on these collaborative activities. Diane Van Ostenberg, RN, was a champion of interacting with the patient advocacy groups. Terri Smith, RN, MSN, and Maggie Riley, MN, RN, CNAA, supported broad initiatives including ONS and the other physician and administrative provider groups. Larry White, MD, made certain that we focused attention on radiation oncology at hospitals and freestanding facilities.

Three decades and counting. ACCC is still relevant and still on mission because as times have changed, so have we. ACCC's incredible flexibility and strong infrastructure are not an accident. Three ACCC presidents had a significant hand in formulating a functional structure that is unlike any other association. Bob Clarke, CEO of Memorial Hospital in Springfield, Ill., was the principal architect. He created a structure that allows the membership and the Board to set the fundamental direction of the organization each year and provides the staff with incentives to stay on target and on task. Few non-profits are so business-oriented. In addition to Clarke, former ACCC Presidents Lloyd Everson, MD, from Houston, and Irv Fleming, MD, from Memphis, had a great deal to say about the flexibility of the organization and played a major role in defending the Association against attempts by outside organizations to influence its policy-setting role.

As unique as our organization may be, with medical oncologists, radiation oncologists, surgeons, academics, practitioners, oncology nurses, hospital administrators, practice administrators, and pharmacists all at the same table, our leadership has always found it easy to agree on what should be done and who should be helped. When physicians have been in trouble, the administrators have said, "Let's get in this fight." And when hospitals are under attack, physicians have often led the defense. When oncology nurses have been given short shrift, the entire organization has made it clear that nurses are equal partners at the table.

What unites us is a common goal: getting the job done for cancer patients and their families…whatever it takes!

*Lee E. Mortenson, DPA, is executive director of the Association of Community Cancer Centers in Rockville, Md.*

# Bringing Clinical Trials to Community Cancer Centers

by Monique J. Marino

The year 2004 marks two milestones for the oncology community—the 30th anniversary of the Association of Community Cancer Centers *and* the 20th anniversary of the Community Clinical Oncology Program (CCOP). Those new to ACCC may not fully understand the integral role the Association played in the development of the CCOPs, but in reality ACCC was the key organization that spearheaded the effort to bring clinical research into community cancer centers. And, as ACCC's Executive Director Lee E. Mortenson, DPA, said, it all started with one phone call from former ACCC President Edward L. Moorhead, II, MD, who uttered these words:

"How 'bout ACCC putting together a 'White Paper' on involving the community docs in research trials and giving it to Congress and the NCI."

ACCC's White Paper turned out to be a handbook on how to develop a community-based clinical trials program. With this tool, Moorhead, Mortenson, and William Dugan, Jr., MD, barnstormed the country, holding workshops and talking to community oncologists interested in setting up these kinds of programs. ACCC also began intensive lobbying efforts on Capitol Hill and at the National Cancer Institute.

And now, as Paul Harvey would say, here's the rest of the story.

Prior to the early 1970s, clinical trials in cancer were primarily conducted at universities. But times were changing. Moorhead, William Dugan, Jr., MD, former ACCC President Robert W. Frelick, MD, former ACCC President Gale Katterhagen, MD, and a handful of other individuals began campaigning under ACCC's banner to involve community physicians in clinical research. An increasing number of well-trained medical oncologists and hematologists were entering community practice, and more than 80 percent of all patients with cancer were being treated in community settings. Indeed, community cancer programs had already proven their ability to handle federal funds and requirements in two earlier programs: the Clinical Oncology Program (COP) to stimulate community hospital cancer programs, and the Community Hospital Oncology Program (CHOP) to develop cancer management guidelines.

"Some of us [community physicians] became familiar with [cancer] drugs used in the 1950s, such as 5 FU, chlorambucil, cyotxan, methotrexate, and others," Frelick said. "Occasionally, pharmaceutical companies sought out community physicians to test new cancer drugs, and a few of us became involved in a cooperative group."

Congress and the NCI (under the leadership of forward-thinking Vincent DeVita, MD) saw this shift in care and recognized the potential of involving community oncologists in cooperative clinical trials. Two programs were launched—the Cooperative Group Outreach Program (CGOP) to recruit community oncologists to learn about and from clinical research studies, and the Community Clinical Oncology Program (CCOP) to expand community involvement in cooperative group clinical trials. ACCC, the American Society of Clinical Oncologists (ASCO), and the American Cancer Society were instrumental in making this happen.

"It also helped to have Gale Katterhagen on the National Cancer Advisory Board helping emphasize the credibility of community hospital oncologists," said Frelick, who in 1982 joined the NCI and soon became project officer for the CCOPs.

In 1982 it was hard to imagine that oncologists in community hospitals would end up playing such an essential role in cancer research. But by the end of the 1980s, the CGOP and CCOP approach had turned the cancer research equation upside down.

"The CCOP gave community hospitals the authority to provide state-of-the-art care in the communities where patients lived," Frelick said.

Several clinical cooperative oncology trial groups operate under NCI sponsorship—the Southwest Oncology Group (SWOG), the National Surgical Adjuvant Breast and Bowel Project (NSABP), the Eastern Cooperative Oncology Group (ECOG), and many others. In the past, membership to these groups had been restricted to physicians based at large universities or teaching institutions. With the advent of CCOP and CGOP, more and more community cancer centers were able to participate in these cooperative clinical trials.

For example, in 1986, CGOP had 467 investigators at 203 CGOP institutions. By 1993, membership had swelled to 1,347 investigators at 309 CGOP institutions. In 2002, 51 CCOPs had been established, with 358 participating hospitals, 2,334 physicians actively accruing patients into clinical trials, and 1,123 physicians referring patients to clinical trials.

In the early 1990s, ACCC was the first oncology group to recognize the latest threat posed to clinical research—federal rules and regulations that focused on reimbursement and which, at least initially, excluded patients on research studies. ACCC invested an enormous amount of time and energy ensuring adequate reimbursement for NCI research efforts, with the ultimate goal of reducing patient suffering and death from cancer.

Today, thanks in large part to efforts by Leslie Ford, MD, associate director of clinical research at NCI, and her staff, the CCOPs have successfully accrued more than 90,000 patients to NCI studies, which now include cancer control as well as treatment research. ACCC-member institutions are involved in most of NCI's cooperative research group activities and participate in numerous pharmaceutical-sponsored drug research studies.

On the eve of ACCC's 30th anniversary, cooperative groups and intergroup mechanisms have allowed oncologists in even the smallest communities to access important clinical research studies. The result: patients benefit by being able to receive the most current treatment, doctors benefit by being able to participate in state-of-the-art research, institutions benefit by being able to keep and treat patients in the community, and science benefits by increasing patient accrual, thereby decreasing the timeline for study completion.

*Monique J. Marino is managing editor at the Association of Community Cancer Centers in Rockville, Md.*

# The Changing Role of the Surgeon in Oncology Care

by Richard B. Reiling, MD, FACS

Thirty years is a long time in modern medicine, and the evolution in medicine and surgery has been galactic.

In the 1970s, surgeons finally relinquished the concept that "more is better" in surgical resections. Modifications of the classical Halsted radical mastectomy, the "gold standard" for almost 100 years, were just being abandoned and not without a struggle. Prior to this, almost all patients were being advised to have some variation of a complete mastectomy and near complete removal of axillary lymph nodes, and it was not until the 1980s that we saw a determined move to breast-sparing surgery for cancer.

Today, we are experiencing greater than 75 percent breast-sparing surgery. Reconstructive surgery, which is almost routine in breast cancer care today, was clearly looked upon with great skepticism 30 years ago.

Precision in radiologic localization and pathologic determination have increased the sensitivity of the surgical approach to remove only the minimally necessary tissue and, at the same time, to remove enough tissue to approach cure or long-term survival. Most recently the perfection of the sentinel lymph node techniques, especially for melanoma and breast cancer, has been useful in determining prognosis and extent of surgical extirpation, as well as the need for radiation and chemotherapy.

Minimally invasive techniques have taken over a great share of the thoracic and abdominal surgical procedures. Today, the scope of minimally invasive surgery is only limited by the equipment and experience of the surgeon. Even some of the concerns, such as port site recurrence, are being shown to be independent of the type of surgery. Major intra-abdominal surgical resections are and have been done by laprascopic techniques, for example, the Whipple procedure for pancreatic carcinoma and adrenalectomies. Even some forays into the neck for thyroid tumors are being done with minimally invasive techniques.

In the 1970s, as the Association of Community Cancer Centers was being formed, the surgical specialty of oncology was only loosely defined. Most oncologic surgery was done by general surgeons and general subspecialists, such as ear, nose, and throat; orthopedics; neurosurgery; and urology. Today, surgical oncology is an established specialty of general surgery, with the other specialties formally recognizing the need for a special expertise in cancer care.

However, as we enter the 21st century, interventionalists, such as radiology and gastroenterology, have assumed many of the responsibilities formerly carried out by the surgeon. The surgeon is no longer the major influence in the treatment planning for a patient's cancer care, even though the surgeon, especially the general surgeon, is the first point of contact that the patient has with cancer care. Clearly the protected realm of cancer diagnosis is no longer that of a surgeon, and it is reasonable to assume that the trend will continue.

Today, the increasing demand by patients and their families for second opinions is now being met in the form of multidisciplinary planning and clinics. Cancer conferences in lock step have evolved from a "show and tell" education experience to a prospective correlative clinic and planning session.

Surgeons now work side-by-side with medical and radiation oncologists in devising treatment plans that combine the modalities and the timing of the various approaches. Such neoadjuvant chemotherapy was almost unheard of 30 years ago. Crude intra-operative radiation therapy is now being resurrected with sophisticated treatment planning and techniques to provide intra-operative and peri-operative adjuncts to care.

This progress will certainly continue and the pre-eminence of major surgical procedures for cancer will diminish. Robotic and minimally invasive techniques will almost completely replace more gross procedures. The integration of immunologic, genetic, and tumor biology into planning and treatment will become commonplace. Patients will expect and deserve thorough planning and treatment. Evidence-based care will become the required standard.

I only wish I could be around for another 100 years and rewrite this synopsis. "You've come a long way, Baby!" Thank you.

*Richard B. Reiling, MD, FACS, is medical director of The Presbyterian Cancer Center in Charlotte, N.C.*

*Over the past 30 years, ACCC has grown and matured from an organization focused on hospital cancer programs to an organization representing all of the cancer provider constituencies. The Association's agenda has broadened from developing community hospital cancer programs to a range of issues that include clinical research in the community, off-label drug reimbursement, state oncology societies, clinical trial reimbursement, hospital-based and office-based chemotherapy reimbursement, radiation therapy reimbursement, multidisciplinary program activities, and membership education. ACCC is now widely recognized for its leadership and representation for community oncology.*

*On the eve of its 30th anniversary, the organization is positioned to continue to provide advocacy and education for its members while encouraging the multidisciplinary approach to current issues. Many individuals have contributed over the years to ACCC's growth and success. We should all be proud of what we have achieved and optimistic for the future of the organization.*

*Albert B. Einstein, Jr., MD, FACP*
*ACCC Past President*
*Executive Director*
*Swedish Cancer Institute*
*Swedish Medical Center*
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# An Insider's View on Medical Oncology

by David King, MD

As part of ACCC's 30th anniversary, I was asked to write a few thoughts on how the field of medical oncology has changed over the last 30 years. Reflecting on the last three decades, many changes come to mind.

Clearly, the tools that we work with have changed significantly—mostly for the better. New cancer drugs, such as Gleevec®, have dramatically improved the treatment of patients with cancer. Additionally, our ability to reduce the side effects of these chemotherapy drugs has also improved by leaps and bounds. Sophisticated cancer care is now available in many local communities where it did not exist 30 years ago. The contribution of the community cancer center to clinical research has been well documented. (See article on page 38.)

Some issues, however, have not changed. While the information and education provided to patients and their families through the lay press and the Internet have improved, the amount of misinformation has likewise increased. The newly diagnosed patient with cancer still presents to us in a fearful state. The part of our job that involves counseling and education of our patients and their families has changed little, and continues to be important—sometimes even more important than the therapy we provide.

The area of change that has caused the most concern and, at times, outright fear is unfortunately reimbursement for services provided. In 1975 as I entered private practice, I *knew* that if I could only be a good medical oncologist, my income would be assured. Now after many years of dealing with the alphabet soup of HMOs, PPOs, HCFA, CMS, AWP, ASP, RBRVS, OPPS, and so forth, I have concluded that my training was woefully inadequate.

Today's medical oncologist must have an understanding of business practices, accounting, finance, and negotiation to survive. Perhaps even more important, today's oncologist must balance what's right for the patient and what's right for a financially viable practice. This balancing act has been a concern of mine for years, since I have seen the pendulum swing more toward the financial viability aspect. Today, many community cancer programs are forced to make decisions based on reimbursement issues and not just on what is right for their patients. After many years of practice as a medical oncologist, my only consolation is my conviction that the overwhelming majority of my friends and colleagues continue to think of their patient first and strive to do what we all set out to do originally—treat our patients as our most precious resource.

*A past ACCC President, David K. King, MD, is in private practice at Internists, Oncologists, Ltd., in Phoenix, Ariz.*

# Radiation Oncology: 1973-2003

by Dale Fuller, MD, FACR

The changes in the delivery of radiation therapy in the last 30 years far transcend the magnitude of all of the changes in the field since its beginning in 1896. We have seen changes in the technology we use; changes in imaging leading to more precise localization of tumors; and changes in the availability of services due to a doubling in the number of facilities offering radiation therapy—from 1,090 facilities in 1977 to an estimated 2,000 such facilities today.

We must also pay tribute and recognize some of the giants whose work laid the foundation for our discipline. While many names are on this long honor roll, Henry S. Kaplan, MD, Gilbert H. Fletcher, MD, and Juan del Regato, MD, are among the greatest contributors. In fact, the American Society for Therapeutic Radiology and Oncology (ASTRO) honored these three physicians with its first-ever Gold Medal Award in 1977.

These three men began their professional journeys as radiologists and became specialists in radiation oncology when the field was then known as therapeutic radiology. Dr. Kaplan applied a scientist's curiosity to acquiring an understanding of the natural history of Hodgkin's disease, until then an incurable disease, and devised an approach to curing it with radiation therapy. Dr. Kaplan went on to become a pioneer in the field of molecular biology as it applied to the treatment of cancer. He also highlighted the importance of a multidisciplinary approach to the treatment of cancer.

Dr. Fletcher is considered one of the founders of modern radiation oncology. His work involved understanding the role of irradiation in controlling

*It seems like only yesterday that ACCC was battling the National Cancer Institute to fund clinical trials research in community hospitals, that ACCC was arguing with Congress for DRG exemptions…and so on…until 30 years have come and gone. Critics called these efforts contentious, feisty, even obnoxious, while others recognized these words as mere synonyms for leadership. As the future of healthcare evolves in the coming years, ACCC must continue to provide this intrepid leadership in understanding and managing changes in our healthcare system.*

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*ACCC Past President*
*Professor of Medicine*
*Chief, Hematology Oncology*
*Drexel University College of Medicine,*
*Philadelphia, Pa.*

sub-clinical disease, and the relationship between tumor volume and the amount of irradiation required to have a 90 percent probability of eradicating a cancer. His efforts led to major advances in the management of cancer in the head and neck area and in gynecologic malignancies.

*One of ACCC's major contributions has been its role in promoting clinical research in the oncology community. ACCC had the insight to promote the development of the National Cancer Institute's Community Clinical Oncology Program (CCOP) in 1982. Our institution, the Ochsner Clinic Foundation, applied for and was awarded one of the initial CCOP grants in 1983 and has remained continuously funded since that time. The CCOP program has promoted the improvement in quality cancer care in this and surrounding communities, which has always been ACCC's primary goal.*

*Still, the oncology community that ACCC has served for 30 years faces great challenges; not the least of which is ensuring adequate funding for chemotherapy administration and clinical research efforts. As ACCC enters its next 30 years of service, it is and has always been aware of these funding and reimbursement problems and will ultimately help to resolve them.*

*Carl G. Kardinal, MD*
*ACCC Past President*
*Principal Investigator Ochsner CCOP*

Dr. del Regato, along with his pathologist colleague Loren Ackerman, MD, helped us gain an understanding of the behavior of malignant disease. Dr. del Regato's monumental textbook *Cancer* was published in a number of editions. He was a charismatic clinician and teacher, as were Drs. Kaplan and Fletcher, and Dr. del Regato influenced many young physicians to enter the field of radiation oncology. Many of these physicians have become leaders in their field today.

These three "giants" in radiation oncology helped us move from the application of knowledge gained empirically through retrospective observation to our current role as clinicians with a solid understanding of the natural history of malignant disease. Much of this transition has occurred within the last 30 years and has had its genesis in the unrelenting work and leadership of men such as these. Without their contributions to our clinical knowledge of cancer, all of the new technology would not have added significantly to our ability to benefit our patients.

Today, we are able to cure more cancers with fewer long-term side effects from radiation using new technology such as IMRT and PET. Still, the radiation oncology community faces new challenges, not the least of which is ensuring adequate reimbursement for these new treatment modalities. In 2004 radiation oncology experienced major payment cuts under the changes to the final OPPS rule that took effect Jan. 1, 2004. What these cuts will mean to community cancer programs remains unclear, but ACCC continues to monitor the impact of these reduced payments. And, even as we celebrate ACCC's 30 years of service, the organization continues its efforts to ensure adequate reimbursement for all cancer services so that we may continue to successfully treat our patients with cancer.

*Dale Fuller, MD, FACR, is a radiation oncologist at St. Paul University Hospital in Dallas, Tex.*

# Oncology Nursing: What a Difference Three Decades Make

by Jennifer L. Guy, BS, RN, OCN®

Oncology nursing has changed dramatically since 1974. The 1970s saw the gown-to-town shift in providing cancer care and precipitated a need for trained oncology nurses. Nurses evolved from clinical trials data collectors to active participants in the management of patients with cancer. At that time, oncology nursing as a specialty had not yet been defined or recognized. Little formal education in cancer nursing existed and training was primarily "on-the-job," but change was underway.

In July 1975, the Oncology Nursing Society (ONS) was established. In 1984 the Oncology Nursing Certification Corporation (ONCC) was created, and in 1986 ONCC administered the first Oncology Certified Nurse (OCN®) examination. Today, ONCC also certifies advanced practice oncology nurses (AOCN®) and pediatric oncology nurses (CPON®).

As of December 2003, ONS had grown to 29,490 national and international members and 218 local chapters. Subspecialties in oncology nursing (bone marrow transplant, radiation oncology, office oncology, etc.) have evolved. Doctoral programs and advanced practice curricula are now available. Back in 1974 the designation of clinical nurse specialist was new, and these members of the healthcare team worked in the hospital. Today, advanced practice nurses are instrumental in optimizing cancer care in all settings.

What oncology nurses do has changed significantly since 1974. Thirty years ago, we worked mostly on inpatient oncology units. Today, we work predominantly in outpatient settings. In the past, surgical oncology nurses cared for patients recovering from mastectomies, laparotomies, total lymph node dissections, and thoracotomies. Today, these same nurses care for the small incisions of lumpectomies, laprascoic surgeries and sentinel lymph node biopsies, and assist with percutaneous needle biopsies done in outpatient surgery and radiology.

In 2004 radiation oncology nurses assure sophisticated positioning under linear accelerators to deliver conformal radiation as opposed to using solder to outline ports and lead bricks to block normal tissue from cobalt radiation as they did 30 years ago.

Today, chemotherapy is prepared by oncology pharmacists using protective equipment. Nurses administer combinations of antiemetics to help with nausea, vomiting, and dehydration. Oncology nurses administer growth factors and cytoprotectants instead of treating cytopenias, sepsis, and stomatitis. Central venous access devices have shifted much of bone marrow/stem cell transplant care to the outpatient setting. Teaching patients self-care, telephone triage, home care, and hospice are integral parts of oncology nursing practice today.

Since 1974, changes in payment for healthcare have altered oncology nurses' interactions with patients. Thirty years ago, oncology nurses rarely discussed how the patient would pay for his or her care. Today, financial issues are a mandatory part of the initial nursing assessment. Oncology nurses seek financial assistance for patients and spend time communicating (and occasionally arguing) with insurers about what care will be reimbursed. Oncology nurses must sometimes inform patients of non-coverage and assist them in making decisions about alternative management.

In 1974 oncology nurses were politically naïve. ACCC introduced the oncology community to medical politics and encouraged nurses to participate in important legislative and regulatory issues. Today, oncology nurses are politically active and a formidable lobbying force.

The relationship between ONS and ACCC continues to grow and strengthen. The two organizations have partnered on a wide range of initiatives, including co-hosting a number of policy institutes to educate legislators about issues important to those providing cancer care. On April 18, 2002, ONS honored ACCC's Executive Director, Lee E. Mortenson, DPA, with the ONS Honorary Member Award in recognition of his significant and outstanding contributions to oncology nursing. In 2003 ACCC sponsored a two-day educational program designed to provide nurse leaders with strategies for creating a more caring and appreciative work environment for their nursing staff and to improve nurse satisfaction in their daily work.

As the cancer care environment evolves, oncology nurses will continue to meet the challenges it presents. Perhaps by ACCC's golden anniversary, oncology nurses will spend their time administering only prophylactic cancer care that is readily and adequately reimbursed without legislative actions!

*A past president of ACCC, Jennifer L. Guy, BS, RN, OCN®, is a consultant and medical writer for Gafus Enterprises in Columbus, Ohio.*

# The Changing Role of the Cancer Administrator

by Luana R. Lamkin, RN, MPH

If you're an administrator in your 30s, your first thought is probably, "Were there cancer administrators in 1974?" There weren't many. But even back in those dark ages, it was a new and growing field.

The mid-1970s were the heyday of the double-digit annual rise in the cost of providing healthcare. Private insurers paid what we billed and Medicare paid under DRGs, but the DRG payments were significantly more generous than those of today. We also were not offering therapies like IMRT and PET that are extraordinarily expensive to provide. The average length of hospital stay was about nine days in 1974, and the vast majority of chemotherapy was delivered to inpatients. In my community, no chemotherapy was given in physician offices. There was absolutely no marketing, no billboards, and no overt competition.

We talked about quality then, but in truth we were just looking at the mistakes we knew were happening. At that time, national care standards did not exist—not even benchmark data. Still, the healthcare industry was beginning to recognize that cancer was different; it required a multidisciplinary and interdisciplinary approach to care. Specialists were rare in community hospitals, but they were beginning to see the need to band together, learn from one another, and create an organization that provided resources, standards, and a voice—ACCC was born.

While other resources were available, such as the Oncology Nursing Society (ONS) and the American Society of Clinical Oncology (ASCO), there was, of course, no Community Clinical Oncology Program (CCOP), no National Comprehensive Cancer Network (NCCN), and very few consultants to rely upon.

Hospices were flourishing, but complementary treatment and palliative care were relatively unknown. The American College of Surgeons (ACoS) was accrediting cancer programs primarily based on a card catalogue of analytic patients in the Tumor Registry department and the presence of tumor boards.

Academic oncology programs were available for physicians and were starting for nursing, but there

was no such training for cancer administrators. In fact, the MBA in health management was a rarity, and few programs were led by administrative or medical directors at the time. The healthcare workforce shortage did not exist. And, while many of them were not cancer specialists, plenty of nurses and physicists were available who truly wanted to care for people with cancer.

Perhaps the most significant difference between today and the oncology community of 30 years ago is in the people and their attitudes. Back then, we were just learning from Elisabeth Kubler-Ross, MD, that people with cancer want to know the facts and deal with them. This approach was such a departure from the way we had cared for patients previously that it invoked dry mouths and sweaty palms among the best clinicians.

In retrospect, I can sum up the difference I see in one word: *Respect*. We have learned to treat patients with greater respect and individuality. We have gained the respect of the rest of the medical community for having a specific body of knowledge. We have the respect of the administrative community as a service line that can make or break the financial health of an organization. We have gained the respect of our legislators. And I believe we have gained the respect of our patients.

*Luana R. Lamkin, RN, MPH, is administrator of Cancer Services OhioHealth in Columbus, Ohio.*

*ACCC has been a key organization advocating for standards of excellence in cancer care in this country. This milestone has been achieved through listening to community-based cancer programs, engaging patients and professionals in dialogue, inviting payers and providers to forums for exchange and resolutions, creating legislative agendas from the ground swells of concern, and insisting on action at all levels for the greater good to be served.*

*Ensuring quality cancer care has been a goal taken up since the infancy of the Association and will continue to be taken up by those who serve and those who are served, together in partnership with each other. More than any other time, collaboration and commitment to purpose will be the challenge for the future of oncology. The dynamic and complex nature of our healthcare delivery systems demands fortitude and focus on the part of both patients and providers in order to preserve standards of care and to pursue the next horizon of excellence. ACCC is the think tank for our future as the cancer care community—those involved—will be a part of the next steps in the solution for maintaining excellence.*

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## The Evolving Role of the Pharmacist

by Ernest Anderson, RPh

In many ways, the role of the oncology pharmacist has evolved in tandem with the role of the pharmacist in hospital pharmacy practice over the past 30 years. Looking back over this period, several events have helped to shape this role.

Thirty years ago, pharmacists compounded chemotherapy for inpatients in some hospitals using a laminar flow hood. Still, many hospitals did not have this capacity, and the nursing staff compounded the chemotherapy on a "clean counter" or on top of the medication cart. In those hospitals that had an outpatient chemotherapy area, nurses typically would manufacture any chemotherapy to be administered.

Slowly, over time, hospital pharmacies began inpatient IV additive programs and began to manufacture antibiotics, large volume parenterals, IV hyperalimentation, and chemotherapy for inpatients in a horizontal laminar flow hood. The number of chemotherapy medications was small. Some chemotherapy was administered by continuous infusion.

As is often the case, reimbursement impacts the type and location of care provided to patients. In the 1980s, with the advent of the new Medicare Prospective Payment System (PPS) utilizing Diagnosis Related Groups (DRGs), an incentive was created to move patient care from the inpatient setting to the outpatient setting. Some hospitals set up a hospital-based chemotherapy infusion clinic and others referred patients to private physician practices or created a new medical office setting outside of the hospital building sometimes on the same campus.

The 1980s also saw a concern for the safety of those healthcare professionals who were handling chemotherapy, either manufacturing or administering. The concern that these operators might be exposing themselves to aerosolized chemotherapy resulted in the use of vertical flow hoods in the pharmacy. All

manufacturing of chemotherapy was restricted to the pharmacy.

In combination, these two factors—reimbursement and safety—resulted in pharmacists being moved to the outpatient chemotherapy area and the installation of vertical flow hoods in these areas. This change was one of the best opportunities for pharmacists to become clinically involved in the care of patients. Pharmacists also assumed greater responsibilities with investigational drug trials, often as a part of multicenter trials.

In the 1990s, pharmacists continued to increase their involvement in the clinical care of patients and became recognized members of the patient care team within oncology and hematology. The early 1990s saw the establishment of board certification for pharmacists in the area of oncology, recognizing clinical expertise among a small number of clinical pharmacists.

Patient safety also began to take center stage in the 1990s. Computer systems that could track the patient's chemotherapy, interface with the laboratory, check for drug/drug interactions, and provide easy access to drug information were developed. Patient safety concerns in the chemotherapy area were sensitized by a few sentinel events in which patient injury and death took place, encouraging all practitioners to review their processes of checks and balances to assure appropriate therapy reaches the patient without the chance for an overdose of a chemotherapy medication.

Virtually all chemotherapy was shifted to the outpatient area unless the patient's illness required admission. Hospice care also helped move patients out of the inpatient hospital to provide end-of-life care for patients in an alternate setting.

By early 2000, pharmacists were introduced to a new role in oncology—that of financial expert. And, pharmacists were expected to carry out this new role while maintaining their clinical, distributive, and patient safety roles.

In 2000 Medicare introduced a new method of reimbursement—the Outpatient Prospective Payment System (OPPS). This new payment system identified certain high-cost drugs with pass-through status and later with their own Ambulatory Payment Classification (APC) method of reimbursement. Hospitals continued to face financial pressures and the oncology unit was identified as an area utilizing high-cost chemotherapy and biotechnology drugs. Pharmacists, although never formerly trained, were forced into a role to assure the billing processes maximized revenue in the oncology area.

The pharmacist has seen the OPPS evolve with many changes in the first three years. Keeping up with the changes has been a chore, requiring that pharmacists monitor Medicare changes and work closely with the finance and coding departments. Pharmacy administrators are often held accountable by hospital administration for expense and revenue in the oncology area, which comprises a large portion of the total budget. Knowledge of reimbursement and financial prowess have become critical factors in the role of the oncology pharmacist.

In 2002 ACCC recognized this new role and began to actively work with oncology pharmacists on legislative and regulatory issues. With the establishment of the Oncology Pharmacy Education Network (OPEN) in 2003, ACCC began to reach out to pharmacists with strategies for ensuring adequate drug payments and improving reimbursement capture. In October 2003 ACCC sponsored its first one-day workshop dedicated solely to pharmacists, which took place the day before ACCC's 20th National Oncology Economics Conference. Today, a special section on ACCC's web site is dedicated to the pharmacist and the issues and challenges involved with the delivery of quality cancer care.

*The National Cancer Act of 1971 led to the training of large numbers of oncologists who brought state-of-the-art cancer care to communities all across the land. The most significant contribution of the Association of Community Cancer Centers was to provide a voice for these oncologists, a voice that had national impact.*

*Today, the cancer community, in common with all healthcare practitioners, is challenged by healthcare costs escalating out of control, driven by twin demons: the insatiable demands of the public for "free" care and the cost of the Byzantine rules and regulations formulated in a desperate attempt to control these demands. Almost 40 percent of the healthcare bill results from that paperwork. Unless individuals can participate in the control of their own healthcare costs in a system that allows choices, the end result will be a single payer—the federal government. Experience around the world tells us where that will lead. ACCC can and must do its share to help the cancer community deal with this problem.*

*John W. Yarbro, MD, PhD*
*ACCC Past President*

Pharmacists have seen the development of their role in the oncology area as a rewarding challenge. Today's pharmacists have developed the ability to wear several hats, each one critical to the oncology practice. Pharmacists must have an expertise in the compounding of medications, clinical application of oncological therapeutics, and an understanding of the reimbursement and financial arena. All of these responsibilities must be carried out while providing the most cost-effective, therapeutically appropriate treatment in the safest manner for the sake of all our patients now and in the future.

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