Although the trial’s outcome could affect thousands of patients, the protocol itself could have another kind of impact. In an effort to facilitate clinical trial participation by oncologists, GOG has simplified data collection and reporting requirements for this study, said Edward Trimble, M.D., head of surgery in NCI’s Cancer Therapy Evaluation Program. The criteria for patient eligibility are minimal, and GOG is not requiring that physicians send in pathology slides for review.

“We hope that this trial can become a model for future large, uncomplicated, community-based cancer trials,” Trimble said.

The evidence suggesting that ERT is safe comes from two studies in the 1980s involving several hundred women who had been diagnosed with stage I disease. In these non-randomized studies, women taking estrogen had no increased risk of recurrence after median time periods, respectively, of 26 and 64 months.

The new trial — prospective, controlled, randomized, and double-blinded — will compare ERT to a placebo, after surgery, in more than 2,000 women with stage I or II disease. Women will be checked every 6 months for 3 years and then annually for 2 more years, according to principal investigator Richard Barakat, M.D., of Memorial Sloan-Kettering Cancer Center in New York City. Findings could be available in about 5 years.

— Caroline McNeil

National Cancer Policy Board Hears Pleas for Priority At First Public Forum

The first public meeting of the newly formed National Cancer Policy Board on March 31 resembled a cancer-related town meeting. The board members listened to a roster of medical specialty groups, cancer advocacy groups, and other organizations vie for priority standing in the board’s “To Do” list, expected to be released this month.

Three new board members were also introduced at this meeting: Bertha A. Ford, a staff nurse at the Columbus Cancer Clinic, Ohio; William L. Roper, M.D., senior vice president and chief medical officer of Prudential Health Care, Roseland, N.J.; and John R. Sefrin, Ph.D., chief executive officer of the American Cancer Society, Atlanta. Fran Visco, president of the National Breast Cancer Coalition, was named to the board as the News went to press. Seventeen other members were named in February (see News, March 5), bringing the total to 21.

Access and Money

The board has stated its expectation to focus on topics that “concern multiple forms of cancer or clinical services, not a specific type or site of cancer, line of research, or clinical service,” but the specialty medical and advocacy groups used their testimony time to promote their own concerns. Concerns voiced by more than one speaker were patient access to clinical trials and cancer-care specialists, especially for patients in managed care systems and underserved populations, and funding for cancer research for particular cancers and as a whole.

Jill Rathbun of the Society of Gynecologic Oncologists asked the board “to address the issue of how insurance coverage, or more importantly a lack of insurance coverage, affects whether an individual will enroll in a clinical trial.” She added that other barriers to participation in trials also exist and that the board should evaluate those and then propose solutions.

The SGO also asked the board to evaluate the direct and indirect costs of lack of access to cancer specialists, “like SGO members,” for women insured under managed care. Rathbun noted that a lack of referral can cause a woman to have unnecessary diagnostic tests and surgeries before a diagnosis of gynecologic cancer is made.

Similarly, the Oncology Nursing Society felt the board should “inform the nation, consumers, payers, provider networks, and legislators about what constitutes quality cancer care,” said ONS President Kathi H. Mooney, R.N., Ph.D.

Mooney cited several examples of how managed care plans foil health care workers, including one that restricted access to palliative therapies and one that removed credentials from name tags so that the patients would not know if a trained nurse or an aide was administering their care.

“Unfortunately, the consumer makes an erroneous assumption that the person in white providing their care looks like...”
a registered nurse and therefore must be one," she said.

The ONS is also concerned about coverage for costs in clinical trials, "since this is the primary method for advancing our knowledge in cancer prevention, detection, and treatment."

Lovell A. Jones, Ph.D., representing the Intercultural Cancer Council, stated that diverse populations must be fully represented in clinical studies and research — which also requires third-party coverage of patient care costs.

The board intends to look carefully at the upcoming report of the President’s Cancer Panel on the effect of managed care on cancer research. That panel spent more than a year holding its own "town meetings" to hear what patients and health care providers felt were the pros and cons of managed care and how that affects cancer research. Transcripts from those sessions have already been made available to the board.

More Money

The National Coalition for Cancer Research said that federal funding of research was far below par compared with private industry and urged the board to take this issue to Congress.

Albert H. Owens, Jr., M.D., president of NCCR, said, "Every successful enterprise devotes some portion of its revenue to research in order to make new and improved products available and to maintain a competitive edge in sales and services. It is reported that the large pharmaceutical companies invest 21.2% of their annual U.S. revenues on research.

"The current annual NIH appropriations is approximately $13 billion, of which $2 billion is allocated to NCI. What portion of our annual health care expenditures (approximately $1 trillion) should be devoted to basic biomedical research? What portion of our Gross Domestic Product (approximately $7.9 trillion)?"

Brook Moran, of the American Foundation for Urologic Disease, a non-profit organization based in Baltimore, felt the board should advocate more funding for prostate cancer research.

"When our government spends more than 22,500 research dollars per diagnosed AIDS case and only $250 per diagnosed case of prostate cancer, our federal research priorities need reexamination," she said.

The Susan G. Komen Foundation expressed interest in more research funding for all cancers, including breast cancer.

The policy board will release its list of priorities early this month, both in written form and on its Web site at: http://www2.nas.edu/cancerbd/.

It also has a listserv, which can be subscribed to by sending electronic mail to listserv@cyrus.nas.edu with the following command in the body of the message: subscribe CANCER-POLICY.

— Kara Smigel

NCI Survivorship Office Champions Patient Issues

When concert pianist Mary Mottl of Shrewsbury, Mo., was diagnosed with breast cancer in 1985, she worried about how her small children would cope if she were to die then. Mottl’s mother died of breast cancer when Mary was only 9 years old, and she knew the pain of cancer survivorship long before her own diagnosis.

Twelve years later, despite adversity, Mottl has continued to play an average of two concerts a month, to practice her music 4 hours a day, and to record a classical CD that will be released this month.

But recently her cancer recurred. She said she grows more tired with every passing day and plays the piano less and less because of her chemotherapy. Also, because of her illness, she was forced to quit her teaching job at St. Louis University, and she worries as the bills mount that she will be dropped by her insurance company.

Millions of Survivors

Mary Mottl is not alone. She is one of the 7 to 10 million Americans who are "cancer survivors" and live in constant fear of cancer recurrence, the late effects of their treatment, and the economic burden of their disease.

It is Mary Mottl’s plight and that of the millions of cancer survivors like her that motivated National Cancer Institute Director Richard Klausner, M.D., to create the Office of Cancer Survivorship last July.

"The NCI has a responsibility to direct its efforts to issues that concern the