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 nonprofit 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 reevaluation," 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
many individuals who have survived cancer and their quality of life beyond treatment," Klausner said. Anna T. Meadows, M.D., the newly appointed director of the OCS, and also director of oncology, Children's Hospital of Philadelphia, agreed: "The burden of a cancer diagnosis does not end when treatment is complete."

Among her office's initiatives, Meadows said, will be research in several areas: long-term medical and psychological effects of cancer treatment; discrimination in the workplace and economic issues; reproduction and fertility problems following treatment; and genetic and other factors that increase the risk of second cancers.

Physiologic Problems

Last November, a panel of 50 experts gathered by her office concluded that many aspects of physiologic function in long-term survivors need to be addressed with site-specific and treatment-related studies. The experts included representatives of the National Cancer Advisory Board, the National Coalition of Cancer Survivorship, the Oncology Nursing Society, and the National Academy of Sciences.

Of greatest concern to the panel, Meadows said, were ischemic heart disease in women treated with radiation therapy for breast cancer, renal failure in men treated for testicular cancer, cognitive function in patients treated with chemotherapy, pituitary-gonadal functioning, sexuality, the effect of pregnancy on morbidity and mortality following treatment, and second cancers.

When it comes to understanding cancer survivorship, Ellen Stovall, executive director of the National Coalition for Cancer Survivorship in Silver Spring, Md., maintains that there are only a handful of good follow-up studies on adult cancer patients, most from NCI clinical trials.

In a 1994 computer survey of cancer survivors conducted by Jacqueline Fawcett, Ph.D., of the University of Pennsylvania School of Nursing in Philadelphia, more than half of the 30 respondents reported physical problems related to diagnosis and treatment. The problems ranged from sexual dysfunction to urinary problems and loss of vision. Sixty-one percent of patients had fears of cancer recurrence. Another 37% said they experienced problems with health insurance or life insurance, including delays in payment.

But when respondents were asked to identify who could help them cope, 83% said "don't know," "no one," or "myself." And when asked to list in order of frequency who should help, they cited physicians, other cancer survivors, nurses, family, and friends.

"As the success of modern cancer therapy has increased the [survival] of many patients, so has the recognition of long-term complications of therapy increased," said Margaret A. Tucker, M.D., chief of NCI's Genetic Epidemiology Branch. "We know now that anthracyclines may cause congestive heart failure and other cardiac problems within 1 year of treatment." It is also apparent that "predisposing factors beyond the treatment itself may have a major impact on the risk of developing a second tumor," she added.

Alterations in the retinoblastoma gene, germline mutations in the p16 gene, and congenital or acquired immunodeficiency states are all examples of the host factors that may increase the risk of developing a second tumor, Tucker said.

"By the year 2000, an estimated one of every 900 young adults will be a survivor of childhood cancer," said Cynthia A. DeLaat, M.D., assistant professor of clinical pediatrics at the Children's Hospital Medical Center in Cincinnati. Pediatric cancer patients suffer from a variety of short-and long-term complications as a result of treatment.

The panel report said the economic impact of follow-up care for survivors needs to be assessed.

— Francis X. Mahaney, Jr.

Awards, Appointments, Announcements

The Passano Foundation, Inc., Baltimore, presented its 1997 Passano Award to James E. Darnell, Jr., Ph.D., for identifying novel mechanisms of gene expression. He is Vincent Astor Professor and head of the Molecular Cell Biology Laboratory at Rockefeller University, New York.

The foundation, whose charter is to further scientific research and make an annual award, has had 20 of its laureates go on to win Nobel Prizes. According to its announcement, the foundation, established in 1945, has as its sole purpose "the encouragement of medical sci-