DEPARTMENT OF HEALTH AND HUMAN SERVICES

NATIONAL INSTITUTES OF HEALTH

Fiscal Year 2006 Budget Request

Witness appearing before the
House Subcommittee on Labor-HHS-Education Appropriations

Dr. Patricia A. Grady, Director
National Institute of Nursing Research

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William Beldon, Acting Deputy Assistant Secretary, Budget

Mr. Chairman and Members of the Committee:

I am pleased to present the Fiscal Year(FY) 2006 President's budget request for the National Institute of Nursing Research (NINR). The FY 2006 budget includes $138,729,000, an increase of $657,000 over the FY 2005 enacted level of $138,072,000 comparable for transfers proposed in the President's request.

I appreciate the opportunity to appear before you today to discuss the exciting work of the National Institute of Nursing Research (NINR) that provides important science to provide necessary improvements in the quality of patient care across the continuum of life. Unique within the NIH, our mission is structured around the science that connects health care providers to patients, their families, and caregivers.

There are many components to our society's healthcare mosaic. Care is delivered through a variety of settings: conventional healthcare sites, community-based clinics, and homes. Patients with exceptional needs – from newborns, the disabled, individuals at the end-of-life – and the underserved, from urban to rural settings, rely on quality care. Through our studies, we seek to understand and manage the symptoms of acute and chronic illness, and thus, to find effective approaches to achieving and sustaining good health.

Let me now share with you some examples of how our research is changing patient care and improving lives.

MOTHERS AND THEIR YOUNG CHILDREN WITH ASTHMA

Asthma, a chronic and sometimes life threatening condition, is associated with

high health costs related to medications, outpatient management, and emergency room visits. Especially for younger children, good asthma management requires close vigilance by the parent or caregiver. Researchers in one study interviewed working mothers of young, inner-city asthmatic children, more than a quarter of whom reported that there was a smoker in the house. While most of the children were under the care of a doctor and were prescribed appropriate asthma medications, many still experienced frequent coughing, wheezing, or shortness of breath. The mothers often did not give medications for coughing, which can be an early sign of an asthma attack. While most were vigilant and strove to provide good asthma management, the study demonstrated that many mothers lack sufficient information on early asthma symptoms and need additional education about asthma in order to provide the best care for their children.

HEALTH DISPARITIES IN RURAL COMMUNITIES

The health care of rural populations is a concern because of poverty, lack of services and/or health vulnerability of the population. NINR's recently funded Rural Nursing and Health Care Research Center provides an interdisciplinary research infrastructure to conduct and disseminate nursing research to address the needs of rural populations. NINR has funded researchers who are making advances with technological interventions for the chronically ill rural populations. The *Women to Women* project is a computer-based communication intervention that is testing a program of health information and social support for women. The program provides educational tools for self-management skills and studies the risks of isolation and chronic illness. This project has influenced health outcomes by creating a more

informed and self-managing patient population. The program may ultimately serve as a model to deliver support and education to remote or vulnerable populations.

CARING FOR THE CAREGIVERS

Dementia-related conditions cause a progressive decline in memory, cognition, and physical function, and affect nearly 10 percent of persons over 65 years of age. The behavior of the patient with dementia can range from forgetfulness to dangerous and aggressive activities. Family caregivers often identify the management of this behavior as a major source of distress and burden.

The Savvy Caregiver Program, an educational program for caregivers, increased the skill, knowledge, and confidence of caregivers. In addition, most caregivers reported a decreased sense of burden and improved ability to deal with dementia-related behavior of the patient. The caregivers underscored their belief in the benefits of caregiving, and stated they would recommend the program to others.

When family caregivers cannot manage the patient with dementia at home, they often must place the person in a long term care facility. The Family Involvement in Care program was developed to help family members contribute to the care of the institutionalized patient. This project tested a program for the nurses and staff on the impact of dementia for the family, and on ways to support a continued family presence. Family members reported more positive feedback to the facility, while the staff participants reported positive outcomes regarding the family caregiving role.

RESEARCH ON CARE AT THE END OF LIFE

The end-of-life process includes numerous challenges: physical, emotional, spiritual, and financial. There also are challenges in health care systems exacerbated by the lack of continuity among caregivers, disruption of social support networks, unshared clinical information, and multiple physical locations for care. Family members experience role changes, stress, and ultimately, bereavement as their loved one traverses life's continuum.

The NINR is charged with leading the Institutes and Centers for advancing a trans-NIH research agenda on end-of-life care. In this role, we support a broad range of studies designed to improve the management of symptoms associated with the end of life; elucidate the broad issues that affect many families across the nation such as communication among patient, family, and care providers; enhance coping with terminal illness; and examine cultural and ethnic influences on end-of-life care.

In one NINR study, researchers interviewed patients with terminal cancer and found that spiritual well-being helped reduce depression, hopelessness, thoughts of suicide, and the desire to hasten death. The investigators concluded that palliative care clinicians should assess the spiritual beliefs and needs of their terminal patients to help them cope with despair and achieve a sense of peace and meaning in their life.

In December 2004, NINR cosponsored an NIH state-of-the-science conference on end-of-life. Nearly one thousand people from around the world came to NIH to review the existing knowledge base on end-of-life and to recommend opportunities for

future research. These recommendations will feature prominently in NINR's forthcoming research plans in this area.

PALLIATIVE AND END-OF-LIFE CARE IN RURAL AND FRONTIER AREAS

Residents living in rural or frontier areas typically have limited access to health care services, particularly at end-of-life. In FY 2006, NINR will initiate studies focused on understanding the scope of the problems associated with limited access to care in rural areas. These studies will examine ways to improve end-of-life care through the use of technology; develop new methods to use existing networks and services; design culturally appropriate interventions for palliative care; and identify possible alternative settings and methods for providing care and supporting family caregivers.

BUILDING NURSING RESEARCH CAPACITY

As our nation is experiencing a shortage of nurses, we are also experiencing a shortfall in the number of nurse scientists. NINR is building research capacity with several innovative initiatives, collaborating with universities nationwide to rapidly develop baccalaureate-to-doctoral fast-track programs. The Graduate Partnership Program (GPP) in Biobehavioral Research, a new pilot training program, partners schools of nursing with the NIH intramural program to provide cutting-edge, mentored research training for outstanding doctoral students.

NINR is also supporting Centers to stimulate research and research training opportunities. One example, the *Nursing Partnership Centers to Reduce Health Disparities*, together with the National Center on Minority Health and Health

Disparities, partners research-intensive universities with minority-serving institutions.

NINR AND THE NIH ROADMAP

NINR has identified two key areas of science within the NIH Roadmap, *Interdisciplinary Research Teams of the Future* and *Re-engineering the Clinical Research Enterprise*, and integrated them within the nursing research agenda. NINR and its investigators have extensive experience in conducting interdisciplinary research projects. Currently, more than one-half of NINR-funded studies appear in non-nursing journals. This shows the promise of future interdisciplinary collaborations and the value of nursing research findings by other disciplines. In the area of improving the clinical research enterprise, most of NINR's research is clinical in nature and research questions are evaluated from the clinical researcher's perspective. Investigators translate research findings into the clinical practice of healthcare providers and develop partnerships to speed new scientific knowledge into mainstream health care.

CONCLUSION

In conclusion, NINR strives to improve the quality of life and quality of health through every stage of life, especially for the most vulnerable in our society. We are committed to training the next generation of nurse researchers, and to continuing to fund rigorous and innovative programs of research to enhance the health of our nation.

Thank you, Mr. Chairman. I will be pleased to answer any questions that the Committee might have.

PATRICIA A. GRADY, PHD, RN, FAAN
DIRECTOR, NATIONAL INSTITUTE OF NURSING RESEARCH

Dr. Patricia A. Grady was appointed Director, NINR, on April 3, 1995. She earned her undergraduate degree in nursing from Georgetown University in Washington, DC. She pursued her graduate education at the University of Maryland, receiving a master's degree from the School of Nursing and a doctorate in physiology from the School of Medicine.

An internationally recognized stroke researcher, Dr. Grady's scientific focus has primarily been in stroke, with emphasis on arterial stenosis and cerebral ischemia. She was elected to the Institute of Medicine in 1999 and is a member of several scientific organizations, including the Society for Neuroscience, the American Academy of Nursing, and the American Neurological Association. She is also a fellow of the American Heart Association Stroke Council.

In 1988, Dr. Grady joined the NIH as an extramural research program administrator in the National Institute of Neurological Disorders and Stroke (NINDS) in the areas of stroke and brain imaging. Two years later, she served on the NIH Task Force for Medical Rehabilitation Research, which established the first long-range research agenda for the field of medical rehabilitation research. In 1992, she assumed the responsibilities of NINDS Assistant Director. From 1993 to 1995, she was Deputy Director and Acting Director of NINDS. Dr. Grady served as a charter member of the NIH Warren Grant Magnuson Clinical Center Board of Governors.

Before coming to NIH, Dr. Grady held several academic positions and served concurrently on the faculties of the University of Maryland School of Nursing and School of Medicine.

Dr. Grady has authored or co-authored numerous published articles and papers on hypertension, cerebrovascular permeability, vascular stress, and cerebral edema. She is an editorial board member of the major stroke journals. Dr. Grady lectures and speaks on a wide range of topics, including future directions in nursing research, developments in the neurological sciences, and federal research opportunities.

Dr. Grady has been recognized with several prestigious honors and awards for her leadership and scientific accomplishments, including being named the inaugural Rozella M. Schlotfeld distinguished lecturer at the Frances Payne Bolton School of Nursing at Case Western Reserve University and receiving the honorary degree of Doctor of Public Service from the University of Maryland. In addition to being named the Excellence in Nursing Lecturer by the Council on Cardiovascular Nurses of the American Heart Association, Dr. Grady also received the first award of the Centennial Achievement Medal from the Georgetown University School of Nursing and Health Studies.

Dr. Grady is a past recipient of the NIH Merit Award and received the Public Health Service Superior Service Award for her exceptional leadership.

DEPARTMENT OF HEALTH AND HUMAN SERVICES
OFFICE OF BUDGET
WILLIAM R. BELDON

Mr. Beldon is currently serving as Deputy Assistant Secretary, Budget in the Department of Health and Human Services. He has been a Division Director in the Budget Office for sixteen years, most recently as Director of the Division of Discretionary Programs. Mr. Beldon started in federal service as an auditor in the Health, Education and Welfare Financial Management Intern program. Over the course of more than 30 years in the Budget Office, Mr. Beldon has held Program Analyst, Branch Chief and Division Director positions. Mr. Beldon received a Bachelor's Degree in History and Political Science from Marshall University and attended the University of Pittsburgh where he studied Public Administration. He resides in Fort Washington, Maryland.