

DEPARTMENT OF HEALTH AND HUMAN SERVICES
NATIONAL INSTITUTES OF HEALTH

Budget Request for FY 2010

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

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National Institute of Nursing Research

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Mr. Chairman and Members of the Committee:

I am pleased to present the President's Fiscal Year 2010 Budget request for the National Institute of Nursing Research (NINR) of the National Institutes of Health (NIH). The FY 2010 budget includes \$143,749,000, which is \$1,870,000 more than the FY 2009 appropriation of \$141,879,000.

NINR's budget request and its research projects are consistent with the President's multi-year commitment for Cancer and Autism.

INTRODUCTION

The National Institute of Nursing Research (NINR) supports clinical and basic research to build the scientific foundation for clinical practice, prevent disease and disability, manage and eliminate symptoms caused by illness, and enhance end-of-life and palliative care. The breadth and depth of NINR's research portfolio is ideally suited to explore some of the most important challenges affecting the health of the American people. An aging population, an increasing incidence of chronic illness, a shortage in the health workforce, and rapidly escalating costs necessitate profound changes in the ways in which we approach health care. These challenges require us to develop new strategies for treating, managing, and preventing illness that are person-centered rather than disease-centered, that focus on preempting the development of chronic illness rather than treating it, and that feature the person as an active participant in managing his or her own health care. The research supported by NINR can significantly contribute to the evidence base for many of the changes that will occur in health care in the coming years and decades. NINR advances science to address current and future challenges through its research programs in health promotion and disease prevention; self-management, symptom management, and caregiving; and end-of-life and palliative care. In addition, NINR maintains a strong commitment to the elimination of health disparities faced by at-risk and underserved populations through continued work to develop culturally appropriate, evidence-based interventions. NINR also trains the next generation of

scientists to ensure the development of the innovative research and faculty workforce of the future. The research goals in NINR's Strategic Plan, *Changing Practice, Changing Lives*, emphasize the areas of public health that demonstrate the greatest needs and in which NINR can have the greatest impact.

Let me now describe our research programs and highlight some of our recent accomplishments.

NINR RESEARCH PROGRAMS

Health Promotion and Disease Prevention

Health care professionals and policy leaders have stressed the importance of preventive care to the health of all Americans. NINR supports research to discover new ways to prevent disease and achieve long-term, positive health outcomes in individuals across the lifespan. NINR-supported scientists explore strategies to understand and promote behavioral changes in individuals, evaluate health risks in diverse communities, and assess issues of patient safety. In recent years, successful efforts in the areas of health promotion and disease prevention research have increasingly involved community members in the design and conduct of the study.

NINR research has an impact on clinical practice. In one example, researchers designed, implemented and evaluated a program to address the health burden and costs associated with premature birth, a condition affecting more than 500,000 infants in the United States every year. The *Creating Opportunities for Parent Empowerment* program (COPE), for parents of premature infants, is an educational-behavioral intervention program that begins 2 to 4 days after admission to a neonatal intensive care unit (NICU) and teaches parents how to care for their premature infant. The researchers found that COPE implementation reduced the length of stay in the NICU by four days, for an estimated healthcare cost savings of at least \$4,800 per infant. Thus, in addition to improving parent and child outcomes, routine implementation of COPE in NICU's across the United States could possibly save the healthcare system more than \$2 billion per year. The results of this study have sparked interest among hospitals and insurers nationwide.

NINR-supported researchers are developing more programs to promote healthy behaviors and prevent disease, including: an outreach intervention designed to reduce HIV-risk among adolescent girls receiving services through community-based health centers; a parent training program designed to promote positive parenting and mental health among low-income ethnic minority families with young children; and a lifestyle-modification program for pre-hypertensive, middle-aged rural women.

Self-Management, Symptom Management, and Caregiving

Given the increasing numbers of people living with chronic illness, whether children with diabetes or elders with heart disease, NINR is developing new approaches to help individuals manage their own health conditions, to decrease the effects of adverse symptoms, and to reduce the burden on caregivers. NINR is improving the quality of life of individuals with chronic illness and their families by supporting research related to self-management, symptom management and caregiving.

Our self-management research explores strategies that help individuals to participate in their own health practices. In one recent example, community “Lay Health Educators” were trained to deliver a health promotion and asthma management program to children in elementary schools from rural towns and unincorporated communities. Children receiving this program demonstrated significant improvements in asthma knowledge, self-management scores, and use of metered dose inhalers. Results from this study suggest that using Lay Health Educators for delivery of an in-school education program may be an effective means for improving children's skills in asthma self-management, especially in hard-to-reach communities.

Our symptom management research focuses on the biological and behavioral aspects of symptoms such as pain and fatigue, with the goal of improving patient health and quality of life. A recent symptom management study aimed to define patient-determined success for treatment of chronic spine pain in four areas: pain, fatigue, emotional distress, and interference with daily activities. This study found that the patients for whom pain was reduced experienced significantly less fatigue, emotional distress, and interference with daily activities. The findings confirm that successful

treatment for chronic pain is not viewed by patients exclusively in terms of pain reduction, but also involves a number of additional quality of life factors.

Research Capacity Development

The increasing demand for nurse clinicians, faculty, and scientists, and the inadequate supply of new nurses to meet that need, continue to burden America's health system. NINR builds research capacity and fosters interdisciplinary training for the next generation of scientists in basic, translational, and clinical research through individual and institutional training and career development awards. NINR training strategies focus on the development of nurse scientists and earlier entry into research careers with special consideration given to underrepresented and disadvantaged populations. In addition, innovative training programs at the NIH, such as the NINR Summer Genetics Institute, the NINR Graduate Partnerships Program, and the new BNC fellowship (a joint venture between NINR, the NIH Clinical Center, and the Bravewell Collaborative), all serve to increase the knowledge and experience base of new scientists, and assist them in their transition to long-term research careers.

End-of-Life

Faced with a complexity of life-limiting and eventual terminal conditions—whether cancer, heart disease, stroke, or neurodegenerative disorders—the challenges experienced by patients and their families as life draws to a close have refocused attention to the end of life and necessitated a better understanding of the dying process, the associated decisions about treatment, and the quality of care patients receive. Focusing on these topics, NINR end-of-life research seeks through science to improve the understanding of the mechanisms underlying palliation, including pain, fatigue, depression, and related symptoms; enhances communication and decision-making processes between patients and family members; and, develops effective strategies to optimize care across diverse settings, populations, and cultural contexts.

One recent study explored the relationship between diagnosis and Advance Directives. As part of a longitudinal study, patients with an expected 2-year survival of less than 50% who had either cancer or amyotrophic lateral sclerosis (ALS) were

interviewed with the goal of determining whether and how end-of-life discussions differed between clinicians and patients. Results showed that cancer patients were less likely than ALS patients to have had advanced care planning discussions. Although these results may reflect perceptions that ALS has a more predictable disease trajectory, that advanced cancer has a greater number of treatment options, or the presence of differing views about hope, this study highlighted that cancer patients may be less than adequately prepared for end-of-life decision-making.

Another recent study examined the life support withdrawal process for patients who died in the intensive care unit (ICU) or within 24 hours of discharge from the ICU, and surveyed family members on their perceptions of the care provided. The researchers discovered that for family members of patients who had an ICU stay of eight days or more, families were more satisfied with care received when withdrawal of life support occurred in a staggered progression. The outcome of this study indicates that clinicians need to work with the family throughout the patient's ICU stay to provide them with accurate information on which to base decisions, and prepare them emotionally for the possible loss of their loved one.

NINR AND THE AMERICAN RECOVERY AND REINVESTMENT ACT

Funding for scientific research received through the American Recovery and Reinvestment Act of 2009 (ARRA) has provided NINR with an enormous opportunity, not only to assist with the Nation's economic recovery by creating and retaining jobs and enhancing infrastructure, but to advance biomedical and behavioral research in areas of critical importance to the NINR mission. NINR is using the funds from ARRA to support additional research projects, to accelerate ongoing research through supplements to current grants, and to create opportunities for introducing prospective scientists to a research career. The additional science supported by NINR through ARRA will, in the long-term, contribute to improving the health of the Nation through enhanced prevention and management of chronic illness and disease.

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

Dr. Patricia A. Grady was appointed Director of National Institute of Nursing Research, 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 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 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 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 the first award of the

Centennial Achievement Medal from Georgetown University School of Nursing and Health Sciences, 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. Dr. Grady was named the Excellence in Nursing Lecturer by the Council on Cardiovascular Nurses of the American Heart Association. In 2005, Dr. Grady received Doctor of Science, Honoris Causa degrees from the Medical University of South Carolina and Thomas Jefferson University, and Columbia University School of Nursing honored her with its prestigious Second Century Award for Excellence in Health Care. In 2008, Dr. Grady received a Doctor of Science, Honoris Causa degree from the State University of New York Downstate Medical Center.

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