

DEPARTMENT OF HEALTH AND HUMAN SERVICES
NATIONAL INSTITUTES OF HEALTH

Fiscal Year 2009 Budget Request

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

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National Institute Of Nursing Research

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Richard J. Turman, Deputy Assistant Secretary, Budget

Mr. Chairman and Members of the Committee:

I appreciate the opportunity to present the Fiscal Year (FY) 2009 President's budget request for the National Institute of Nursing Research (NINR). The FY 2009 budget is \$137,609,000, which is \$133,000 more than the comparable Fiscal Year 2008 appropriation of \$137,476,000.

INTRODUCTION

The mission of NINR is to support research to establish the evidence base for patient care across the lifespan. From premature infants in the neonatal intensive care unit, to middle-aged adults with chronic illness and elders at the end of life, NINR-supported research focuses on developing innovative and effective techniques and interventions that prevent disease and disability, and improve quality of life and health outcomes for patients and their caregivers.

Currently, our Nation is facing significant healthcare challenges: an aging population living longer with chronic illness; a growing racially and culturally diverse population; and an increased demand for nurses. As the Director of NIH has stated, these realities necessitate a new system of health care that is personalized, preemptive, predictive, and participatory. These realities require a shift to strategies of health care that are increasingly person-centered rather than disease-centered, that focus on preventing the development of chronic illness rather than treating it, and that feature the person as an active participant in managing his or her own care. NINR has supported research to establish this person-centered model of health care for over twenty years, and we will continue to be leaders in this exciting new world.

Accordingly, NINR funds research in several key areas: self-management, symptom management, and caregiving; health promotion and disease prevention; and end-of-life. In addition, NINR research seeks to understand the special needs of at-risk and underserved populations with its emphasis on health disparities. Finally, by continuing our efforts to enhance research capacity, NINR addresses the current research workforce challenges by supporting new scientists and nursing faculty. The

research goals in our Strategic Plan, *Changing Practice, Changing Lives*, emphasize the areas of public health that have the greatest needs and in which NINR can have the greatest impact.

Let me now highlight our recent accomplishments and share our plans for the future.

NINR RESEARCH PROGRAMS

Quality of Life

Given the increasing numbers of people living with chronic illness, whether children with diabetes or elders with heart disease, we need better ways to facilitate individuals to manage their own illnesses, decrease the effects of adverse symptoms, and reduce the burden on caregivers. NINR improves the quality of life of individuals with chronic illness by supporting research related to self-management, symptom management and caregiving. Self-management research explores strategies that help individuals to participate more in their own health practices. Symptom management research focuses on the biological and behavioral aspects of symptoms, such as pain and fatigue, with the goal of improving patient health. Caregiving research addresses the quality-of-life issues experienced by care recipients as well as formal and informal caregivers across diverse health care settings.

An example of NINR research to improve quality of life is a recent study involving adolescents with diabetes. These individuals often experience poor metabolic control, leaving them at risk for a range of cardiovascular and other complications. As part of the ABCs of Diabetes study, a group of adolescent diabetics received a 6-week program of coping skills training (CST) along with education in diabetes management. The CST taught skills in communication, social interaction, conflict resolution, and behavior modification. Afterward, the CST participants were followed for up to five years. As they entered adulthood, participants showed a low level of diabetes complications such as hypertension or kidney disease, and most reported feeling satisfied with their quality of life. These findings indicate that CST can help young

adult diabetics maintain a good quality of life and good metabolic control, decreasing their risk of long-term adverse health consequences from their disease.

Health Promotion and Disease Prevention

NINR seeks to discover health predictors and strategies to prevent the development of disease and achieve long-term, positive health outcomes in individuals of all ages. Efforts involve promoting behavioral changes in individuals, evaluating health risks in diverse communities, and assessing issues of patient safety. In recent years, successful efforts in these areas of research have increasingly involved community members in the design and conduct of the study. This is especially true in studies that involve difficult-to-reach populations, such as inner city residents who may experience health disparities.

In one recent example, a group of inner city Black men with high blood pressure (HBP) participated in a 5-year community-based HBP intervention. Half received a less intensive program involving education, a referral to community HBP care sources, and annual health evaluations. The other half received a more intensive program of HBP treatment from an interdisciplinary health care team consisting of a nurse, a community health worker, and a physician. The intensive program included HBP check-ups, education on healthy diet and lifestyle behaviors, and free medications. Compared to those in the less intensive group, those in the more intensive intervention had a decrease in the onset and progression of left ventricular hypertrophy, a form of heart damage caused by high blood pressure.

Research Capacity Development

The increasing demand for nurse clinicians, faculty, and scientists, and the inadequate supply of new nurses to meet that demand, remain a significant National challenge for America's health care 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 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. These researchers serve as nursing faculty, and increase enrollment and education of nurses.

In 2007, NINR solicited proposals for a new initiative on the design and testing of interventions in chronic illness. These awards, intended for investigators and institutions with proven and long-established research programs, will support shared resources and a collaborative research effort for several large research projects. The awards will allow a group of investigators, using multiple approaches funded as individual subprojects, to conduct innovative, high-impact, and interdisciplinary research on topics of critical importance to the Institute related to chronic illness.

End-of-Life

NINR's End-of-Life program focuses research on: palliative care to alleviate pain and related symptoms; advance directives; and family decision-making. As the lead Institute at NIH for end-of-life research, NINR's End-of-Life research program seeks to advance the understanding of the dynamic interactions of these various factors, and to develop interventions that optimize patient and caregiver quality of life across care settings and cultural contexts. In one recent study, NINR-supported researchers surveyed family members of intensive care unit (ICU) patients on their level of satisfaction with the care provided in the ICU. Family members of patients who had died in the ICU actually reported greater satisfaction with their level of involvement in decision-making and with clinician communication than families of patients who had survived. This research does not necessarily indicate that dying patients in the ICU receive better care, but it does underscore the importance of ICU clinicians devoting time and attention to the needs of patients and their families, and it points to ways to improve the ICU experience and decrease stress for all ICU patients and their families.

NINR recently solicited applications for Centers of Excellence in Self-Management or End-of-Life Research. The first awards under this program were made in late FY 2007. These Centers will serve as a nexus for the emergence of end-of-life research as an interdisciplinary science, training investigators from multiple backgrounds and enhancing collaboration to increase the quality and quantity of innovative, interventional research projects in end-of-life and palliative care science.

VISION FOR THE FUTURE

As we journey into a new era of healthcare that is personalized, predictive, preemptive, and participatory, we envision that the innovative, patient-centered research supported by NINR will rise to an unprecedented level of importance as chronic diseases become even more prevalent. NINR's focus on research that enhances quality of life, improves patient self-management, and discovers better ways to prevent and manage disease make the Institute ideally suited to help realize a new vision of American health care. In the coming years, NINR will continue to support research to establish the evidence base for patient care across the lifespan and across all diseases and conditions. NINR will increase its efforts to translate and disseminate the results of successful research to the health care community and to the public. NINR stands ready to take on the unique opportunity to shape the future direction of health care.

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

PATRICIA A. GRADY, Ph.D., 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.

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

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.

Dr. Grady has published 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 being named the inaugural Rozella M. Schlotfeld distinguished lecturer 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 American Heart Association, Dr. Grady also received the first Centennial Achievement Medal from the Georgetown University School of Nursing and Health Studies. She has also received Doctor of Science, *Honoris Causa* awards from Thomas Jefferson University and the Medical University of South Carolina, as well as the Second Century Award for Excellence in Health Care from Columbia University.

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
Richard J. Turman**

Mr. Turman is the Deputy Assistant Secretary for Budget, HHS. He joined federal service as a Presidential Management Intern in 1987 at the Office of Management and Budget, where he worked as a Budget Examiner and later as a Branch Chief. He has worked as a Legislative Assistant in the Senate, as the Director of Federal Relations for an association of research universities, and as the Associate Director for Budget of the National Institutes of Health. He received a Bachelor's Degree from the University of California, Santa Cruz, and a Masters in Public Policy from the University of California, Berkeley