

DEPARTMENT OF HEALTH AND HUMAN SERVICES
NATIONAL INSTITUTES OF HEALTH

Fiscal Year 2012 Budget Request

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 2012 Budget request for the National Institute of Nursing Research (NINR) of the National Institutes of Health (NIH). The FY 2012 budget includes \$148,114,000 which is \$3,857,000 more than the comparable FY 2011 appropriation of \$144,257,000.

INTRODUCTION

I appreciate the opportunity to share with you some of the exciting areas of research that we support at the National Institute of Nursing Research (NINR). As you know, a unique combination of societal trends challenges our Nation's health, including an aging population, increased chronic illness and obesity rates, and shortages in the health care workforce. At NINR, we address these issues by supporting research across the life span that: builds the scientific foundation for clinical practice; improves quality of life through managing and easing symptoms of illness; promotes health and prevents disease through biological and behavioral interventions; and enhances end-of-life and palliative care. We also seek to ensure future discoveries by training the next generation of nurse scientists. NINR's emphasis on clinical research and training places NINR in a position to make major contributions to trans-NIH initiatives to enhance the evidence-base for health care decisions, promote translational research, and support new investigators and new ideas. NINR was established 25 years ago, in 1986, as the National Center for Nursing Research. This year, we are commemorating our 25th anniversary through a series of scientific outreach events to celebrate our longstanding emphasis on translating science to improve health and clinical practice. In our first event, a scientific symposium entitled "Bringing Science to Life," some of our distinguished scientists presented cutting edge research on topics as varied as: the role of sleep in health and safety; managing chronic illness in racially/ethnically diverse groups; testing interventions to educate and support parents with premature infants; and understanding the biological underpinnings of muscular dystrophy. This Anniversary is an opportunity to review what NINR science has accomplished, and more importantly,

to envision and plan the next phase of evidence-based research to meet future health and health care needs, challenges, and priorities. As we look forward to the next 25 years, we are confident that NINR-supported science will play an ever-increasing role in addressing the most pressing issues facing our Nation's health. I would, next, like to share with you some examples of the research that we support and how it improves quality of life.

CHILDHOOD AND ADOLESCENCE: RISK AND RESILIENCE

From birth through young adulthood, children and adolescents face many health challenges and also demonstrate incredible resilience. NINR supports research to promote positive outcomes for children and families facing a myriad of challenges. For example, chronic health conditions in children, such as diabetes, arthritis, and obesity, pose challenges for the entire family and require sustained attention to treatment adherence and health assessment. NINR-funded scientists have made advances both in understanding the family's role in children's health and in improving assessment strategies. One study found that although parents detected significant pain in their child following the child's surgery, they tended to under-treat it, suggesting that educating parents about pain management may be beneficial. Another study found that screening children's waist circumference, which can be easily implemented in schools, identifies more cases of high blood pressure than the usual measure of body mass index alone. A current initiative led by NINR aims to improve self-management of chronic illness in children. An increasing challenge later in childhood comes from HIV, with adolescents and young adults comprising one third to one half of new infections in the U.S.,¹ despite numerous prevention campaigns. Moreover, adolescents from racial/ethnic minority groups are disproportionately affected.² A new NINR initiative supports projects to examine psychosocial, cognitive, and neurological predictors of HIV/AIDS risk decision-making in adolescents. This research will provide an evidence-base to

¹ National Institute for Child Health and Human Development. AIDS/HIV. 2008.

² Centers for Disease Control and Prevention. 2008. HIV/AIDS among youth.

guide future culturally and developmentally relevant interventions to prevent HIV/AIDS.

CHALLENGES AND CHANGES IN AN AGING POPULATION

The population of our Nation is aging rapidly, due in large part to increased longevity and the aging of the baby boomers. These changes are giving rise to significant challenges, resulting in a need for: improved strategies to manage co-occurring chronic illnesses; better interventions to support family caregivers; and new ways to address health disparities and meet the needs of an elderly population that is more racially and ethnically diverse than ever before. One pressing challenge is the increase in the number of older adults with multiple chronic illnesses, such as heart disease, diabetes, and arthritis. Such older adults have complex care needs, face long-term self-management of illness, and may experience poor coordination of care in the community. In a recent NINR-supported Nurse Coordinated Care Intervention, advanced practice nurses developed individualized care plans for older adults, which included family members and ongoing follow-up care. The intervention improved health outcomes and reduced costs of care for Medicare patients. A new NINR initiative, that benefits not only older adults but individuals across the life span, supports research that translates basic genomic science to clinical practice with the goal of preventing and alleviating symptoms of chronic illness. Such efforts have the potential to improve quality of life for older adults and families. Another challenge is Alzheimer's disease (AD), which is incurable, affects up to 5.1 million Americans, and is expected to dramatically increase in incidence by the year 2030.³ NINR is addressing the quality of care for AD patients, and the quality of life of, and burden on, family caregivers. For example, researchers funded by NINR and the National Institute on Aging (NIA) developed an intervention to teach caregivers about AD, stress management, and maintaining their own health. The intervention showed promising improvements in emotional, mental, and physical health in racially diverse groups.

³ National Institute on Aging. 2009 Progress report on Alzheimer's disease: Translating new knowledge.

END OF LIFE: SUPPORTING INDIVIDUALS AND FAMILIES

As a society we are living longer lives than ever before; however, we are also more likely to die from chronic and sometimes painful illnesses⁴ that require families to make complex decisions about life and death issues, often without adequate support and information. As the lead NIH Institute on issues related to end-of-life research, NINR supports research leading to evidence-based end-of-life and palliative care that ultimately assists individuals, families, and health care professionals in alleviating symptoms, planning for end-of-life decisions, and promoting psychological, social, spiritual, and physical well-being. NINR's Office of Research on End-of-Life Science and Palliative Care, Investigator Training, and Education coordinates research, training, and educational efforts in end-of-life and palliative care science. One NINR-supported study recently examined the effectiveness of a program to communicate patient preferences for end-of-life decisions to clinicians. Compared to traditional practices such as Do-Not-Resuscitate orders, the program led to fewer unwanted life-sustaining treatments without affecting quality of remaining life. In addition, a new NINR initiative begun in 2011 will support research to address issues related to end-of-life and palliative care for individuals with chronic illness who also experience life-threatening acute illness. Finally, on August 10-12, 2011, NINR, with support from partners across the NIH, will convene a forum entitled "The Science of Compassion: Future Directions in End-of-Life and Palliative Care." This forum is intended to energize and mobilize end-of-life and palliative care research and to draw attention to the end-of-life and palliative care processes, the care options available to patients and their families, and the obligations of health service communities to address these complex needs.

⁴ Centers for Disease Control and Prevention and The Merck Company Foundation. The state of aging and health in America 2007. Whitehouse Station, NJ: The Merck Company Foundation; 2007.

TRAINING THE NEXT GENERATION OF SCIENTISTS

NINR places strong emphasis on equipping the next generation of scientists with the necessary skills to conduct research that improves the Nation's health. In light of the societal trends that will characterize the coming decades, NINR recognizes that tomorrow's nurse scientists need to be trained in rigorous, innovative, and interdisciplinary research that reaches diverse individuals, families, and communities. NINR supports young scientists and junior and senior scholars through grant funding, fellowships, and career development awards. NINR also offers an intensive summer training program, the Summer Genetics Institute, to improve research and clinical practice among graduate students and faculty by providing a foundation in molecular genetics. Additionally, our Pain Boot Camp, held for the first time in 2010, is a one-week research intensive program where participants learn innovative pain research methodology from nationally and internationally known scientists. NINR's efforts to invest in new investigators and new ideas are critical investments in preparing a nursing workforce to address the health care challenges of the coming years.

FUTURE DIRECTIONS IN NURSING SCIENCE

Nursing science is at the forefront of efforts to improve health and health care practice. NINR is currently formulating its new strategic plan and will continue its focus on the unique social, cultural, societal, genetic, and biological factors that contribute to disease prevention, health promotion, and self-management of illness. We look forward to the next 25 years in which nursing science, focused on individuals, patients and families, will make critical contributions to improving health care practice and quality of life across the disease spectrum and across the lifespan. Thank you, Mr. Chairman. I will be happy 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 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 Medicine and School of Nursing.

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.