

DEPARTMENT OF HEALTH AND HUMAN SERVICES
NATIONAL INSTITUTES OF HEALTH

Fiscal Year 2015 Budget Request

Statement for the Record

Senate Subcommittee on Labor-HHS-Education Appropriations

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Director, National Institute of Nursing Research

April 2, 2014

Mr. Chairman and Members of the Committee:

I am pleased to present the President's Fiscal Year (FY) 2015 Budget request for the National Institute of Nursing Research (NINR) of the National Institutes of Health (NIH). The FY 2015 NINR budget is \$140,452,000 which is \$128,000 more than the comparable FY 2014 appropriation of \$140,324,000.

I appreciate the opportunity to share with you a brief summary of some of the exciting areas of research and future scientific directions of NINR. The mission of NINR is to promote and improve the health of individuals, families, and communities. We fulfill this mission by supporting clinical and basic research to build the scientific foundation for clinical practice, prevent disease and disability, manage and eliminate symptoms caused by illness, enhance end-of-life and palliative care, and train the next generation of nurse scientists. Today, I offer an overview of NINR's efforts and accomplishments in five key scientific areas and provide examples of how the research we support improves quality of life, health, and wellness across the lifespan.

SYMPTOM SCIENCE: PROMOTING PERSONALIZED HEALTH STRATEGIES

NINR is committed to finding new and better ways to treat the symptoms of chronic and acute illnesses which can cause significant suffering for individuals and families. While we still have much to learn about the unique ways people experience symptoms and respond to treatments, recent advances in genomics are providing new opportunities to develop improved, personalized strategies to address adverse symptoms of illness, such as pain, fatigue, and disordered sleep. By providing a better

understanding of the basic underlying biological and genetic mechanisms of symptoms, NINR-supported researchers are making important contributions to improving health and quality of life. For example, one NINR-supported project found that, for pregnant women with depression, poor sleep was associated with higher levels of inflammatory chemicals in the body known as cytokines, as well as adverse pregnancy outcomes such as preterm birth. Other NINR-supported scientists identified pro- and anti-inflammatory biomarkers that predict how patients experience pain at different stages of breast cancer treatment, drawing a new link between pain and inflammation. Discoveries such as these pave the way for the development of personalized and effective treatments for adverse symptoms of illness.

SELF-MANAGEMENT OF CHRONIC ILLNESS

According to the CDC, chronic illness accounts for more than 75% of health care costs in the US, and often requires long-term management of illness among individuals, families, and health care providers. Learning how to manage chronic illness presents challenges to individuals of any age as well as their family members, from children remembering to bring their asthma medication with them to school to older adults maintaining daily activities as they face multiple chronic conditions, such as arthritis and heart disease. To address such challenges, NINR supports research that enables individuals with chronic illness and their caregivers to take an active role in understanding and managing their condition, and improving their quality of life. One current NINR-led initiative aims to equip families with effective strategies for

improving self-management of chronic illness in children and adolescents, enabling them to follow treatment regimens and make healthy lifestyle choices while still allowing “kids to be kids.” Another initiative emphasizes family-centered self-management that integrates family members as partners in care while promoting self-management for individuals of any age; this initiative has the potential to strengthen the ability of family members to work together to make treatment decisions, manage symptoms, and navigate the health care system. Through efforts like these, NINR’s investment in self-management research contributes to helping people live active and healthy lives in the face of chronic illness.

WELLNESS: PROMOTING HEALTH AND PREVENTING ILLNESS

Another area of emphasis at NINR is on wellness research, which seeks to understand the physical, social, behavioral, and environmental causes of illness, identify healthy lifestyle behaviors, and develop interventions to promote health and prevent illness across the lifespan and in diverse communities. One study supported by NINR is refining and examining the effectiveness of a home-based sensor system for older adults, which monitors pulse, breathing, and restlessness while sleeping, and alerts health care providers to potential illness so that they can intervene early. Such warning systems may allow older adults to stay active and remain in their homes longer. In another project, researchers developed a teacher-delivered healthy lifestyles intervention that improved health behaviors and academic outcomes in high school adolescents. NINR also maintains its commitment to promoting wellness in vulnerable

groups who are disproportionately affected by chronic illness. We currently lead an initiative to reduce health disparities in minority and underserved children through the development of culturally-appropriate, multifaceted interventions.

ENHANCING END-OF-LIFE AND PALLIATIVE CARE

Addressing the needs of patients with life-limiting illness through high-quality, effective end-of-life and palliative care continues to be a critical focus of NINR. As the lead NIH Institute for end-of-life research, NINR supports research to ease symptoms and support patients and their caregivers in coping with advanced illness, while also addressing the challenges of planning for end-of-life decisions. As an example, NINR-supported scientists recently found that pain continues to be underdiagnosed and undertreated for hospitalized patients at the end of life, suggesting that more work is needed to better understand the needs of individuals facing life-threatening illnesses. Recognizing that palliative care is a critical component of maintaining quality of life at any age and at any stage of illness, not just at the end of life, NINR supports initiatives to enhance palliative care. Given that a diagnosis of serious illness in a child is particularly difficult for families, NINR launched the Palliative Care: Conversations Matter™ campaign to raise awareness of pediatric palliative care and to provide evidence-based materials to help health care providers initiate often difficult conversations with pediatric patients and their families. NINR also continues to support a palliative care research cooperative to enhance the evidence base for palliative care interventions. A new NINR initiative to promote use of and long-term sustainability of

the cooperative will encourage researchers across the country to capitalize on the existing resources and expertise and streamline the research process.

LOOKING TOWARD THE FUTURE: NURSE SCIENTISTS

A primary goal of NINR is to prepare the next generation of nurse scientists to address health challenges and to contribute to an innovative, multidisciplinary, and diverse scientific workforce. NINR funds training and career development grants and programs to prepare nurse scientists to conduct research to build the scientific foundation for clinical practice. NINR's Summer Genetics Institute is an intensive training program on molecular genetics designed to improve research and clinical practice among graduate students and faculty. This year, our week-long Methodologies Boot Camp focuses on using Big Data in symptom research, and provides a research intensive program for participants to learn new state-of-the-art methodologies from nationally and internationally known scientists. By training nurse scientists to use new, innovative scientific methodologies, NINR advances nursing science to improve health.

In closing, thank you for the opportunity to share with the Committee some of the ways the science we support impacts the health of the Nation. In FY 2015, NINR will continue our mission to improve quality of life by advancing nursing science and by supporting research to inform high-quality and effective clinical care.

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

Dr. Patricia A. Grady was appointed Director of NINR on April 3, 1995. She earned her undergraduate degree in nursing from Georgetown University, and 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 been primarily in stroke, with emphasis on arterial stenosis and cerebral ischemia. She is a member of several distinguished scientific organizations, including the Institute of Medicine, Society for Neuroscience, American Academy of Nursing, and 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 Nursing and School of Medicine. In 1988, Dr. Grady joined the NIH as an extramural research program administrator in the National Institute of Neurological Disorders and Stroke (NINDS) managing 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 and, 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 authored or co-authored numerous published articles and papers on hypertension, cerebrovascular permeability, and arterial stenosis. 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. She was the first awardee of the Centennial Achievement Medal from the Georgetown University School of Nursing and Health Sciences, and she was named the inaugural Rozella M. Schlotfeld distinguished lecturer at the Frances Payne Bolton School of Nursing at Case Western Reserve University and received the honorary degree of Doctor of Public Service from the University of Maryland. In 2005, Columbia University School of Nursing honored Dr. Grady with its prestigious Second Century Award for Excellence in Health Care. During that same year she also received Doctor of Science, *Honoris Causa*, degrees from Thomas Jefferson University and the Medical University of South Carolina. Dr. Grady was recently named one of the top 100 Most Powerful Women in Washington. She is a past recipient of the NIH Merit Award and received the Public Health Service Superior Service Award for her exceptional leadership.