



National Health Council

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**Testimony of Myrl Weinberg, FASAE, CAE
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Submitted to the Senate Appropriations Subcommittee on Labor, Health
and Human Services, Education, and Related Agencies
Regarding Fiscal Year 2014 Department of Health and Human Services Appropriations
May 6, 2013**

Dear Chairman Harkin and Ranking Member Moran:

On behalf of the nation's leading patient advocacy organizations, thank you for the opportunity to submit testimony on the significance of funding for federal health research agencies and other programs that are designed to improve the health of our nation. As work begins on the Fiscal Year (FY) 2014 Labor-HHS appropriations bill, the NHC urges the Subcommittee to maximize funding for essential health programs, including those at the National Institutes of Health (NIH), Centers for Disease Control and Prevention (CDC), Health Resources and Services Administration (HRSA), Substance Abuse and Mental Health Services Administration (SAMHSA), and the Agency for Healthcare Research and Quality (AHRQ). We urge Congress to refrain from shying away from its longstanding commitment to serve people with chronic conditions, the individuals who use our health system on a daily basis.

The National Health Council (NHC) is the only organization of its kind that brings together all segments of the health care community to provide a united voice for the more than 133 million people living with chronic diseases and disabilities and their family caregivers. Made up of more than 100 national health-related organizations and businesses, its core membership includes the nation's leading patient advocacy organizations, which control its governance. Other members include professional societies and membership associations, nonprofit organizations with an interest in health, and major pharmaceutical, medical device, biotechnology, and insurance companies.

The NHC fully appreciates the challenging fiscal environment facing the country and your important role in guiding our nation through these complex and difficult times. The NHC recognizes that federal resources must be carefully allocated so as to ensure that such investments produce the greatest good for the American people.

In turn, let us not forget that federal support of health programs at HHS is moving us closer to making the impossible possible – saving medical expenses through effective prevention efforts and new treatments, and saving lives in the process.

The NHC and its member patient organizations cannot overstate that federal support of medical research, prevention programs, and health care delivery is vital to people living with chronic diseases and disabilities. As we depict in Figure 1, these services should not be considered in

isolation, but rather serve as essential building blocks toward strengthening the collective health care system.

Investment in biomedical research is leading the discovery of biomarkers – physical signs or biological substances that indicate the presence of conditions such as **osteoarthritis**, one of the leading causes of disability in the elderly and the most common type of arthritis in the U.S., usually affecting middle-aged and older people. This type of research will advance our understanding of disease progression and earlier detection and aid in expediting clinical trials on novel treatments.

Funds to pay for the study of rare or less common diseases will help to greatly improve our understanding of human health – and the more common conditions that burden us all. For example, research on **alpha-1 antitrypsin deficiency** – a disease affecting no more than 100,000 people – fueled new areas of investigation on COPD, a respiratory condition found in more than 12 million individuals.

The path to discovery supported by the federal government can result in cutting-edge, cost-effective programs. A widely-regarded NIH clinical trial on **diabetes** and subsequent translational research found that modest weight loss helped prevent type 2 diabetes for 58 percent of participants and positive results could be obtained for less than \$300 per person per year. These findings led to the creation of CDC's National Diabetes Prevention Program, which serves individuals with prediabetes in local communities across the country.

Research, prevention efforts, and programs that provide access to services and treatments each contribute importantly to enabling patients to manage their health. As baby boomers age, the prevalence of and deaths from diseases such as **Alzheimer's** and **heart disease** are projected to increase. Clearly, now is not the time to decrease our nation's investment in research that holds the key to the prevention, treatment, and cure of America's leading and most costly causes of death.

The NHC would be happy to provide the Subcommittee with numerous personal patient stories that demonstrate why appropriate funding of research, prevention, and health delivery programs is crucial to the millions of men, women, and children in this country living with chronic diseases and disabilities. We understand the difficulty you face in reaching consensus on a funding level that balances the needs of our country with the needs of people with few or possibly no treatment options.

But how do you place a cost figure on people like Debra – a woman diagnosed with **chronic kidney disease** who, after many years of dialysis, underwent a successful kidney transplant that was made possible because of advancements based on federally funded research? She was able to give back to society as a volunteer at Walter Reed Army Medical Center, helping others confronted with organ failure to deal with the changes in their lives and remain positive.

If we fail to take aggressive and deliberate action now to appropriately fund essential health programs, we will pay a terrible cost later – both in terms of health care expenditures and human lives.

The NHC appreciates the opportunity to submit this written testimony to the Subcommittee. We understand that you face many hard decisions and again urge you to maximize funding for health programs that benefit people with chronic diseases and disabilities so that patients will be able to live longer, healthier, and more productive lives.

Figure 1. Funding the Continuum of Care for Patients with Chronic Diseases and Disabilities

