



December 5, 2008

The Honorable Barack Obama
President-Elect of the United States of America

Dear President-Elect Obama:

The Friends of NCHS—a broad alliance of 150 organizations that want to ensure the National Center for Health Statistics' continued vital role in monitoring our nation's health—congratulate you on your election and look forward to working with you and your new administration. As you prepare to take office in January 2009, we hope you will consider two key issues of concern to our thousands of constituents: the funding and placement of NCHS. At a time when both you and Members of Congress are considering major health reform, the data NCHS collects are needed now more than ever to track Americans' health and evaluate our progress improving it.

Investment Needed to Restore and Modernize Data Collection

Currently housed within the Centers for Disease Control and Prevention (CDC), NCHS is the nation's principal health statistics agency and in this capacity provides critical data on all aspects of our health care system—chronic disease prevalence, health care disparities, emergency room use, teen pregnancy, infant mortality, causes of death, and rates of insurance to name a few. These data are used by the Census Bureau in evaluating its data and informing its population estimates and projections; by the food and business community in developing nutrition fortification policies and marketing strategies; by state and local governments; by federal policymakers; and by demographers, epidemiologists, health services researchers, and other scientists. The health data collected by NCHS are an essential part of the nation's statistical and public health infrastructure, as demonstrated by the breadth of organizations participating in the Friends of NCHS—American Diabetes Association, American Cancer Society, American Heart Association, March of Dimes, General Mills, and Kraft, among others.

Yet years of underinvestment have forced NCHS to undermine, eliminate, or further postpone the collection of such vital information to the point where key data users now question whether NCHS itself is in good health. These cuts will have a negative and lasting impact because NCHS' work is central to both private and public efforts to address the nation's health care needs, the spiraling costs associated with providing health services, and the research required to improve outcomes through both prevention and treatment. Specifically:

- The sample size for the National Health Interview Survey (NHIS), which has monitored trends in illness, disability, and health insurance coverage for over 50 years, has been cut in half. Such cuts jeopardize data on health insurance coverage at a time when policymakers need these data to formulate and evaluate health system changes. These cuts will also have significant adverse effects on our ability to understand the health status of minority groups and health disparities at a time when our society becomes increasingly diverse.
- The Nursing Home Survey, which was last conducted in 2004, has been postponed indefinitely. Further delays in the collection of these essential data will prolong our understanding of the provision and financing of long-term care as more and more aging and disabled Americans seek care in these sites of service.
- The National Hospital Discharge Survey, which has been conducted annually since 1965, will not be fielded in 2009 due to these budget constraints. Doing so will mean no new data on the characteristics of inpatients discharged from U.S. hospitals, e.g., average length of stay and rates of surgical and non-surgical procedures by age, race, and gender. In addition, work has been suspended indefinitely on the survey redesign, which would provide a wider range of data to reflect changes in health care delivery.
- Starting April 2009, NCHS will purchase from states through the National Vital Statistics System only “core items” of birth and death data (e.g., place of residence, age of mother, race of parents, and gender). Nearly all data items that are routinely used to monitor maternal and infant health, such as use of prenatal care, smoking during pregnancy, medical risk factors, and educational attainment of parents, would be considered “enhanced data items” and would not be collected from all states. As a result, our ability to monitor and track select *Healthy People 2010* objectives—including those related to Maternal and Child Health, Tobacco Use, and Occupational Safety and Health—will be compromised.

Without a budget increase in fiscal year 2010, NCHS will be forced to implement other cuts, including:

- Deeper cuts to the NHIS sample, or taking the survey out of the field altogether.
- Reducing by half its National Health and Nutrition Examination Survey (NHANES) sample, eliminating the practice of oversampling of minority populations, or taking NHANES out of the field. Doing so would severely limit or eliminate the only national source of information on a range of health measures, including obesity, diabetes, and heart disease, among others.
- Postponing the Home Health and Hospice Survey, further limiting our understanding of long-term and end-of-life care.

Based on past precedent, the Friends of NCHS are very concerned that data collection efforts, once cut, will not be restored. By way of background, when NCHS has faced

budget shortfalls and cut data collection in the past the data are only restored years later. Under severe budget constraints, as we see now, the data are never restored (e.g., the elimination of data collection on marriage, divorce, and abortions).

As you prepare the fiscal 2010 budget, we respectfully ask that you consider providing NCHS with \$137.5 million as a down payment toward a funding level of \$175 million in 2013. NCHS needs this funding now to restore these and other data collection efforts and to revise, pretest, and plan data collection activities for calendar year 2010 and beyond.

In addition, NCHS needs \$8 million in one-time, supplemental funding to support the states and territories as they implement the 2003 birth certificates. Future supplemental funding will be required to implement the 2003 death certificates in all states and complete the automation of data collection. Today only about half of the states and territories use the 2003 birth or death certificates to collect “enhanced” vital statistics. Fewer states collect both, and even fewer do so electronically (see attached list). Modernizing the National Vital Statistics System will improve data quality, efficiency, interoperability, and security.

Evaluating the Placement of NCHS

There is some evidence to suggest that NCHS’ chronic funding situation is due to more than how it has fared in the annual budget process. Some experts suspect that NCHS’ organizational location within the CDC may contribute to the agency’s challenges. These experts posit that NCHS would benefit from being located in another federal agency that is better-aligned with its mission (e.g., Agency for Healthcare Research and Quality), or elevated to a position of prominence within the Department of Health and Human Services (e.g., the Office of the Secretary), where NCHS would have greater visibility, autonomy, and ability to secure funding.

The Committee on Population Statistics (COPS) of the Population Association of America, a member of the Friends of NCHS, issued a report titled, *Safeguarding Vital and Health Statistics* on the organizational placement of NCHS. The report is posted at: <http://www.popassoc.org/files/public/COPS-NCHSfinal.doc>. To inform their analysis COPS collected publicly available information and conducted confidential interviews of key stakeholders, prior NCHS officials, and current NCHS staff.

The report details the implications of the agency’s location within CDC, providing some evidence that NCHS’ current placement may compromise its independence and impact its control over resources. The report also discusses potential options for relocating the agency within HHS. The Friends of NCHS ask the transition team and the new administration to consider this information and to evaluate whether elevating NCHS as an independent statistical agency could better serve the nation’s data needs.

The nation relies on the health data NCHS collects, and the need for timely, credible data will greatly increase if we pursue fundamental health reform. As we know from past health reform efforts, a lack of credible health information can severely hamper Congressional consideration and action. The Friends of NCHS believe that your goals

for health reform and Americans' improved health status necessitate the restoration and modernization of NCHS' important data collection initiatives, as well as the promotion of NCHS as a national statistical agency within HHS. Please know that the Friends of NCHS and our grassroots partners stand ready to support you in your efforts.

Please contact Emily Holubowich at emily.holubowich@academyhealth.org or 202.292.6743 with any questions or comments.



AARP

Abt Associates, Inc.

Alaska Native Tribal Health Consortium

Alliance for Aging Research

Alpha-1 Association

Alpha-1 Foundation

Altarum Institute

American Academy of Pediatrics

American Academy of Physician Assistants

American Association for Clinical Chemistry

American Association for Dental Research

American Association for Health Education

American Association for Respiratory Care

American Association of Colleges of Nursing

American Association of Colleges of Pharmacy

American Autoimmune Related Diseases Association

American Brain Coalition

American Cancer Society Cancer Action Network

American College of Clinical Pharmacy

American College of Emergency Physicians

American College of Healthcare Executives

American College of Nurse-Midwives

American College of Obstetrics & Gynecology

American College of Preventive Medicine

American Dental Education Association

American Dietetic Association
American Geriatrics Society
American Health Information Management Association
American Heart Association
American Medical Informatics Association
American Nurses Association
American Optometric Association
American Osteopathic Association
American Public Health Association
American Psychiatric Association
American Psychological Association
American Speech-Language-Hearing Association
American Society of Nephrology
American Society of Pediatric Nephrology
American Society for Reproductive Medicine
American Society for Nutrition
American Urological Association Foundation
American Thoracic Society
Aplastic Anemia & MDS International Foundation
The Arc of the United States
Arthritis Foundation
Asian & Pacific Islander American Health Forum
Association for Clinical Research Training
Association of American Medical Colleges
Association of Black Cardiologists, Inc.
Association of Maternal and Child Health Programs
Association of Minority Health Professions Schools
Association of Population Centers
Association of Public Health Laboratories
Association of State & Territorial Health Officials

Association of Women's Health, Obstetric, and Neonatal Nurses
Asthma and Allergy Foundation of America
Aveta, Inc.
Brown University, Warren Alpert Medical School, Center for Gerontology and Health
Care Research
Building Bridges, Inc.
C3: Colorectal Cancer Coalition
Case Western Reserve University School of Medicine
Center for Science in the Public Interest
Children and Adults with Attention-Deficit/Hyperactivity Disorder
Coalition for the Advancement of Health through Behavioral and Social Sciences
Research
Coalition for Health Services Research
Commonwealth of the Northern Mariana Islands Health and Vital Statistics Office
Congressional Black Caucus Foundation, Inc.
Consortium of Social Science Associations
COPD Foundation
Council of Professional Associations on Federal Statistics
Diabetes Action Research and Education Foundation
District of Columbia State Center for Health Statistics, Vital Records Division
Early Intervention Research Institute, Utah State University
Easter Seals
Emergency Medicine Network
Epilepsy Foundation of America
Fenway Community Health Center
Gay Men's Health Crisis, Inc.
General Mills
Grocery Manufacturers Association
Gundersen Lutheran Medical Center
Hadassah
Health Capital Consultants, LLC

Hearing Industries Association
Hearing Loss Association of America
Hirshberg Foundation for Pancreatic Cancer Research
Huntington's Disease Society of America
Infectious Diseases Society of America
Institute for the Advancement of Social Work Research
The Institute for Healthcare Quality Research and Education
International Waldenstrom's Macroglobulinemia Foundation
International & American Associations for Dental Research
Jacksonville Emergency Consultants, Inc.
The Jewish Guild for the Blind
Johns Hopkins University
The Joint Commission
Kidney Cancer Association
Kraft
Last Acts Partnership
Leonard Davis Institute of Health Economics
Lymphoma Foundation of America
March of Dimes Foundation
Maryland Department of Health and Mental Hygiene
Maryland Patient Advocacy Group
MATRIX Public Health Consultants, Inc.
Mental Health America
MJSahl Consulting
MMM Healthcare, Inc.
Musella Foundation for Brain Tumor Research & Information, Inc.
Medstat
The Melody Arons Center for Pre-School Research and Education
National Association for Public Health Statistics and Information Systems
National Committee for Quality Assurance

National Health Council
National Association of the Deaf
National Association of County and City Health Officials
National Business Group on Health
National Campaign to Prevent Teen Pregnancy
National Coalition for LGBT Health
National WIC Association
National Cued Speech Association
National Disability Sports Alliance
National Fragile X Foundation
National Health Law Program
National Hispanic Medical Association
National Hospice and Palliative Care Organization
National Multiple Sclerosis Society
National Organization for Hearing Research Foundation
National Osteoporosis Foundation
National Psoriasis Foundation
National Quality Forum
National Sleep Foundation
Nestle USA
North American Society for Pediatric Gastroenterology, Hepatology and Nutrition
NTM Info & Research, Inc.
Parent Project Muscular Dystrophy
Parkland Health and Hospital System
Pfeiffer University
Pituitary Network Association
Platelet Disorder Support Association
Post-Polio Health International
The Ohio State University College of Public Health
Partnership for Caring

Physicians for Human Rights
Population Association Of America
Prevent Blindness America
Public Health Foundation
Quality Community Health Care, Inc.
Research! America
RTI International
Service Employees International Union
Simmons School for Health Studies, Center for Health Policy Research
Snack Food Association
Society for Investigative Dermatology
Society for Neuroscience
Society for Women's Health Research
Southeast Emergency Consultants, Inc.
State and Territorial Injury Prevention Directors Association
Strategic Affairs Forecasting
Trust for America's Health
Tulane Center for Applied Environmental Public Health
UCB, Inc.
United Cerebral Palsy
University of California, San Francisco
The University of Georgia College of Pharmacy
University of Illinois at Chicago-School of Public Health
University of Michigan School of Public Health
University of Southern Maine, Institute for Health Policy, Muskie School of Public Service
University of Washington Department of Health Services
VHL Family Alliance
Virginia Commonwealth University, Department of Health Administration

Virginia Department of Health, Division of Health Statistics

Vision Council of America

WellPoint, Inc.

Well Spouse Association