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President/CEO

January 21, 2009

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The Honorable Charles B. Rangel
Chairman, Ways and Means Committee
United States House of Representatives
1102 Longworth House Office Building
Washington, DC 20515

The Honorable Dave Camp
Ranking Member, Ways and Means Committee
United States House of Representatives
1139E Longworth House Office Building
Washington, DC 20515

Dear Chairman Rangel and Ranking Member Camp:

On behalf of the Association of Academic Health Centers (AAHC), I am writing with regard to privacy requirements in the health information technology provisions of the stimulus package and to recommend that any new provisions not create barriers to the conduct of research and the advancement of science in the United States. The current regulatory environment is already having a significant negative impact on biomedical research in this country; adding more far-reaching provisions would further jeopardize the stability and viability of the research enterprise, which is integral not only to the advancement of science but also for the future U.S. economy.

The AAHC, representing more than 100 academic health centers nationwide, is dedicated to improving the nation's health care system by mobilizing and enhancing the strengths and resources of the academic health center enterprise in health professions, education, patient care, and research. AAHC studies have shown that the HIPAA Privacy Rule has negatively affected the cost, scope, and pace of research across the nation. The Rule has also had detrimental effects on the number of research participants being recruited, the diversity of the research participant population, and the ability of researchers to access specific data sources such as medical records, data warehouses, tissue repositories and genetic datasets. In addition, the Privacy Rule has put significant strain on the resources of academic health centers, therefore limiting the ability of researchers to pursue important avenues of scientific inquiry. Finally, it should be noted that there is no evidence to show that the Privacy Rule has had any significant benefit for research participants.

The protection of the privacy and confidentiality of patients and research participants is a fundamental tenet of research. However, studies have shown that the HIPAA Privacy Rule's paradigm is ill-suited to the realities and needs of the research environment. Therefore, we urge the Committee not to expand already problematic privacy requirements with respect to biomedical research performed within covered entities or by their business partners without full review and assessment of current barriers. Privacy requirements that do not take research into consideration will ultimately undermine the research enterprise and the country's ability to compete globally in science.

Academic health centers provide enormous public benefit and serve as the economic engines of their communities and regions through education, research, and health care delivery. We recognize the broad range of interrelated interests and issues represented in the stimulus package. However, without attention to the impact of privacy provisions on research, the nation risks creating serious and threatening consequences for the future. The AAHC is please to provide additional information and assistance if needed.

Sincerely,

A handwritten signature in black ink, appearing to read "Steven A. Wartman". The signature is fluid and cursive, with a long horizontal stroke at the end.

Steven A. Wartman, MD, PhD
President and CEO