Coalition for Patient Privacy

April 5, 2006

Via Facsimile and Hand Delivered

The Honorable William M. Thomas
Chair
Committee on Ways and Means
Washington, DC

The Honorable Charles B. Rangel
Chair
Ranking Minority Member
Committee on Ways and Means
Washington, DC

The Honorable Joe Barton
Chair
Committee on Energy and Commerce
Washington, DC

The Honorable John D. Dingell
Chair
Ranking Minority Member
Committee on Energy and Commerce
Washington, DC

The Honorable Nancy L. Johnson
Chair
Committee on Ways and Means
Subcommittee on Health,
Washington, DC

The Honorable Fortney H. “Pete” Stark
Chair
Ranking Minority Member
Subcommittee on Health,
Committee on Ways and Means
Washington, DC

The Honorable Nathan Deal
Chair
Committee on Energy and Commerce
Subcommittee on Health,
Washington, DC

The Honorable Sherrod Brown
Chair
Ranking Minority Member
Subcommittee on Health,
Committee on Energy and Commerce
Washington, DC

Dear Representative:

We, the undersigned organizations, applaud your efforts toward bringing the American healthcare system into the 21st Century by using technology to control costs and to reduce medical errors. Yet, we urge you to build a patient-centered system with patient privacy rights as the core of the health IT system.

We believe that the benefits technology can bring will be fully realized only if the health IT system is built upon the foundation of medical ethics and patient control of access to their sensitive identifiable medical records. The privacy standards in state and common law, Constitutional law, and medical ethics must be incorporated into the design of all regional and national health IT systems and networks.

Americans must trust the health IT system, must have confidence in the security of the system and must continue to trust their healthcare providers. Unless patients are assured of security, they will avoid treatment, lie about their symptoms and health issues, omit critical medical data, and delay care, endangering their health and the health of others because they know that their records will be used and shared without their permission.

The proper balance to ensure timely access to medical records for treatment and preserve patient control of medical records means allowing access in emergencies if consent cannot be obtained, but requiring patient permission before records are disclosed in everyday situations.

Without control, patients will not use the healthcare system in an effective manner, if at all, driving up costs and increasing the danger to everyone. Further, if they do not trust the privacy of electronic data systems and networks, their data will be incomplete and filled with inaccuracies and omissions. Corrupted, incomplete and false data will not enhance or improve medical outcomes or research.
We urge you to build a foundation for medical information technology that is based on the following longstanding ethical and privacy principles and protections:

- Restore the patient's right of consent
- Give patients the right to opt-out of having their records in any national or regional electronic health system
- Give patients the right to segregate their most sensitive medical records
- Require audit trails of all disclosures
- Deny employers access to medical records
- Require that patients be notified of all suspected or actual privacy breaches
- Preserve stronger privacy protections in state laws
- Enact meaningful enforcement and penalties for privacy violators

Sincerely,

American Civil Liberties Union
American Conservative Union
Asian American Justice Center
California Consumer Health Care Council
Christian Coalition of America
Common Cause
Computer Professionals for Social Responsibility
Consumer Action
Electronic Privacy Information Center
Fairfax County Privacy Council
Family Research Council
Free Congress Foundation
National Asian Pacific American Families Against Substance Abuse
National Center for Transgender Equality
National Health Law Program
Patient Privacy Rights Foundation
Population Research Institute
Privacy Activism
Privacy Rights Now
Privacy Rights Clearinghouse
Republican Liberty Caucus
Right March.com
Thoughtful House Center for Autism
U.S. Bill of Rights Foundation
U.S. Public Interest Research Group
U.S. Public Policy Committee for the Association for Computing Machinery

cc: Every Member of the U.S. House of Representatives

For additional information, contact:
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Coalition for Patient Privacy

American Civil Liberties Union, www.aclu.org
American Conservative Union, www.conservative.org
Asian American Justice Center, www.advancingequality.org
California Consumer Health Care Council, www.cchcc.org
Christian Coalition of America, www.cc.org
Common Cause, www.commoncause.org
Electronic Privacy Information Center, www.epic.org
Fairfax County Privacy Council, www.FairfaxCountyPrivacyCouncil.org
Family Research Council, www.frc.org
Free Congress Foundation, www.freecongress.org
National Asian Pacific American Families Against Substance Abuse, www.napafasa.org
National Center for Transgender Equality, www.nctequality.org
National Health Law Program, www.healthlaw.org
Patient Privacy Rights Foundation, www.patientprivacyrights.org
Population Research Institute, www.pop.org
Privacy Activism, www.privacyactivism.org
Privacy Rights Now, www.privacyrightsnow.com
Privacy Rights Clearinghouse, www.privacyrights.org
Republican Liberty Caucus, www.rlc.org
Right March.com, www.rightmarch.com
Thoughtful House Center for Autism, www.thoughtfulhouse.org
U.S. Public Interest Research Group, www.uspirg.org
U.S. Public Policy Committee for the Association for Computing Machinery, www.acm.org