patientprivacyrights

January 19, 2009

Honorable Charles B. Rangel
Chairman
House Committee on Ways and Means
1102 Longworth HOB
Washington, DC 20515

Honorable Henry A. Waxman
Chairman
House Committee on Energy & Commerce
2125 Rayburn HOB
Washington, DC 20515

Honorable David Camp
Ranking Member
House Committee on Ways & Means
341 Cannon HOB
Washington, DC 20515

Honorable Joe Barton
Ranking Member
House Committee on Energy & Commerce
2109 Rayburn HOB
Washington, DC 20515

Honorable Pete Stark
Chairman, Health Subcommittee
House Committee on Ways & Means
239 Cannon HOB
Washington, DC 20515

Honorable Frank Pallone, Jr.
Chairman, Health Subcommittee
House Committee on Energy & Commerce
237 Canon HOB
Washington, DC 20515

Honorable Wally Herger
Ranking Member, Health Subcommittee
House Committee on Ways & Means
242 Cannon HOB
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Honorable Nathan Deal
Ranking Member, Health Subcommittee
House Committee on Energy & Commerce
2133 Rayburn HOB
Washington, DC 20515

Honorable John Dingell
Chair Emeritus
House Committee on Energy & Commerce
2328 Rayburn HOB
Washington, DC 20515

Dear Congressmen:

You have taken critical steps to protect Americans' jobs and opportunities with the privacy protections incorporated into the Health Information Technology for Economic and Clinical Health Act, or "HITECH Act". This legislation addresses many of the issues that the Coalition for Patient Privacy, representing millions of Americans, brought to your attention (letter and signatures attached). **We stand ready to fight with you to protect consumers and ensure that our most intimate information, our health records, is *only* used to improve our health.**

Ensuring privacy results in two important outcomes.

First, ensuring privacy protects employees at a time when over eleven million Americans are unemployed. The last place anyone wants to be is in the "Unemployable" or "Uninsurable" lines; unfortunately, the two are often connected. Our sensitive health data should never be used to put us in either category. People should be hired based on whether they can do what is required, not on employers' fears that they cannot do good work because of a diagnosis, a medicine they take, their DNA or a genetic test. Thirty five percent of Fortune 500 companies admitted to looking at employee's health records before making hiring and promotion decisions.[1] This pre-hiring review of potential employees is inappropriate.

Second, privacy is the key to implementing a successful health IT system Americans trust. We all want to innovate and improve health care. But without privacy, our system will crash as would any computer system with a persistent and chronic virus. If we fail to ensure privacy and engender trust Americans will avoid participation or worse, avoid care altogether and undoubtedly misrepresent their medical histories.

<u>The HITECH Act ensures that patient protections trump profit, and that increased accountability and transparency follow the health IT provisions in the economic stimulus.</u>

By far the most important provision in the HITECH Act is the prohibition on the sale of protected health information (SEC. 4405(e)). Personal health information should not be sold and shared as a typical commodity. Health information is different; it is extremely sensitive and can directly impact jobs, credit, and insurance coverage. It is critical to put a stop to current data sales and misuse, but also to prevent the development of future businesses that sell personal health information as a commodity while doing nothing to improve Americans' health.

In addition, we strongly support the improved enforcement provisions of the bill. Periodic audits, state attorneys general enforcement, a compensation scheme for privacy victims and applying penalties to business associates are essential. The breach notification provision is likewise very strong.

It is critical that taxpayer dollars go only to funding systems that are capable of segmenting specific and sensitive information. Requiring the HIT Policy Committee to make recommendations is a positive step. Previous language requiring the National Coordinator to ensure segmentation capabilities would be a stronger protection.

Expanding our right to obtain audit trails of the uses of our health information to include treatment, payment and health care operations is another important improvement. We

[1] 65 Fed. Reg. 82,467

encourage you to require business associates to maintain audit trails as well as covered entities and shorten the timeframe for this provision to go into effect.

The HITECH Act provides a more consumer-friendly structure for the HIT Policy and Standards Committees. We hope the less prescriptive membership structure for these committees will allow for greater consumer participation. We applaud the efforts to increase participation by providing funding for consumer advocacy groups and not for profit entities that work in the public interest.

We continue to advocate that our right to health information privacy be explicitly reaffirmed in statute. Furthermore, Congress can do more to ensure Americans have greater control over the uses of their health information. We are supportive of the measure directing the Secretary to narrow the definition of health care operations, though we would prefer to see those kinds of limitations put in statute.

A January 18, 2009 *New York Times* article clearly described the challenge we face: we must protect the consumer over special interests.[2] We should not continue to allow business as usual when it harms the American public. At least one technology giant, Microsoft, comes to the table willing to marry health IT and privacy. "Health information technology will succeed only if privacy is protected," said Frank C. Torres, director of consumer affairs at Microsoft. "For the president-elect to achieve his vision, he has to protect privacy."

Thank you for the tremendous work and collaborative efforts of your respective committees. The HITECH Act is truly a giant step forward in protecting privacy and promoting health IT. We are united in our strong support for your common sense protections.

Sincerely,

/s/

Deborah C. Peel, MD
Founder & Chair

/s/

Ashley G. Katz, MSW
Executive Director

Encl. Coalition for Patient Privacy letter to Congress 1/14/09

cc: U.S. House of Representatives

[2] "Privacy Issue Complicates Push to Link Medical Data" by Robert Pear, January 18, 2009, *New York Times*