

COALITION FOR PATIENT PRIVACY

May 11, 2008

Honorable Max Baucus (D-MT)
U.S. Senate
Chairman, Senate Finance
511 Hart Senate Office Building
Washington, D.C., 20510-2602

Honorable Charles Grassley (R-IA)
U.S. Senate
Ranking Member, Senate Finance
135 Hart Senate Office Building
Washington, DC 20510-1502

Honorable Charles B. Rangel (D-NY)
U.S. House of Representatives
Chairman, Ways and Means
2354 Rayburn House Office Building
Washington, D.C., 20515-3215

Honorable Jim McCrery (R-LA)
U.S. House of Representatives
Ranking Member, Ways & Means
242 Cannon House Office Building
Washington, D.C., 20515-1804

Honorable John Dingell (D-MI)
U.S. House of Representatives
Chairman, Energy & Commerce
2328 Rayburn House Office Building
Washington, D.C., 20515-2215

Honorable Joe Barton (R-TX)
U.S. House of Representatives
Ranking Member, Energy & Commerce
2109 Rayburn House Office Building
Washington, D.C., 20515-4306

Re: Electronic Prescribing Legislation

Dear Member:

The Coalition for Patient Privacy urges you to include privacy protections in any measures supporting or mandating electronic prescribing. While e-prescribing is attractive to many, we can also state affirmatively that Americans do not want their private prescription information data mined and used without their permission. The Coalition urges you to insure any e-prescribing legislation recognizes Americans' right to health privacy and prohibits the use of prescription data for purposes other than prescription filling.

Our current system facilitates the daily data mining and sale of every prescription from all 51,000 pharmacies in the United States. This has been the reality for over a decade. You cannot keep a prescription private in the U.S. or stop your data from being sold. Even paying cash will not stop the sale of your prescription information.

Mandating e-prescribing without privacy provisions endorses and encourages the current practices. It sets Americans up for even greater violations of their private health records in the future.

We encourage you to seize this golden opportunity to insure progress and privacy.

How would you feel if your prescription regimen was emblazoned on your shirt for the entire world to see? Did you know that the primary purchasers of prescription records are insurers, drug marketers and employers? What kind of judgments would be made if others knew you took an anti-depressant, a cholesterol-lowering, an anti-anxiety or weight loss medication? What about medicine for a sexually transmitted disease? If you are a diabetic, do you want to be bombarded by unsolicited mail about new diabetic drugs or want your doctor to be pressured to change your medications? Or would you rather discuss that private matter with your trusted doctor?

Clearly, Americans want to keep matters related to their health between themselves and their health care professionals. Americans do not want their private prescription information data mined or made public. All Americans want is to get the prescriptions and treatment they need --

safely and privately. In late 2007, the state of West Virginia and Express Scripts learned the lesson the hard way. When the 200,000 state employees learned their prescription records were being sold to data miners, they were outraged. Express Scripts promptly agreed to stop this practice when they were faced with losing 200,000 customers.¹

The Coalition for Patient Privacy recommends the following basic principles in any e-prescribing legislation:

- include a right to health information privacy (the right to control access to personal health information);
- require that any prescription data transmitted via e-prescribing be used only for the express purpose of prescription filling and submitting the necessary codes to the insurer for payment;
- include a provision requiring prompt notification of privacy breaches;
- include a provision that creates meaningful penalties and enforcement mechanisms for violations detected by patients, advocates and government regulators;
- include provisions enhancing the security of e-prescription data such as encryption when data is transmitted, stored or retained in any storage and retrieval systems, including access devices, readable cards or other methods;
- ensure physicians who decline to use e-prescribing are not penalized;
- ensure transparency by requiring annual reporting to patients listing everyone who has accessed their prescription data;
- include a provision ensuring stronger state privacy laws are not pre-empted;
- require reporting of privacy complaints to the Centers for Medicare and Medicaid Services (CMS);
- require CMS to provide an annual report to Congress on privacy complaints made; and
- ensure prescription technology allows those with disabilities to be able to use e-prescribing tools efficiently and effectively.

The future impact of greatly expanding the electronic transmission of our private prescription records without privacy will undoubtedly result in a vast array of unintended consequences. Those consequences may include breaches of private information and ultimately discrimination based on illness or genetic risk of disease.

The Coalition for Patient Privacy cannot stress enough the opportunity before you to avoid exacerbating the invasive data mining practices. You have the perfect opportunity to stand tall for privacy, efficiency and quality. Your constituents and the American public will be grateful for your forward thinking. We look forward to working with you and your staff on this issue.

Sincerely,

The Coalition for Patient Privacy

American Association of People with Disabilities www.aapd.org

American Association of Practicing Psychiatrists

American Association of Small Property Owners www.aaspo.org

American Civil Liberties Union www.aclu.org

American Council for the Blind www.acb.org

American Psychoanalytic Association www.apsa.org

Citizens for Health www.citizens.org

Confederation of Independent Psychoanalytic Societies www.cipsusa.org

Consumer Action www.consumer-action.org

Consumers for Health Care Choices www.chcchoices.org

The Cyber Privacy Project

Electronic Privacy Information Center www.epic.org

(continued)

¹ <http://wvgazette.com/section/Opinion/200711265>

"Anyone today who thinks the privacy issue has peaked is greatly mistaken...we are in the early stages of a sweeping change in attitudes that will fuel political battles and put once-routine business practices under the microscope." Forrester Research

Equal Justice Alliance www.EqualJusticeAlliance.org
Fairfax County Privacy Council www.fairfaxcountyprivacycouncil.org
Gun Owners of America www.gunowners.org
Just Health www.justhealthnow.org
Liberty Coalition www.libertycoalition.net
The Multiracial Activist www.multiracial.com
National Association of Social Workers www.socialworkers.org
National Center for Transgender Equality www.nctequality.org
Pain Relief Network www.painreliefnetwork.org
Patient Privacy Rights www.patientprivacyrights.org
Private Citizen, Inc. www.privatecitizen.org
Republican Liberty Caucus www.rlc.org
Tolven, Inc. www.tolven.org

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

For additional information please contact:

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