

Congress of the United States  
Washington, DC 20515

## Privacy is a Non-Partisan Issue Put a "STOHP" to Invasions of Your Privacy

April 10, 2003

Dear Colleague:

On April 14, modifications to the Department of Health and Human Services Privacy Rule will become effective, loosening the control that Americans have over the use and disclosure of their personal health information. These modifications weaken vital protections in the rule and create dangerous loopholes that expand unauthorized access to the personal health information of millions of Americans.

According to a recent Harris poll, large majorities of Americans are worried that their private information is at risk of being released or used without their permission. For example, 69 percent of respondents agreed with the statement: "Consumers have lost all control over how personal information is collected and used by companies." When it comes to private medical information, Princeton Survey Research Associates reports that 1 in 6 people in the United States has done something out of the ordinary to keep personal health information confidential, such as withholding information from their doctor, providing inaccurate information, or, in some cases, avoiding health care altogether.

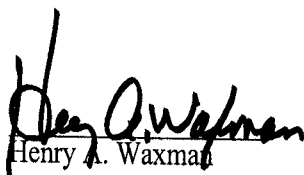
We are introducing The Stop Taking Our Health Privacy (STOHP) Act to put patients' privacy first by closing the massive privacy loopholes that HHS opened in the areas of:

- 1. Consent:** The STOHP Act restores the right of patients to decide whether to permit the use and disclosure of their personal health information for purposes of health care treatment, payment and so-called "health care operations." Last summer, HHS eliminated patient consent in these three important cases, denying patients the fundamental right of deciding for themselves whether their health information can be used or disclosed.
- 2. Marketing:** The STOHP Act ensures that patients are not unwitting victims of marketing campaigns disguised as objective medical advice. Our bill reverses the change that HHS made to the marketing definition. This change allows health providers to send unsolicited health recommendations to patients that are paid for by drug companies without informing patients of the financial connection between the company and the health provider or giving recipients the opportunity to opt-out of future communications.
- 3. Disclosures to FDA-regulated entities such as drug companies:** The STOHP Act narrows the purposes for which personal medical information can be used or disclosed to these entities without patient consent. Our bill limits nonconsensual disclosure to these entities for the purpose of strict public health priorities such as drug recalls. The August modifications created a broader exemption that allows nonconsensual disclosure of patient information to drug companies for a wide range of activities, which may include marketing campaigns.

If you would like to co-sponsor the STOHP Act or receive additional information, please have a member of your staff contact Mark Bayer at 5-2836 (Rep. Markey), Kristen Amerling at 5-5051 (Rep. Waxman), or Karen Folk at 6-3400 (Rep. Dingell).

Sincerely,

  
Edward J. Markey

  
Henry A. Waxman

  
John D. Dingell