

HAAC

Hepatitis C Action & Advocacy Coalition

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BY EMAIL

The Honorable Edward Kennedy
U. S. Senate
527 Hart Senate Office Bldg.
Washington, D. C. 20510

Dear Senator Kennedy:

HEPATITIS C ACTION & ADVOCACY COALITION (HAAC-SF) strongly objects to the new rule proposed by the Health and Human Services entitled "Standards for Privacy of Individually Identifiable Health Information". We represent persons living with Hepatitis C and their right to confidentiality of medial records is of utmost importance.

As a current example, hepatitis C (HCV) patients are already experiencing problems with one drug maker, Schering-Plough, through its registration program of PEG-Intron (an HCV treatment). Schering is circumventing existing confidentiality laws by forcing patients to give detailed identifying information directly to the company or its representatives in order to receive that treatment. The company is further using this information to conduct direct-to-consumer promotion of its products in follow up contact to these patients.

Such an example shows that we need to strengthen existing laws, not eviscerate them as the current HHS proposal does.

Thank you for your help and leadership on this important matter.

Sincerely,

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Statement of Purpose

The Hepatitis C Action & Advocacy Coalition (HAAC) is a grassroots, all-volunteer group of individuals committed to non-violent direct action to end the Hepatitis C crisis. We work to provide access to life-extending treatments to people with Hepatitis C, foster effective prevention efforts, encourage sound public health policies, and to ensure adequate funding and resources for the care, treatment, and prevention of Hepatitis C. We work cooperatively with government and industry when progress is being made, and take to focused, non-violent direct action when progress is stalled.

We accept no money from pharmaceutical companies.

Ending the Hepatitis C crisis is our highest priority.