



April 19, 2018

Chairman Greg Walden
Energy and Commerce Committee
2125 Rayburn House Office Building
Washington, D.C. 20515

Vice Chairman Joe Barton
Energy and Commerce Committee
2109 Rayburn HOB
Washington, D.C. 20515

Chairman Michael Burgess, M.D.
E&C Health Subcommittee
Energy and Commerce Committee
2336 Rayburn House Office Building
Washington, D.C. 20515

Dear Chairman Walden, Vice Chairman Barton, and Subcommittee Chairman Burgess,

I am writing you about the legislation often called “Jessie’s Law.” **We are concerned about the impact of this legislation on patient rights, patient privacy, and patient access to timely and essential medical care. We request that the legislation not be passed.**

This legislation is found in a variety of bills, including H.R. 3545 (Murphy) and S. 1850 (Manchin). We understand that your committee is key to whether the legislation passes.

To be clear, here are a few of our concerns:

- 1. Patients who are or have undergone substance abuse treatment will lose their confidentiality and privacy rights.**

Allowing the so-called HIPAA “privacy” rule to govern sharing of confidential substance abuse treatment means that people who receive such treatment will have their information broadly shared.

HIPAA is a permissive *disclosure* rule.

HIPAA facilitates broad sharing of patient information without patient consent, for all sorts of purposes that do not directly relate to the care of the patient. In short, **HIPAA is a “no-privacy” rule.** HHS, in a 2010 federal rule, listed the number of covered entities (more than 700,000) and business associates (1.5 million) governed by HIPAA. HIPAA permits sharing of patient information with these entities and BAs without patient consent for many reasons if the holder of the data provides access to the information, including payment, treatment and health care operations (nearly 400 words long), and 12 “national priority purposes” such as law enforcement, public health and research.

2. **Under HIPAA, which would become the governing law, the *security* of patient data would become the focus (after broadly shared), not the privacy of patient data.**

Confidentiality is regularly breached by HIPAA.

As Richard Sobel, former Senior Research Associate at Harvard Medical School Program in Psychiatry and the Law, wrote in a 2007 Hastings Center Report (**The HIPAA Paradox: The Privacy Rule That's Not**), "*HIPAA is often described as a privacy rule. It is not. In fact, HIPAA is a disclosure regulation, and it has effectively dismantled the longstanding moral and legal tradition of patient confidentiality.*"

3. **CFR 42, Part 2 is critical for timely and accurate medical care for substance abuse.**

The federal law protects consent rights because it was understood that individuals could be harmed by eliminating their consent rights. They may not seek care when they should, they may not seek care on a timely basis, they may not provide the necessary full and frank disclosures necessary to receive timely and accurate medical care. This reality has not changed.

4. **CFR 42, Part 2 privacy and consent protections are what every patient should have for every medical condition.**

HIPAA destroyed patient privacy rights, patient consent requirements, and the confidentiality of the patient-doctor relationship. It breached the ethical requirement of medicine, instead fulfilling the data-sharing desires of the data industry, government agencies, and third-party payers.

The only place those critical and ethical elements are still found is under CFR 42, Part 2. These consent requirements should not be eliminated. They should be expanded across the entire health care system to once again provide all patients with confidentiality in the exam room.

We request that you refuse to undo the privacy protections and consent requirement of CFR 42, Part 2—and then begin to bring those protections back to all patients in all exam rooms and hospital beds everywhere.

Thank you for your consideration.

Sincerely,



Twila Brase, RN, PHN
President and Co-founder