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April 14, 2021

The Honorable Senator Charles E. Schumer  
Office of the Majority Leader  
United States Senate  
322 Hart Senate Office Building  
Washington, DC 20510

Dear Leader Schumer,

April 14 is the 18<sup>th</sup> anniversary of the federal regulation called the "HIPAA privacy rule." This is a misnomer. **HIPAA is not a privacy rule.** It is considered a permissive data-sharing rule.

As David Brailer, former Coordinator of the Office of the National Coordinator of Health Information Technology once said, "**You can't force a covered entity to give your data to someone you choose, and you can't stop them from giving it to someone they choose.**"<sup>1</sup>

The public wrongly believing that HIPAA protects their privacy while **2.2 million entities**, according to a 2010 HHS rule,<sup>2</sup> are allowed to access, share, analyze, dissect and use their data without their consent if those who hold it ("covered entities" such as hospitals, clinics, health plans) choose to share it. This authority to intrude, to surveil, has increasingly led to **outside interference** in medical decision making. It also means unbiased second opinions and frank conversations are difficult for patients to secure.

This year marks the **25th anniversary of the Health Insurance Portability and Accountability Act of 1996 (HIPAA)**, the law that eliminated patient privacy rights and authorized the computerization of medical record data, thus facilitating easy and broad access. The Act was signed into law on August 21, 1996. The associated HIPAA rule, ostensibly written to protect patient privacy, went into effect 18 years ago today, on April 14, 2003. The fact that HIPAA does not protect privacy can be seen in the 10-year strategic data partnership between Mayo Clinic and Google,<sup>3</sup> and in **Google's "Project Nightingale"** with the Ascension health systems analyzing millions of patients and their data in 21 states.<sup>4</sup>

**OUR REQUEST:** As the nation's leading patient-centered organization for the protection of patient privacy rights, we are asking you on this the 25<sup>th</sup> year of HIPAA to introduce legislation that:

- 1) Rescinds the 2003 federal rule officially titled, "Standards for Privacy of Individually Identifiable Health Information" and all its amendments.
- 2) Imposes informed, written, voluntary patient consent for the sharing of patient information.

We would be pleased to talk with you about our request and to assist you in any way with this critically important legislation.

Sincerely,

Twila Brase, RN, PHN  
President and Co-founder

<sup>1</sup> "Brailer on Who Owns Medical Records," Bernie Monegain, Healthcare IT News, May 1, 2015.

<sup>2</sup> <http://forhealthfreedom.org/Newsletter/September2010.html#Article3>

<sup>3</sup> "Mayo Clinic selects Google as strategic partner for health care innovation, cloud computing," Dusk Anastasijevic, Mayo Clinic, September 10, 2019.

<sup>4</sup> "Google's 'Project Nightingale' Gathers Personal Data on Millions of Americans," Rob Copeland, The Wall Street Journal, November 11, 2019.