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**Testimony in Support of Senate Bill 130,
An Act Concerning Patient Information and the All-Payer Claims Database
February 24, 2016**

Good afternoon Senator Gerratana, Representative Ritter, and distinguished members of the Public Health Committee. My name is David McGuire, and I am the Legislative and Policy Director at the American Civil Liberties Union of Connecticut (ACLU-CT) and I am here to testify in support of Senate Bill 130.

The ACLU-CT remains concerned that many provisions in the regulation of the all-payer claims database (APCD) negatively impact the privacy of Connecticut patients. The ACLU-CT strongly supports the concept that citizens should have control over their own medical information and how doctors, group practices and insurance companies share it with third parties. Medical records are extremely sensitive and personal, and people must have adequate control of this information.

All-payer claims databases are large databases that gather medical, pharmacy and dental claims, as well as eligibility and healthcare provider files, from people's private and public insurance. Typically, ADCP's include information about health care service dates, diagnosis and procedure codes, drug codes, the names of prescribing physicians, patient demographics such as date of birth, gender, or zip code, and patients' encrypted social security numbers. Collectively, this information can provide states with valuable insights regarding public health trends and costs. Individually, however, patients must be able to protect their sensitive personal information when a state implements one of these systems.

We know that nationally, patients have attempted to shield themselves from stigma, discrimination, or violence by paying out of pocket for medical services, asking doctors to change diagnoses, or frequently switching physicians in order to prevent having all of their medical records stored in one location. Some people have lied about conditions or gone without medical treatment completely in order to avoid creating medical record trails. People are worried about their medical privacy. Indeed, according to the Pew Research Center, people consider their health care information as second only to social security number in terms of sensitivity. It is important for Connecticut to acknowledge and respect these legitimate concerns by ensuring that the state's all-payer claims database meets its goals of transparency and better public health information while also defending patients' rights.

Creating an understandable and accessible mechanism for patients to opt-out, as provided by this bill, will give patients control over whether and how the state accesses their medical information and prevent the severe violations of privacy rights that the system could otherwise create. The ACLU-CT

prefers an opt-in option, which other states have found to be much more effective than an opt-out option, but we understand that the opt-out option presented in this bill may be more realistically attainable.

For these reasons, we urge you to protect patient privacy and support Senate Bill 130. Thank you for your consideration.