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HIPAA PRIVACY RULES AND THE IOWA REGISTRY FOR CONGENITAL AND INHERITED DISORDERS

The Health Insurance Portability and Accountability Act (HIPAA) regulations contain several major components, three of which are final: the Privacy Rule, Electronic Transactions and Code Sets, and the Security Rule. Covered entities (health plans, health care clearinghouses, and health care providers who transmit certain health claim information electronically) must be in compliance with the privacy regulation portion of HIPAA by April 14, 2003.

The Privacy Rule requires covered entities to obtain consent or authorization from an individual for certain uses and disclosures of identifiable health information. However, the Privacy Rule expressly permits covered entities to release identifiable health information to public health authorities under certain circumstances without obtaining consent or authorization from the patient.

First, although the requirements of HIPAA generally preempt state law, HIPAA provides for certain exceptions to this general preemption rule. One such exception applies when state statute and state administrative rules provide for "the reporting of disease or injury, . . . or for the conduct of public health surveillance, investigation, or intervention." 45 CFR 160.203. Iowa Code chapter 136A and 641 Iowa Administrative Code sections 1.3 and 4.7 authorize the Iowa Registry for Congenital and Inherited Disorders to access hospital records, physician records, clinical charts, vital records, and other medical information of patients with birth defects and genetic disorders for the purpose conducting birth defects surveillance. These provisions of law are not preempted by HIPAA and therefore a hospital, clinic, or health care provider is not required to obtain consent or authorization from a patient or parent prior to releasing this information to the Registry.

HIPAA also provides for a number of “permitted disclosures,” i.e. those disclosures of protected health information for which consent or authorization is **not** required. HIPAA authorizes such disclosures “to the extent that such use or disclosure is required by law and the use or disclosure complies with and is limited to the relevant requirements of such law.” 45 CFR 164.512(a). HIPAA further authorizes disclosures for public health activities to “a public health authority that is authorized by law to collect or receive such information for the purposes of preventing or controlling disease, injury, or disability, including, but not limited to, the reporting of disease, injury, vital events such as birth or death, and the conduct of public health surveillance, public health investigations, and public health interventions[.]” 45 CFR 164.512(b)(1)(i). Hospitals, clinics, and health care providers are required by Iowa law to allow the Registry to access to medical information about patients with birth defects and genetic disorders. Hence, HIPAA does not require that covered entities obtain consent or authorization prior to releasing birth defect and genetic disorder medical information to the Registry. In short, HIPAA provides no legal basis for hospitals, clinics, or health care providers to prohibit the Registry from obtaining information related to birth defects and genetic disorders.