



Questions & Answers About Medical Privacy Rights For Parents of Children with DSDs or Intersex Conditions

The Health Insurance Portability and Accountability Act of 1996 (HIPAA) is a federal law with regulations that ensure certain medical privacy rights. Your state may have additional privacy protections that go beyond HIPAA's. Below are some answers to common questions about medical privacy.

Question: What should I do if I am uncomfortable with the way my hospital labels my/my child's medical condition in their medical records?

Answer: Under HIPAA, you have a right to request an amendment to your medical records. The doctor or hospital must respond to your request in writing (usually within 60 days), and if they deny the request they must give a reason.

Doctors and hospitals use a list of neutral codes to bill your insurance company. You can request that they use these codes to label your child's condition as well. For example, there are new billing codes for AIS that don't have "pseudohermaphrodite," "male," or "testicular feminization" in the name. The hospital can log the child's condition using a term like "androgen insensitivity syndrome" or "46,XY DSD" in its records.

Your hospital staff may not be aware of these new codes. You can ask them to amend the medical records to reflect the new language. It is also a good idea to request a "discreet" label for your child's file.

Question: Will my/my child's medical information be kept private among the hospital staff?

Answer: Doctors and hospitals are required to limit employee access to your child's health information. Only staff members that need to know this information should be allowed to see it. Casual gossip about patients with other employees or with outsiders is also prohibited.

The federal department of Health and Human Services suggests that hospitals with computerized systems can limit employee access by letting them see only certain parts of the medical record, based on what they need to know to fulfill their job duties. Some hospital systems track which employees have accessed a given record.

See www.hhs.gov/hipaafaq/administrative/215.html.

Also, hospitals are required to designate someone as the privacy officer. The hospital staff should be able to tell you who this person is, and it should be listed on the privacy disclosure you receive during your first hospital visit.

The privacy officer should be able to explain what steps the hospital has taken to protect private patient information, and also what steps they have taken to train their staff in privacy procedures.

(See www.hhs.gov/hipaafaq/about/189.html for a general explanation of what HIPAA requires hospitals to do.)

Question: How can I know if the hospital has shared my/my child's medical information with other people or organizations?

Answer: A patient has the right under HIPAA to request a list of unauthorized disclosures of their private health information not related to treatment or payment. A patient can request this information once a year for free (the doctor or hospital can charge if you ask more often).

Question: If I believe a doctor/hospital has violated my/my child's privacy rights, what can I do?

Answer: If you believe a medical provider has violated your privacy rights under HIPAA and you are unable to resolve things with that provider, you can file a complaint with the Office for Civil Rights. There is information about filing a complaint at www.hhs.gov/ocr/hipaa.

You can also contact AIC. We may be able to help with information, resources, or other assistance. Our website is www.aiclegal.org. You can contact us by email at director@aiclegal.org or by phone at (707) 793-1190.

Also, depending on where you live, you may have other privacy rights under state law.

There is more information about protecting the privacy of your health records and about state law at the following websites:

Center on Medical Records Rights and Privacy
<http://hpi.georgetown.edu/privacy/records.html>

Health Privacy Project
www.healthprivacy.org

Privacy Rights Clearinghouse
www.privacyrights.org/fs/fs8a-hipaa.htm#14

Advocates for Informed Choice uses innovative legal strategies to advocate for the civil rights of children born with variations of reproductive or sexual anatomy. The project engages parents, doctors, attorneys and intersex activists in strategy discussions; stimulates legal dialogue about the fundamental rights of children born with intersex conditions or DSDs; and employs traditional and non-traditional legal tools to ensure justice for children born with intersex conditions or DSDs. These activities are grounded in a sense of respect and compassion for the children, parents, doctors and intersex adults involved.