

QUESTIONS AND ANSWERS ABOUT RETRIEVING MEDICAL RECORDS



It is a good idea for parents of intersex children to keep a copy of their children's medical records. Also, some intersex adults want to see their records so they can understand more about their childhood treatment. However, some intersex people and their families have reported difficulty in obtaining medical records.

In the past it was common to keep information about diagnosis or treatment secret from the patient and sometimes from the parents. Some medical providers may be unaware of new ethical and legal standards that require sharing of information with patients and their representatives.

QUESTION

Can I request my (or my child's) medical records?

ANSWER

The Health Insurance Portability and Accountability Act of 1996 (HIPAA) is a federal law with regulations that ensure certain rights for health care consumers. HIPAA requires health care providers, health plans, and health care clearinghouses to allow you access to your medical records. Providers must give you information about how you can obtain copies of your medical records or ask for a summary of your medical file.

In addition to HIPAA, about half the states have laws that allow patients or their designated representatives to access medical records. Laws usually allow health care facilities to charge a "reasonable" fee for copying records.

If you receive care in a federal medical facility, you have a right to obtain your records under the federal Privacy Act of 1974 (5 U.S.C. sec. 552a, www.justice.gov/opcl/privacy-act-1974).

Generally, parents have a right to request their child's medical records.

QUESTION

What should I do to request a copy of my (or my child's) medical records?

ANSWER

HIPAA does not require a written request. However, if your provider requires a written request, you must be given notice of this. Some hospitals may have a form specifically for requesting records. The provider's privacy policy should tell you how to request your medical records.

Even if your doctor does not require a written request, it is a good idea to make your request in writing and keep a copy. That way you have a record of important details such as when you filed your request and the record you requested. There is a sample of a letter to request medical records below.

Usually you should get copies of your records within 30 days of the request. Under HIPAA, if the process takes more than 30 days, you must be given a reason. Your state law may give you the right to receive your records more quickly. HealthInfoLaw.org provides state-by-state information.

Before composing your request for medical records, visit this site for information about your state: <http://www.healthinfo.org/comparative-analysis/individual-access-medical-records-50-state-comparison>.

ANSWER (CONTINUED)

First, gather the following information to begin your search:

- The names and addresses of the hospitals from which you want records.
- The dates of treatment at each hospital and the names of the doctors that treated you (if you know). If you don't have exact dates, provide a time range, like 1980-1983. Also, check your birth certificate for the hospital name, the hospital registration number, and the name of the doctor who attended your birth.
- Your birth date.
- Your birth parents' names.
- Any other information you have that might help identify your records.

Second, when you contact the hospital to request your medical records:

- Be firm but polite. You have a much better chance of success when the person handling the request is on your side.
- Multiple attempts may be necessary. If you're making a verbal request and the first person you talk to isn't helpful, try different departments or different times to find someone who is able to help you.
- If you or your birth mother have hyphenated last names, insist that they search under both parts of the name. Alphabetizing of hyphenated names is not always standardized.
- If your name was changed after birth, try both names.
- Records from different family members are often filed together, so it may be helpful to provide the names of your immediate relatives also.

If you have difficulty getting a response, try the following tips:

- It can be helpful to submit a letter from your current treating physician or mental health provider along with your request letter, stating that:
 - you are under their care,
 - you are aware that you are (or your child is) intersex (or name your specific medical diagnosis), and
 - in their professional opinion as your treating physician/counselor, it would not be harmful for you to see your (or your child's) entire medical record.
- You can also ask your current treating physician to request the records on your behalf. In this case you must complete a release of information form from the hospital from which you are requesting the information to your treating physician.
- You can provide a letter from an attorney outlining your rights to your medical information under HIPAA. A copy of the letter should be sent to the hospital's legal office. If you take this step, we recommend contacting an attorney in your state. You can call the state bar association for attorneys that deal in health issues, or HIPAA.

QUESTION

Can I be charged for my (or my child's) medical records?

ANSWER

Under HIPAA you can be charged a “reasonable” fee for copying records. You may also be charged for postage if you ask that records be mailed to you. HIPAA allows 30 days for a provider to respond to your request for records, with one 30-day extension for good reason. Your state laws may include a lower fee for copies of records or a shorter time for the provider to respond to your request.

QUESTION

What should I do if the medical records are very old?

ANSWER

Use the following tips:

- Ask the facility or provider if there is a special form for historical searches.
- If you are told that the documents have been accidentally destroyed due to fire or flood, ask to see documentation of the event. (We have heard of many intersex people being turned away with such stories.)
- Even if your physician moved, retired or died, his or her estate may have retained your records. You may be able to locate your records by contacting:
 - Your physician's business partners
 - The health information manager at a nearby hospital where the physician practiced
 - The local medical society
 - The state medical association
 - The state department of health
- HIPAA does not include a record retention period. In some situations, state or federal laws require retention of medical records for a certain period of time. However, it is possible that the records no longer exist, which means there is no way to obtain the information. While this is unfortunate, it is important to bear this possibility in mind.

QUESTION

What should I do if I am denied access to the medical records?

ANSWER

Under HIPAA, you are not guaranteed access to psychotherapy notes. Your request can also be denied if the provider decides the information you want could reasonably endanger your life, your physical safety, or that of another person. A written denial letter is usually required. In some cases you can appeal a denial. If so, you should be given instructions on how to appeal in the written denial.

If you believe your HIPAA rights have been violated, you can file a complaint with the U.S. Department of Health and Human Services's Office of Civil Rights.

U.S. Department of Health and Human Services
Office of Civil Rights
200 Independence Avenue, S.W.
Washington, D.C., 20201
Phone: (866) 627-7748
Web: www.hhs.gov

Your state's medical privacy law might also enable you to file a complaint with state regulators. See www.healthprivacy.org or www.healthinfo.org for more on state laws.

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

interACT believes that **the law, properly used,** is a tool for **achieving justice;** and that **justice, properly understood,** has compassion at its heart.

Legal advocates have always played an important role in **protecting the most vulnerable** members of society, such as **children born with intersex traits** or **variations of sex development.**

