

Health Insurance Portability and Accountability Act (HIPAA) Notice of Privacy Practices

Dear patient or family member/legal guardian:

As you may know, on April 14, 2003, new federal regulations regarding privacy practices became effective. This new federal legislation called HIPAA (Health Insurance Portability and Accountability Act) requires that our practice tell you how we protect your private health information. You are entitled to request a restriction on the medical information we use or disclose about you/your child's diagnosis, treatment, counseling, billing/payment, or for the evaluation of our services.

In the Division of Genetics, your medical information has always been treated as personal and private. We abide by the regulations of:

Children's Hospital (www.chnola.org/PrivacyNotice.htm)
and LSUHSC (www.lsuhs.edu/no/administration/rs/).

We strive to maintain good faith efforts to keep the privacy of our patients at the highest level. However, there are some specific areas of concern regarding evaluations in the field of Clinical Genetics. Please print this notice with the rest of the chart, read the following areas of concern, indicate, by making a check mark, that you agree to the areas/information requested. Please sign and date the form and fax it with the rest of the history you are sending us.

Detailed information. One of the most important regulations of HIPAA deals with obtaining the minimum necessary information to provide treatment, receive payment and improve operation. In Genetics, however, we need to obtain as extensive family, prenatal, natal, perinatal and postnatal histories as possible. The less information provided, the lower the accuracy of the diagnoses. Sometimes only extensive family information allows us to establish the diagnosis, pattern of inheritance or other information important for our assessment.

Pictures. During our evaluation we usually take pictures of the patient and family. These are important to document our findings, to facilitate the diagnostic search (in most complex cases), to evaluate the possibility of normal familial variation, to check progression or changes in the physical appearance with growing/aging through the years, etc. We frequently request that you bring pictures of parents and other relatives at different ages for more in-depth evaluation. Pictures are an important part of the genetic evaluation. Pictures may also be used for teaching. At the time of the consultation we will request that you sign a consent form. These pictures will NOT be used for any publication (books, journals, web pages, etc.) without a specific authorization signed by you/family member/legal guardian for this purpose. No names will be disclosed at any time.

Copies of letters. After evaluation in our clinics, we usually send a letter to the referring physician summarizing our evaluation. The evaluation includes positive antecedents and findings, diagnosis or possible diagnosis, and a diagnostic plan, including recommended tests, consultations and follow-up, and genetic counseling issues, if possible. We send copies to most, if not all of, the physicians/professionals involved in the care of your child or yourself. A copy is also mailed to you. We will also be happy to send copies to any physicians/health providers/family members with whom you want us to share our evaluation. You can list their names and addresses on page one of our new electronic form that you can obtain from our Web sites (www.chnola.org/clinical_serv_genetics.htm; www.medschool.lsumc.edu/pediatrics/clinics/defaultgenetics.htm; www.lsuhs.edu/no/centers/genetics/hereditaryhealing/article_clinicalevaluation.htm)

or our office. After our evaluation, you may decide to change some of the designated recipients. This should be no problem at all. We might also send a copy to the Office of Disabilities in order to help you to get SSI, if applicable.

- Disclosure of a genetic diagnosis to other family members.** The establishment of some genetic diagnoses or patterns of inheritance may have implications for other members of your family. For instance, they may also be affected or be carriers with risk of having affected children, etc. In case this is the situation in your family, please, at the end of the evaluation, provide us clear written guidelines (including name, address and phone number) on whom you would like to receive a copy of our report or be contacted regarding their potential risk.
- Communication of diagnosis to insurance companies.** We usually provide only the diagnosis to the insurance companies for billing purposes. In exceptional cases we might send a copy of the full report to demonstrate the level of complexity and the comprehensive evaluation we performed in order to avoid or reduce a charge to the family.
- Communication of diagnosis or list of birth defects for public health activities.** We may disclose medical information about your newborn to the Office of Public Health. As you may know, the state legislature is making obligatory the communication of all newborns/stillbirths with congenital anomalies to the Birth Defects Registry of Louisiana.
- Presence of medical students/residents/Ph.D.s' students/fellows.** LSU and Children's Hospital, like most institutions where you can find a clinical geneticist, are academic institutions. Therefore, teaching is very important. In Clinical Genetics, as in most other areas of medicine, the best way to learn about the evaluation of patients with different disorders is by attending clinics with experienced specialists. If, due to a particular reason, you do not want to have students present, please let us know in advance. The presence of students usually obliges specialists to perform a more thorough evaluation, which benefits the patient.

Please print this form, fill it out, sign it, and fax it with the rest of the information you are sending us. Place a check mark by those areas of concern that you agree to. We are looking forward to seeing you in our clinic and providing you and your family the best possible care.

Name	Signature	Date
------	-----------	------
