

NOTICE OF INFORMATION AND PRIVACY PRACTICES
Indiana State Department of Health (ISDH)
Genomics/Newborn Screening Program
Effective March 31, 2010, Version 2.0

Please Review Carefully

This notice describes how personal and medical information about you or your newborn may be used and disclosed and how you can get access to this information.

Department's Legal Duty

Federal and State laws restrict the use, maintenance, and disclosure of personal and medical information obtained by a State agency and requires certain notices to individuals whose information is maintained. In compliance with these laws, you and those providing information are notified of the following:

Department Authority and Purpose for the Genomics/Newborn Screening Program

The ISDH Genomics/Newborn Screening Program (NBS) collects information related to newborn screening as permitted in Indiana Code §16-38 *et.seq.* This information is collected electronically and includes such things as your name, address, medical care given to you and your newborn. Testing is required by law §16-41-17 and the program regulations contained in the Indiana Administrative Code (410 IAC 3-3) and if the required information is not provided, serious illness or permanent damage for affected newborns could result.

If you have religious objections to this testing, you may say "no" to the testing in writing and sign a form advising you that your hospital, doctor, and clinic staff are not responsible if your baby develops problems because those disorders were not identified and treated early.

Uses and Disclosure of Health Information

The ISDH uses health information about you or your newborn for screening, to provide health care services, to obtain payment for screening, for administrative purposes, and to evaluate the quality of care that you or your newborn receives. The information will not be sold to any organization or entity.

The law also allows the Department to use or give out certain information we have about you or your newborn for research purposes. (Indiana Code § 16-41-17).

The NBS Program may change its policies at any time subject to applicable laws and regulations. You may request a copy of our current policies or obtain more information about our privacy practices by contacting the ISDH Privacy Officer at 2 N. Meridian St., Indianapolis, IN or consulting our website at <http://www.in.gov/isdh/23500.htm>.

Individual Rights and Access to Information

The Newborn Screening Program must have your written permission to use or give out personal or health information about you for any reason that is not described in this notice. You can revoke your authorization at any time, except if the Newborn Screening Program has already acted because of your permission by contacting the ISDH Privacy Officer at 2 N. Meridian St., Indianapolis, IN or consulting our website at <http://www.in.gov/isdh/23500.htm> .

You have the right to look at or receive a copy (you will be charged) of your or your newborn's health information and receive a list of instances where we have disclosed health information about you or your newborn for reasons other than screening, payment or related administrative purposes.

You have a right to have information in your or your child's records changed if information is missing or you believe the information is incorrect. If the information you want to change did not come from Newborn Screening Program, we may not be able to change it, but we will keep a copy of your request with our records.

You have a right to ask that Newborn Screening Program contact you only in writing or at a different address, post office box, or telephone number. Newborn Screening Program will contact you the way you have asked if this is necessary to keep you safe.

You have a right to ask Newborn Screening Program not to use or share your or your newborn's information in the ways listed in this notice. However, we may not be able to comply with your request.

Newborn Screening Program may not retaliate in any way if you choose to file a complaint or use any of your privacy rights in this notice.

Important: Newborn Screening Program does not have complete copies of your health records. If you want to look at, get a copy of, or change your health records, please contact your doctor, clinic, or health plan.

Notices

This privacy notice is from the Newborn Screening Program. You may get other privacy notices from your doctor and other health care programs.

How Do You Use Your Rights

If you believe that we have not protected your or your newborn's privacy or have violated any of your or your newborn's rights you may file a complaint by calling or writing: ISDH Privacy Officer, at 2 N. Meridian St., Indianapolis, IN or consulting our website at: <http://www.in.gov/isdh/23500.htm>,

Or:

You may contact the Indiana Attorney General's office – Consumer Protection Division, 302 West Washington Street, 5th Floor, Indianapolis, IN 46204. Phone number (317-232-6330, or toll free at 800-382-5516. Web site: <http://www.in.gov/attorneygeneral/>

Or:

You may also contact the regional office of the Department of Health and Human Services, Office for Civil Rights at 233 N. Michigan Ave. – Suite 240, Chicago, IL, 60601. Phone number (312)886-2359; (312)353-5693 (TDD), fax number (312)886-1807, or toll free at 866-627-7748. Web site: <http://www.hhs.gov/ocr/privacy/>

HIPAA permits complaints to be filed with any or all of these entities, even if your own information was not involved in any potential violation.