

A GUIDE TO THE PRIVACY OF YOUR FAMILY HISTORY INFORMATION

➤ *What is family history and why is it important?*

Family history reflects shared genes, environment and behaviors. Family history information on traits and diseases that run in families provides clues to genetic factors that are unique to individuals and their family members. This history can be used by your health care professional to assess your risk for some diseases as well as your relatives' risk. With a complete and accurate family history, your health care provider can work with you on a plan to prevent disease or catch it early, when early diagnosis, intervention, treatment, or prevention can be most effective.

➤ *Questions & Answers***How will my health care provider use my family history information?**

Your health care provider should collect your family history information as part of a comprehensive medical examination. Your family history information will then become part of your confidential medical record. That information can be used to better screen, diagnose, and treat you.

Do I need to tell my family members my medical information?

It is generally believed that relatives need to communicate with each other about disease risks which may affect other family members. While you are not legally obligated to reveal medical information to your family members, sharing your family history information with your relatives improves their ability to act on important health information.

What are my responsibilities with respect to my family history?

- Decide whether you are willing to provide family history information and whether you would like to know your disease risks.
- Talk with your family about your decision and medical concerns.
- Communicate your decision to your health care provider.
- Make your family history information available to your health care provider.
- Collect and maintain up-to-date family history information.
- Protect your family history information as you protect all of your medical information.

What are my health care provider's responsibilities with respect to my family history information?

- Provide you with complete and accurate information about the use of your family history and what information is required for a complete history.
- Respect your decision to know or not to know your risks.
- Collect and maintain your family history as part of a comprehensive medical evaluation.
- Use your family history information to guide diagnosis and treatment.
- Maintain patient confidentiality within the boundary of his or her legal and ethical obligations.
- Discuss with you the effects of your disease risks on you and your relatives.
- Refer you for further genetic testing and counseling if necessary.

What if I want to tell other members of my family? For example, can I share the health information I know about my mother with my sisters?

You may choose to reveal information to your family members at your discretion. You may be ethically obligated to respect your family members' wishes, but sharing information you know about family members with other family members is legally permissible.

What if I really don't want to know my risk of future disease?

If you do not want to know your risk, you should communicate your decision to your health care provider(s). You should not presume that your provider is aware of your desire to know or not to know the results of any assessment or test. If you choose not to know, you may be preventing yourself or your family members from seeking care options.

Can my provider tell any of my family members about the family history I report?

Without your permission, your health care provider may not tell family members any information about your evaluation and treatment, including your family history. In very limited instances, a provider may have a duty to warn at-risk relatives about harm that may be prevented. If so, your provider must first ask you to inform your relatives. Only if you refuse may a provider possibly tell your family members. This duty is very limited.

Can my provider share my family history information with other people who work in their office?

Your provider is legally obligated to maintain patient confidentiality. The Health Insurance Portability and Accountability Act ("HIPAA") is a federal law that governs the flow of your health information. Under HIPAA, your provider must ensure that your information is shared with only those staff members necessary to ensure your care. Your state laws may also provide additional privacy protection.

Can my health insurance company ask my doctor for my family history information?

Generally, HIPAA prevents your provider from unauthorized disclosure of your information. Your state laws may prevent health insurers from gaining access to your family history information.

Could I be discriminated against based on my family history information?

Despite media attention, very few cases of genetic discrimination have been documented. On the federal level, the Americans with Disabilities Act may provide some protection against genetic discrimination. State law may also provide protection against genetic discrimination.

For More Information:

- **U.S. Surgeon General's Family History Initiative:** The U.S. Surgeon General offers an electronic tool to create a personalized family health history to be used in consultation with your health care provider. This tool, My Family Health Portrait, may be accessed online at <https://familyhistory.hhs.gov/>.
- For more information about your state laws, visit the **National Conference of State Legislatures** Web site: <http://www.ncsl.org/programs/health/genetics/ndishlth.htm>
- For more information about your health information privacy rights, visit the **U.S. Department of Health & Human Services** Web site on health consumer rights: http://www.hhs.gov/ocr/hipaa/consumer_rights.pdf