

DOES IT RUN IN THE FAMILY?

1

A Guide to Family Health History



GEISINGER
GENOMIC MEDICINE INSTITUTE

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This toolkit will help you collect, organize, and understand your family health history. In “A Guide to Family Health History”, each section includes choices of activities. Choose the activity that works best for you.

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Do you have questions or concerns?
Contact us at familyhistory@geisinger.edu
or 570-214-6065



What is family health history?



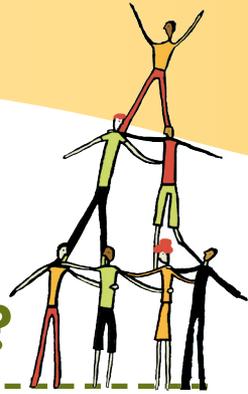
Family health history is a collection of information about diseases that run in your family, as well as the eating habits, activities, and environments that your family shares. Knowing about diseases in your family can help you make healthy choices.

Your family's health is one part of the history of your family. While collecting your family health history, pay attention to events, stories, and experiences as well. Gathering your family history helps you share your family stories and health information with your family members and children.

“Learning about your family’s medical history can help you partner with your doctor to set goals to personalize your path to better health”

– Marc S. Williams, MD
Director
Genomic Medicine Institute
Geisinger Medical Center

How can family health history affect my health?



You inherit many things from your parents and grandparents. They pass on culture and values through photos, recipes, stories, spiritual practices, and music. You also inherit how you look—for example, how tall you are and the color of your eyes. **Small structures in cells called genes carry information** for these characteristics and how your body works. Your genes were passed on to you from your parents.



Being prepared

After a wonderful pregnancy we were excited to have a beautiful baby girl. The call from the newborn screening program asking us to come for a repeat test for cystic fibrosis (CF) was a shock. After testing, our baby was diagnosed with CF, and we were told we are carriers for the disease. During our pregnancy we had been offered genetic screening for CF but declined because there is no family history. I later found out my cousin was a carrier for CF; it would have helped to know that family history.

Some genes can make it more likely that you will get certain diseases. When members of your family share health problems, you might be at risk for getting the same health problems in the future. This is because family members can have genes, lifestyle, and environment in common. However, you may be able to **prevent illness by knowing your family health history** and by making healthy choices.

Our daughter is an adorable seven year old and we love her. We wish that we had been more educated about CF during the pregnancy and knew our family history. This way we would not have been shocked and unprepared.



How can my choices affect my health?

Many things shape your health. Some things—such as your genes—are outside of your control. Other things—such as what you eat, if you smoke or exercise, and what you do for a living—**can be influenced by the choices you make.** To make healthy choices, you need to understand your current health, your risk for developing certain diseases, and your environment.



Dr. Christopher Still



I am a Geisinger internist and obesity medicine specialist who focuses on weight management and obesity treatment.

One trend we are seeing more often in clinic is multiple generations of obesity in a family. Once an individual becomes obese, the risk for the next generation to become obese is greater, and it is more likely to begin at a younger age. I've met some families where grandparents

Family health history is
the first step on the road
to better health.



became obese in their 50s or 60s, their children became obese in their 30s or 40s, and their grandchildren became obese in their teens or 20s or even younger.

The younger a person is when they become obese, the greater the risk for them to develop diabetes; heart disease; high cholesterol; high blood pressure; stroke; gallbladder disease; osteoarthritis; sleep apnea and other breathing problems; and different types of cancer at a younger age. Awareness of a family history of obesity can help family members recognize their own risks for obesity and adapt healthier lifestyles.

What information should I collect?

Who to collect information on:

- Yourself
- Your parents
- Your brothers and sisters
- Your children
- Then move on to aunts, uncles, cousins and grandparents.



Basic information to collect:

- Name and how you are related (myself, parent, child, etc.)
- Ethnicity, race, and/or origins of family
- Date of birth (or your best guess—for example “1940s”)
- Place of birth
- If deceased, age and cause of death

Collect stories about your ancestry and culture. This is a great chance to preserve your family’s memories.



You don’t have to collect everything!

Be sure to record age at onset of symptoms (when the disease started)

Health history:

- Alzheimer's disease
- Asthma and allergies
- Birth defects (such as cleft lip, heart defects, spina bifida)
- Blindness/vision loss
- Cancer (such as breast, ovarian, colon, prostate)
- Current and past medications
- Deafness/hearing loss at a young age
- Developmental delay/ learning disorders
- Diabetes/sugar disease
- Heart disease
- High blood pressure
- High cholesterol
- History of surgeries

- Immunizations
- Mental health disorders (such as depression, schizophrenia)
- Obesity
- Pregnancy (such as number of children, miscarriages, complications)
- Stroke
- Substance abuse (such as alcohol, drugs)
- Sudden death/ruptured vessels

Lifestyle:

- Exercise
- Habits (such as smoking, drinking, regular doctor/ dentist checkup)
- Hobbies and activities
- Nutrition and diet
- Occupation

It is important to learn what you can.

How do I collect family health history?

Talk to your family

Your relatives are the best source of information about your family. Family history is often shared during conversations at family events like birthday parties, weddings, reunions, religious gatherings, holiday dinners, and funerals. These events provide an opportunity to ask family members about their lives.



Use what you have

Check first to see if your family has existing family trees, charts, or listings of family members. This information may be written in baby books, photo albums, birthday date books, a family bible or other religious records. Review your own medical history with your doctor to make sure you are not forgetting anything.

Plan an individual conversation

After you have brought up the idea of collecting your family health history, you may want to talk with certain family members to get a more complete record of what they know. If possible, it may be helpful to record these interviews so you can go back later and review them. This guide includes questions to ask.

Send a survey

You may wish to send out a survey asking for health information from relatives. One quick and easy way to collect this information is to put it in a holiday newsletter. Not everyone will feel comfortable filling out a survey. Be sure to explain exactly why you are asking questions.

Need help? Have questions?

Call us at 570-214-6065 or
email familyhistory@geisinger.edu

Tips for collecting family health history



- Start with your parents if they are still living. Often, older relatives are good sources of information.
- There is often a “family historian”. Talk with relatives to determine who this person is and speak with them to get more information.
- If you are adopted, you may be able to learn some of your family history through your adoptive parents. You may also ask to see the adoption agency records.

Patient from State College

My mother was diagnosed with breast cancer at 39, and her mother was diagnosed at 54 with breast cancer. I pushed to have mammograms because of this family history. At 34 I was found to have Paget’s disease by my dermatologist, which led to a breast biopsy and a diagnosis of cancer. I have been proactive with my medical care and believe that my diligence is why I’m still here.

Years later, my younger sister was diagnosed with breast cancer at 40. Due to this history, my gynecologist strongly recommended I have genetic testing. I saw an oncologist and genetic counselor at Geisinger, and the testing found a BRCA gene mutation.

- It is important to **respect others**. Some relatives may not want to share their medical histories. Some may not know their family history.
- It can be scary to find out about a health concern in your family. **Sharing family history with your healthcare provider can help** you understand if you are at risk.
- Family members may not clearly identify all diseases. Ask questions that invite family members to describe behaviors that might suggest health issues. For example, someone who suffered from “the blues” may have had depression.

This mutation increases my risks for recurrent breast cancer, ovarian cancer or other cancers such as melanoma. My sisters, mother, nieces and cousins could have inherited the mutation and have an increased risk for cancer.

I have shared my genetic test results and medical history with family members so they can also have the genetic testing. My nieces are in their 20s and need to be aware of this history so they can be proactive and get early screening. Now that I know my BRCA mutation, I plan on having my ovaries removed to greatly reduce my risk for ovarian cancer.

How do I ask my family members about family history?

On the next page is a list of sample questions that will help you talk with your family members. These questions will help you learn about your family stories, as well as health patterns and any impact environment, lifestyle, and family history may have on family health. Be sure to **add your own questions** that relate more specifically to your family.

Prepare ahead of time

- Write down what you already know—such as family members’ names, where they were born, or how many children they have.
- Pick the questions you will ask ahead of time.
- It may be helpful to record the interviews on a tape recorder or video camera.



Robert’s story

Type II diabetes is a disease that affects many generations in my family: my great-grandmother, my grandmother and some of her siblings, my father and his sister. A few years ago, two of my sisters and I began experiencing symptoms the doctor classified as “pre-diabetes.” Since we have a strong family history of type II diabetes, the doctor orders frequent lab work to monitor our health status.

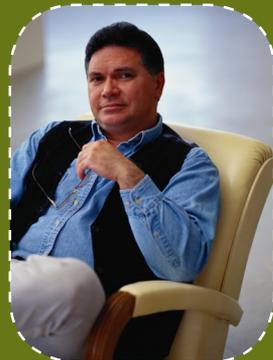
During the conversation

- Write down health-related information provided by your relative.
- Try to keep the questions short and avoid questions that can be answered with a simple “yes” or “no.”
- Use follow-up questions such as “why,” “how,” and “can you give me an example.”
- Do not expect people to know the answers to all of your questions.
- Be sensitive to a person’s wishes not to talk about certain topics.
- Ask your family member to show you pictures, recipes, letters, and other family keepsakes. These can help people remember details and can lead to more family stories.

Try not to interrupt—let your family member tell his or her story!

Last year, following my doctor’s advice, I modified my lifestyle by eating healthier meals and snacks and increasing my activity level. My pre-diabetes symptoms have since subsided, and my lab work is consistently within normal limits.

To find out more about diabetes, visit www.diabetes.org.



Sample questions

These questions are examples. You should change them to fit your conversation.

Questions about childhood

- Where were you born?
- Where did you grow up?
- Did you experience any health problems (for example, allergies) as a child?
- Do you have any brothers or sisters? Are they living? How old are they?

Questions about adulthood

- What jobs have you had? Can you tell me about a typical day?
- What was your work environment like?
- Do you have children? What are their names and when were they born? Did they have any health problems?
- What habits (sun exposure, physical activity, smoking, etc.) have you had that could have affected your health?
- Did you have any health problems or illnesses as an adult? At what age? Did any of these problems require medical treatment or surgery?



Questions about parents and grandparents

- When and where were your parents born? What do you know about them (for example, their jobs and hobbies)?
- When and where were your grandparents born? What do you remember about them?
- Did your parents or grandparents have any health problems?
- Do you know if your parents or grandparents took medicine on a regular basis? If so, for what? Did they use home remedies? What kinds and for what?

Questions about family life

- Has your family lived anywhere that caused them health problems (e.g. disaster areas, waste sites)?
- What foods does your family usually eat? Describe a typical family breakfast or dinner. Do you eat special foods for special occasions?
- Does anyone smoke? Drink a lot of alcohol?
- Is anyone overweight or obese?
- Has anyone had problems in pregnancy or childbirth? What kinds of problems?
- Are there any diseases that you think might run in our family?
- Was anyone screened or had genetic testing for a serious disease like cancer? What was the result?
- Where did your ancestors come from (e.g. Germany or Europe) and what was their religious background?
- Is there anything else you would like to tell me about your life or health concerns in our family?

How can I organize my family health history?



The family health history information you collect can be written down or typed into the computer. It is important to write down all of the information so it makes sense to you, your family, and your healthcare provider. We have included some ideas below to help you organize your information.

Family health portrait

A family health portrait is like a family tree showing family members and their health. Because it is a simple picture of your family health history, it can be easily shared with your healthcare provider. [Turn to page 18 for more information.](#)



Isabel's story

My grandmother died of a massive heart attack when she was 39 years old. Even though my mother was so careful about healthcare for our family, she did not know that she had a very serious heart condition. She felt just fine, but during a routine checkup two years ago, a doctor discovered my mother's uncontrollable heart arrhythmia. Mom was taken to the hospital immediately, and a cardiac pacemaker was implanted the following day. Since the doctors knew my grandmother had died of a heart attack at a young age, they took my mother's symptoms very seriously.

This knowledge about my mother's and grandmother's health scares me, but I feel it is good to know. I know you can feel healthy but have

Healthcare Provider Card

Included with this pamphlet or online (www.geisinger.org/genomics), you will find a card to fill out and bring to your provider. The card focuses on concerns you have about your family health history. It also gives your provider more information on how to best use your family health history to figure out your risk for getting a disease.



a serious health condition. Whenever I go for my checkups, I always talk to my doctor about my grandmother's and mother's heart conditions. She checks my heart thoroughly and always runs a special test on it because of my family health history.

Though I can't change what happened to my mom and grandmother, I can use the information to manage my health better and lower my risk of heart disease.



How can I draw a family health portrait?

If you have access to the Internet, you can use the U.S. Surgeon General's **My Family Health Portrait** to create a family health history tree on your computer.

Visit www.familyhistory.hhs.gov to access the tool.

You can also draw your own family health portrait. Use the example on the next page to help guide you.

Instructions for drawing a family health portrait

- Write your name and the date at the top of a large piece of paper.
- Draw yourself at the center using a square if you are a man or a circle if you are a woman.
- Draw your parents above you and label each symbol with his or her name and birth date (or approximate age).
- Draw a line between them and then draw a line down to you.
- When possible, draw your brothers and sisters and your parents' brothers and sisters from oldest to youngest, going from left to right across the paper.
- Add the health information you collected for each individual.
- Add your family's country of origin and any other information you have collected.
- For additional help contact us at FAMILYHISTORY@geisinger.edu.

Family Health Portrait Legend male female deceased

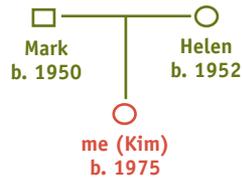


Kim's story

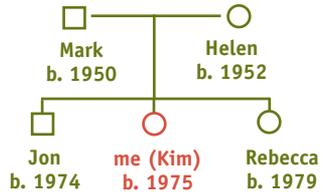
- 1** To start my family health portrait, I added myself. Any women on the portrait are drawn with a circle. Under my name, I wrote my birth date.

○
me (Kim)
b. 1975

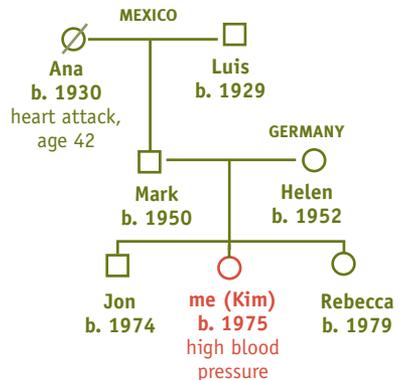
- 2** Next, I drew in my mother and father. Any men in the portrait are drawn as squares. I connected my parents to each other using one line and drew another line that connected to me.



- 3** Next, I added my brother and sister and their birthdates. I connected each of them to the line that connects my parents.



- 4** For my father's parents, I put their names above his and drew one line connecting them to each other and another line connected to my father. I also added my family's ancestry. Finally, I drew a line diagonally through my grandmother's circle to show that she died at age 42.



What now?

- Save your family health history and update it with new information you learn about your family.
- Find out more about the diseases that run in your family and how to stay healthy.
- Share information with your family.
- Using the Healthcare Provider Card, take your family health history to your healthcare provider.
- If you are interested in participating in any research studies at Geisinger, go to the research tab on MyGeisinger or go to www.geisinger.org/genomics.
- If you have questions or concerns, contact us at familyhistory@geisinger.edu or 570-214-6065.



MyCode™

MyCode is a repository of patient genetic samples that allows researchers at Geisinger to find new ways to prevent, diagnose and treat diseases. Blood and saliva samples are collected during a routine visit. Any Geisinger patient is invited to participate in MyCode. To learn more about MyCode, please go to www.geisinger.org/genomics or call 1-866-910-6486 for more information.

Resources

The Smithsonian Folklife and Oral History Interviewing Guide

www.familyoralhistory.us/news/view/the_smithsonian_folklife_and_oral_history_interviewing_guide

The American Folklife Center

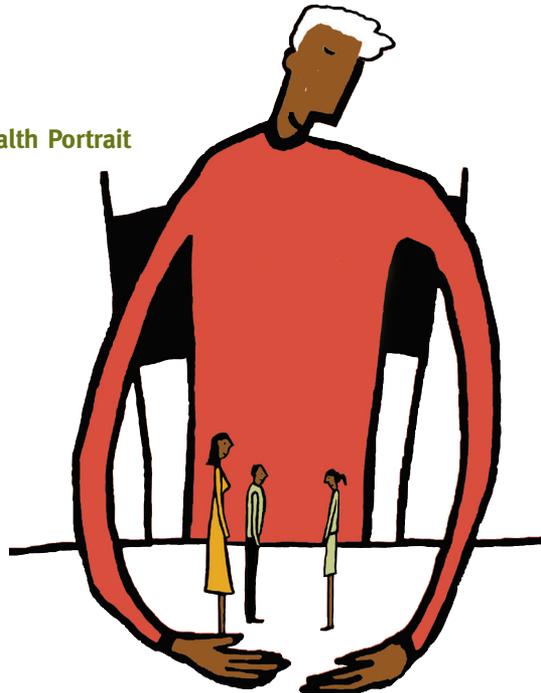
www.loc.gov/folklife/fieldwork

Surgeon General's My Family Health Portrait

familyhistory.hhs.gov

Geisinger Genomic Medicine

www.geisinger.org/genomics



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www.weismarkets.com

The logo for Weis Markets, featuring the word "weis" in a bold, lowercase, sans-serif font.

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