

DOES IT RUN IN THE FAMILY?

1

A Guide to Family Health History



GENETIC ALLIANCE

Contents

This toolkit will help you collect, organize, and understand your family health history. In “Book 1: A Guide to Family Health History”, each section includes choices of activities. Choose the activity that works best for you.

Introduction	1
--------------	---

Collect

Information to collect	6
How to collect	8
How to ask questions	12
Sample questions	14

Organize

How to organize	16
Family health portrait	18

Understand


What now?	20
Resources	21

Read “Book 2: A Guide to Understanding Genetics and Health” to learn more about:

1. Why is genetics important to my family and me?
2. Which diseases might run in my family?



What is family health history?



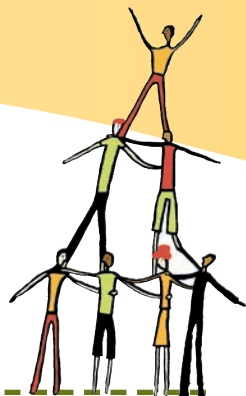
Family health history is information about diseases that run in your family, as well as the eating habits, activities, and environments that your family shares. Knowing about the diseases that run in your family can help you make healthy choices.

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.

“Family health history can be found in the choices you make, the stories your family shares, and the culture of your community. Discover it and improve your health!”

– Sharon F. Terry
President & CEO
Genetic Alliance

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.

Carlos' story

Every man in my family has dropped dead before the age of 50—my father, my grandfather, and my uncles. I always assumed that I wouldn't make it to 50.

A few years ago my cousin told me that he told his doctor about our family health history. His doctor did some tests and found out that my cousin was at risk for heart disease—maybe even a heart attack.

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.

He put my cousin on medication to lower his cholesterol and told him to stop eating so many fried foods.

I talked to my doctor and got the same tests and advice. Last year, I threw the biggest 50th birthday party ever!



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 getting certain diseases, and your environment.

Kathleen's story

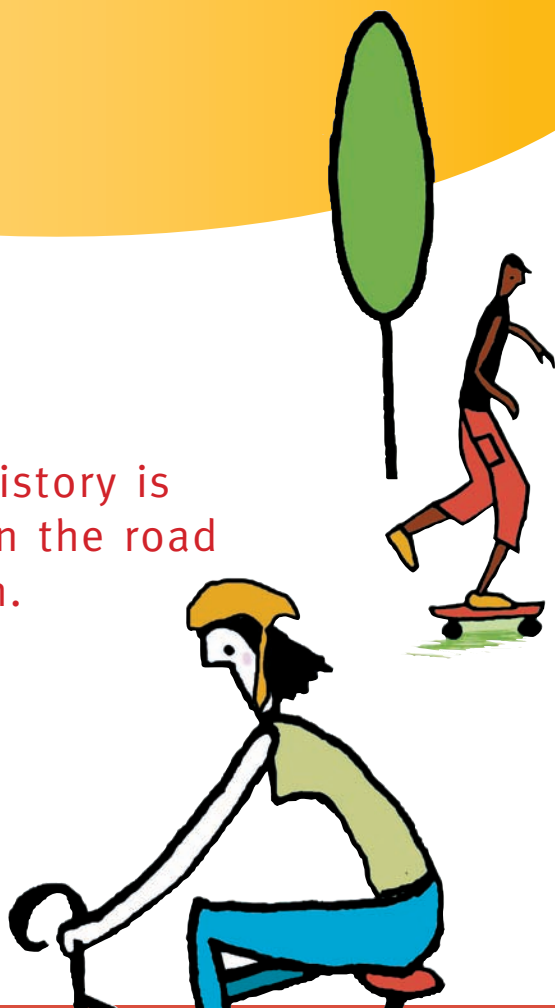
photo by rick guidotti



I've always known that some of the relatives on my father's side of the family died in early adulthood. At 23, I started to experience heart problems. I worried that I would die young like my aunt Kathleen, after whom I was named. Like many of my relatives who died, I was unusually tall, and everyone said I was Aunt Kathleen's "spitting image."

I was in medical school at the time and drew a family tree. When I shared my family health history with a few

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



specialists, they did some tests and diagnosed me with Marfan syndrome. I contacted all of the members of the family who I feared were affected, and they were able to get lifesaving treatment.

Now I don't live in fear that I might die suddenly like my aunt. I don't worry for my daughter Marissa, who also has Marfan syndrome. We take the proper medication, get checkups regularly, and can get on with our lives. Our ancestors did not die in vain. Their story was heard and saved many.

To find out more about Marfan syndrome, visit www.marfan.org.

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)

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 while talking at family events like birthday parties, weddings, reunions, religious gatherings, holiday dinners, and funerals. These events provide a chance to ask family members about their lives.



Use what you have

Check first to see if your family has 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, record these talks so you can go over them later. 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.

Tips for collecting family health history



- Start with your parents if they are still living. Often, older relatives are good sources of information and can be the “family historian.”
- 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.
- It is important to **respect others**. Some relatives may not want to share their medical histories. Some may not know their family history.



Lisa's story

When I became pregnant, I talked with my parents about diseases that run in our family. I wanted to be prepared for anything that could affect my child. My parents told me that, before I was born, my aunt had a baby boy who seemed healthy. A few weeks later, however, he became very ill with vomiting and wasn't eating. The doctor diagnosed him with a genetic disorder called MCADD (Medium Chain Acyl-CoA Dehydrogenase Deficiency) and put him on a special diet and medication. Unfortunately, some damage had already been done.

When I told my doctor this, she checked to see if MCADD was included in our state's newborn screening program. Luckily, it was. When my daughter was

- 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. For example, someone who suffered from “the blues” may have had depression. Ask family members to talk about how relatives acted.

born, we paid close attention to her newborn screening results. She too has MCADD, but we were able to start treatment right away. Now she is a healthy, active three-year-old. By learning about my family health history, I was able to ensure that my baby stayed as healthy as possible from the moment she was born.



To find out more about MCADD, visit www.fodsupport.org.

How do I ask my family members about family history?

On the next page is a list of 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. **Add your own questions** that relate to your family.

Prepare ahead of time

- Write down what you 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.
- Record the interviews on a tape recorder or video camera.



Michael's story

Since I am adopted, I thought there was no way for me to put together a family health history. Even though my adopted family and the adoption agency tried to help, they didn't have the answers I needed about my birth family's health. How can I have a family health history without having my questions answered?

During the conversation

- Write down health-related information given by your relative.
- Try to keep the questions short. 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.
- Respect 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 lead to more family stories.



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

There is something I can do. I am starting my family health history with me and my health issues—like the fact that I started wearing glasses when I was 12 years old. I will pass the information on to my children, and they will be able to add to our family history.



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 normal day?
- What was your work environment like?
- Do you have children? What are their names? 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 as an adult? At what age? How was this treated (e.g. medicine, 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?
- Has anyone had problems in pregnancy or childbirth? What kinds of problems?
- Are there any diseases that you think might run in our family?
- 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

Online (www.geneticalliance.org/ccfhh), 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**.

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 the ancestry and any other information you have collected.

Family Health Portrait Legend ☐ male ☐ female ☒ deceased

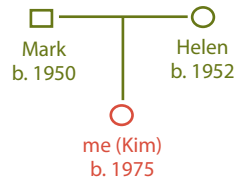


Kim's story

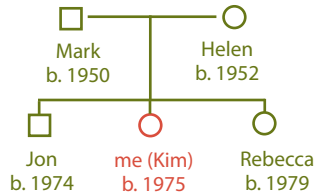
- 1** To start my family health portrait, I added myself. Any women on the portrait are drawn with a circle. Under my name, I wrote my birth date.

○
me (Kim)
b. 1975

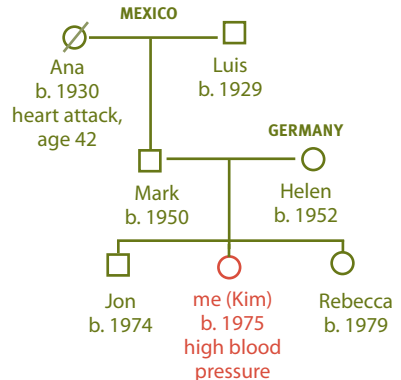
- 2** Next, I drew in my mother and father. Any men in the portrait are drawn as squares. I connected my parents to each other using one line and drew another line that connected to me.



- 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.
- Take your family health history to your healthcare provider.
- Read the next booklet, “Does It Run In the Family? A Guide for Understanding Genetics and Health.”



Resources

Genetic Alliance Family Health History Resources

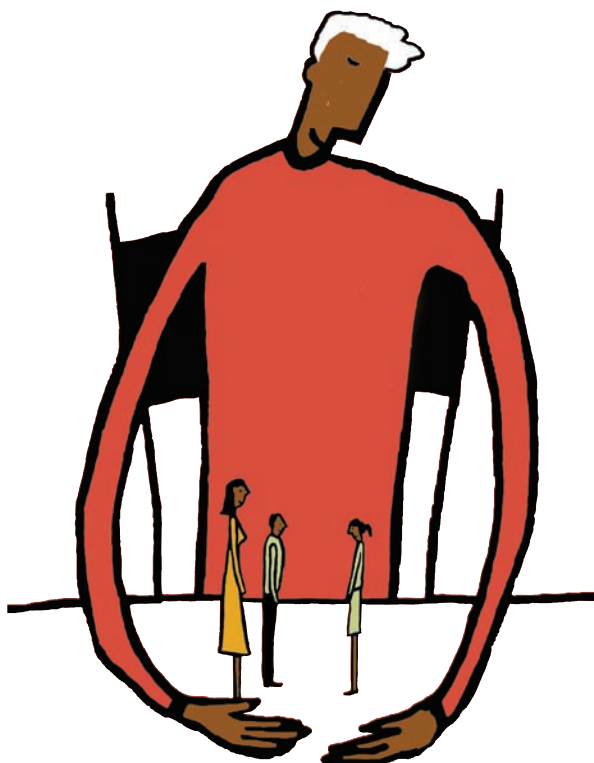
www.geneticalliance.org/familyhealthhistory

The Smithsonian Folklife and Oral History Interviewing Guide

www.familyoralhistory.us/news/view/the_smithsonian_folklife_and_oral_history_interviewing_guide/

and visit the American Folklife Center website:

www.loc.gov/folklife/fieldwork





Genetic Alliance

WWW.GENETICALLIANCE.ORG

4301 Connecticut Ave. NW, Suite 404

Washington, D.C. 20008-2369

Phone: 202-966-5557 Fax: 202-966-8553

info@geneticalliance.org

Genetic Alliance transforms health through genetics. We promote an environment of openness centered on the health of individuals, families, and communities. We bring together diverse stakeholders that create novel partnerships in advocacy; integrate individual, family, and community perspectives to improve health systems; and revolutionize access to information to enable translation of research into services and individualized decision making.



U. S. Department of Health and Human Services

HRSA

Health Resources and Services Administration

*Funded in part by a grant (U33 MC06836) from the Maternal and Child Health Bureau,
Health Resources and Services Administration.*