DOES IT RUN IN THE FAMILY?

A Guide to Family Health History

THE GENOMEDICAL CONNECTION
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.

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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 lifestyle 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.

“Knowing your family health history could save your life.”

— Francis Collins, MD, PhD
Former director of the National Human Genome Research Institute (NHGRI) at the National Institutes of Health (NIH)
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.

Richard’s story

I never knew my father. He died when I was 6 months old from a heart attack. He was 42. My brother was 10 years older than me and did many things that my father would have done, like go to my ball games and buy me my first bike. When I was 30, he died of a heart attack at the age of 40. I went to the doctor and he ran some tests. My cholesterol and lipids were high. My doctor recommended that I start exercising and he put me on some medicine that
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.

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helped lower these levels. Today my cholesterol and lipid levels are being followed closely. I am 66 years old, and the oldest living male in my family. It is important for my daughter, and my brother’s daughters, to know this history. It could save their lives.

– Richard, Greensboro, NC
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.

Amy’s story

I had breast cancer at the age of 33. I had never talked with my family about cancer. After I was diagnosed I found out that my mother’s cousin had been treated for breast cancer. Because of my young age and family history I saw a genetic counselor to talk about testing for changes in the BRCA 1 and BRCA 2 genes. I was tested and found to carry a change in the BRCA 1 gene. This means I am more likely to get breast cancer again and possibly ovarian cancer in the
Family health history is the first step on the road to better health.

future. The genetic counselor told me that I would be less likely to get breast or ovarian cancer if I had surgery to remove my breasts and ovaries. She also said I should tell my family about my test results. I decided to have the surgery to remove my breasts and ovaries. I also told my mom and cousins about my test results. At this time they have chosen not to be tested. I am a mother of three children. I plan on telling my children, especially my daughter, when they get older. This will be important for them so they can make decisions about knowing their chance of getting cancer.

– Amy, High Point, NC
What information should I collect?

**Who to collect information on:**

- You
- 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 (Ashkenazi Jewish, Hispanic, German, etc.)
- 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!
Who to collect info from

Collect the medical and health information on:

- yourself
- your brothers and sisters
- your children
- your parents
- then go back a generation at a time and include:
  - grandparents
  - aunts and uncles
  - cousins
  - nieces and nephews

Basic info to collect:
- name and relationship to you (myself, parent, child, etc.)
- Race, ethnicity and/or origins of family
- date of birth (or if the information is unavailable, write your best guess—for example “1940’s”)
- Place of birth
- if deceased, age and cause of death

It’s not necessary to collect everything! It is important to learn what you can.

- History of surgeries
- Mental health disorders (such as depression, schizophrenia)
- Obesity
- Pregnancy (such as number of children, miscarriages, problems)
- Stroke
- Substance abuse (such as alcohol, drugs)
- Other

Lifestyle:

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

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)
- Colon polyps
- Current and past medications
- Deafness/hearing loss at a young age
- Deep vein thrombosis, or DVT (blood clot in leg)
- Developmental delay/learning disorders
- Diabetes/sugar disease
- Heart disease
- High blood pressure
- High cholesterol

Be sure to record age at onset of symptoms (when the disease started).
How do I collect family health history?

Talk to your family
Your family members 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.

Sandra’s story

My father was diagnosed with colon cancer at age 70. I did not think much about this until my younger sister was diagnosed with polyps on her colonoscopy. She told me that I needed to get screened too. I went in for a colonoscopy and polyps were also found. I went back 5 years later and more polyps were found. My doctor told me that I needed to have another colonoscopy in 3 years, rather than 5 years. I am glad that I know my family health history. I can make sure that I get screened more frequently for colon cancer. I can also let other family
• 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.

members know about this history. I have two sons in their 30s. I have been talking with them about the importance of knowing their family history of colon cancer and polyps so that they can be screened as needed.

– Sandra, Liberty, NC
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.

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**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 and raised?
- Did you have any health problems? How old were you when the problems started?
- Do you have any brothers or sisters? Are they living? How old are they?
- Did any of your brothers or sisters have health problems? How old were they when the problems started?

Questions about adulthood

- What jobs have you had? Can you tell me about a normal day?
- What was your work setting like?
- How many children do you have? What are their names? When were they born?
- Did you have any children that died at an early age? If so, what did they die from?
- Did your children have any health problems? How old were they when the problems started?
- Did you have any health problems? At what age? How was this treated (e.g. medicine, surgery)?
Questions about other family members
• When were your parents born? Did they have any health problems?
• Does your father have brothers and sisters? How old are they? Do they have any health problems?
• Does your mother have brothers and sisters? How old are they? Do they have any health problems?
• When were your father's parents born? Did they have any health problems?
• When were your mother's parents born? Did they have any health problems?
• Do you know if your parents or grandparents took medicine on a regular basis? If so, for what?

Questions about family life
• Has your family lived anywhere that caused them health problems?
• Does anyone smoke? Drink a lot of alcohol? Is anyone overweight?
• Has anyone had problems in pregnancy or childbirth?
• Has anyone we talked about died? At what age? What did they die from?
• Are there any diseases that ‘run in the family’?
• What is your family's ethnic background (e.g. Mexican, African-American, German, Ashkenazi Jewish, etc.)?
• Has anyone ever been screened or had genetic testing for a serious disease like cancer? What was the test result?
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.

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**Becky’s story**

My mother was 1 of 10 children. There were 4 sisters in her family, and 3 of them had breast cancer. My mother had breast cancer at age 46. Later on she was diagnosed with melanoma, lung cancer, and a tumor in her throat. She died at age 58. Her father had a large family too. He died of laryngeal cancer and two of his sisters died of breast cancer. Every year when we get together for family reunions it seems someone else has been diagnosed with cancer. The family was seen at the MD Anderson Cancer Center in Houston, Texas and was found to carry a change in one of the BRCA genes. The whole family was urged to sign up for the testing at the last family reunion. Even though I have not
been tested, I am glad that my family talks about our cancer history. Getting screened regularly helps ensure that if I develop cancer I will catch it early. I am worried about my children’s risk for cancer. I made sure that they know about it. We talked about the family history of cancer and they have told their doctors about their risk.

– Becky, Randleman, NC

Healthcare Provider Card
In your toolkit, 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.
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.


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 starting with the oldest to the 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.
Sheila’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.

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 grandfather's square to show that he 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 Genomedical Connection
www.genomedical.com

The Genomedical Connection brochures on family history, breast cancer, colon cancer, and thrombophilia
www.genomedical.com/you_and_your_family/brochures.cfm

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
The mission of The Genomedical Connection is to create a model that supports proactive healthcare in Guilford County through the use of genomic medicine. Genomic medicine is intended to promote health and prevent disease by using family health history and genetic information to assess a patient’s disease risk and to manage health based on risk.