A Guide to Family Health History
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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 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 entire 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 heritage and culture with your relatives and future generations.

“You want your genes tested? Let’s do one of the best genetics tests there is. Let’s talk about your family health history.”

— John J. Mulvihill, MD
University of Oklahoma
College of Medicine
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, your height 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.

Gerri’s story

I never thought much about bunions until my feet became so painful that I had to have surgery. My doctor said there was a good chance that developing bunions runs in my family. I started wondering, “OK, who is it?” It turned out that my mother had bunions, too.

Our doctor has already told my teenage daughter that she is likely to get bunions some day. She looked at my feet and said, “Thanks, Mom”.
Some genes can increase your chance of developing certain diseases. When members of your family share health problems, you might be at risk for developing 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 being aware of your family health history and by making healthy choices.

When I was growing up, the style was to wear pointy-toed shoes. I know that wearing those shoes helped to cause the bunions. I think that wearing shoes with a wider toe box might help. It might be possible to prevent it. My daughter is more sensible about the shoes she wears; I’ll give her that.
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, whether you smoke, whether you 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.

Carla’s story

What I’ve learned from my family is that some people should never “take” that first drink. Addiction has affected my whole family: me, my brother and sister, our mom. I know it has affected my niece, and I’m not sure who else. My brother and sister still have problems, especially my brother. He’s been in and out of rehabs and prison; he just can’t get it. Drinking and drugs have caused so much heartache and stress for my family, as well as serious health problems like hepatitis C.
Use your family’s past to set priorities for a healthier future.

I’ve been clean for 21 years. I feel blessed that I got help for my problem. I’ve had this awful fear for all of his life that my son would be an addict too, because everyone in the family was. I probably went overboard. When he was younger, I used to tell him, “If you start, if you just take one drink, you’ll end up in rehab.”

My son is 26 now, and “knock on wood,” he seems OK. We can’t control other peoples’ lives, but I believe I’ve made a difference. Because of the positive role models and education he had as he was growing up, the cycle of addiction was broken.
What information should I collect?

**Who to collect information on:**
- Yourself
- Your parents
- Your brothers and sisters
- Your children

Then move on to your extended family.

**Basic information to collect:**
- Name and relationship to you (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 heritage and culture. This is an excellent opportunity 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

You don’t have to collect everything! It is important to learn what you can.

- Mental health disorders (such as depression, schizophrenia, anxiety)
- Obesity
- Osteoporosis (weak bones)
- Pregnancy (such as number of children, miscarriages, complications)
- Sickle cell anemia or trait
- Stroke
- Substance abuse (such as alcohol, drugs)

Health history:

- Alzheimer’s disease
- Arthritis
- 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

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

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 recorded 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’re not forgetting anything.

Plan an individual conversation
After you’ve introduced the idea of 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 is a good idea to record these interviews so you can go back later and review them. This guide includes sample questions to ask.

Send a questionnaire
You may wish to send out a questionnaire or survey asking for health information from relatives. If you would like to use email, there are helpful tools available on the internet (see last page of this booklet). You may want to send your questionnaire by mail, along with a holiday newsletter. Remember that not everyone will feel comfortable sharing their information in this way, and 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. They may refer you to the “family historian.” Often, older relatives are good sources of information.

• If you are adopted, you may be able to collect information from your adoptive parents or the adoption agency. If not, begin a new health history with your medical records.

• It is important to respect others. Some relatives may not want to share their medical histories. Some may not know their family history.

Lily’s story

Diabetes runs in my family. It basically killed my mother and grandmother. My grandmother did her best to fight it. She followed the diet and lost a lot of weight. She never needed insulin, but she had complications. During her last three years, she had a sore on her leg that never healed. My mother, on the other hand, wouldn’t follow the diet and never lost weight. She had a lot of problems—heart problems, vision problems. She became bedridden. Her brother is following a similar path. He takes pills to control it, but he won’t diet or exercise.
• It can be alarming 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.

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I don’t want to live forever, but I want a good quality of life to the last day. I exercise and watch my weight. I signed up for a clinical research project on diabetes prevention. It’s for people like me with affected family members.

I want to learn everything I can so my children won’t have to deal with it. What I mean is, I don’t want my children to have to deal with diabetes, but, also, I don’t want to be a burden to them.
How do I ask my family members questions 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 relatives’ names, where they were born, or how many children they have.
- Pick the questions you will ask beforehand.
- Try to record the interviews on a tape recorder or video camera.

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**Tiffany’s story**

I’ve been taking care of my mother because she has breast cancer. We’ve been talking, and I’ve learned that there's a lot of cancer in my family that I never knew about. I’m using the family health history tool to get the information organized enough to take to my doctor.

I’ve heard on the news that genetic tests are available, but they sound expensive and complicated. I don’t know if I would want
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.”
- Don’t expect people to know the answers to all of your questions.
- Be sensitive to a person’s desire not to talk about certain topics.
- Consider asking your relative to show you photographs, recipes, personal letters, and other family memorabilia. These help people remember more details and can lead to more family stories.

Try not to interrupt—let your family member tell his or her story!
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 have 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)?
- Do you believe you are at risk for any health problems? Why is that?
Questions about parents and grandparents

• When and where were your parents born? What do you know about them (for example, their jobs and hobbies)?

• Where and when 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?

• Has anyone had problems in pregnancy or childbirth? What kinds of problems?

• Are there any diseases that you think might run in our family?

• What kinds of physical activity do you enjoy with your 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 summarize all of the information so it makes sense to you, your family, and your healthcare provider. We have included some useful and creative ideas below for organizing your information.

**Family health portrait**

A family health portrait is a special version of a family tree showing relatives 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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**Jenna’s story**

My son has PKU, a rare problem that means he has to be on a special diet. For him, eating normal food can cause brain damage. We found out right after he was born, when his newborn screening came back positive. Additional tests showed that he did have PKU and that he had it because of a gene he got from me and his dad. It didn’t make sense to us, because we’d never had anything like this in our family. Now I know that each and every person has a few genes that can cause serious problems if the odds work out that way – if all the planets are aligned, so to speak.
Healthcare Provider Card
Additional resources are available through the Heredity Project and 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 determine your risk for getting a disease.

It’s been hard to talk to and educate our family members. A lot of them would like to think that this has got nothing to do with them. Still, I’m glad we found out about the PKU before my son’s brain was damaged. We have newborn screening to thank for that. Knowledge is power. When you know what your risks are, you can deal with it.

For information on PKU and newborn screening, visit health.state.tn.us/NBS
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 country of origin and any other information you have collected.

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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.

2. Next, I drew in my mother and father. I connected them 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. Any men in the portrait are drawn as squares.

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 where each side of the family was originally from. 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 diseases that run in your family and learn how to stay healthy.
- Share information with your family.
- Take a clear summary of 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

CDC (Centers for Disease Control & Prevention), Office of Public Health Genomics, Family History: Resources & Tools
www.cdc.gov/genomics/public/famhist.htm

Memphis Public Library, Guide to the Genealogy Collection
www.memphislibrary.org/history/guigen.htm
The University of Tennessee Health Science Center
66 N. Pauline, Suite 633
Memphis, TN 38163

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