A Guide to Family Health History
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 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.

‘Doc, I want my genes tested.’
‘Yes, I’ll do one of the best genetics tests there is. Let’s talk about your medical family history.’

– John J. Mulvihill, MD
Chief, Section of Genetics
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.

Amanda’s story

When my son was born, I noticed that he had a few brown birthmarks. I didn’t think much about it because I also had several birthmarks. At his six month check up, his pediatrician was concerned by the number of birthmarks and recommended that we see a geneticist. I was confused about what birthmarks had to do with genetics, but followed the pediatrician’s recommendation and saw the geneticist. The geneticist took a family history and did a physical exam on both me and my son, looking closely at our skin. We were both diagnosed with a genetic condition
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.

known as neurofibromatosis type 1 or NF1 for short. NF1 is a genetic condition that causes café-au-lait (brown birthmarks) and neurofibromas (bumps) on or under the skin. I have learned that there can be mild cases and severe cases of NF1 within the same family. Also, that my son and I each have a 50% chance of passing it on to future children.

**To find more about NF, visit www.ctf.org.**
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.

Beth’s story

Several of my aunts died from breast cancer, so I was very worried when I was diagnosed with breast cancer at the age of 42. When I talked about my family health history with my doctor, he was also concerned and referred me to a geneticist. At the appointment with the geneticist, I learned that some individuals inherit a gene that puts them at an increased risk for developing breast cancer at a younger age than the general population. I decided to
Family health history is the first step on the road to better health.

I underwent testing for these genes, and I was surprised when the test came back positive. Knowing that I have this gene was powerful information. I was able to make important health decisions, like prophylactic mastectomy (removal of breast) and oophorectomy (removal of ovaries) to greatly reduce my risk of developing additional cancers.

To find more about inherited breast and ovarian cancer, visit www.myriadtests.com/brac.htm
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!
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
- Height
- 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 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. Paired with a holiday newsletter, this may be a quick and easy way to collect information. 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 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 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.

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 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.

Dana’s story

Being Native America presented certain challenges when trying to find out about my family health history. My mother died at the young age of 38. Due to the stigma of alcoholism in Native American culture, the doctor gave the wrong cause of death. As a result of this confusion, I had grown up in fear that I was going to die at the same very young age. I was so scared as I approached my 38th birthday because I did not know why she
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!

died and I had a fear that I would die too! However, when I found out my mother’s true diagnosis, I was so relieved. It really helped that I found out her true health history. Later that same year, I trained very hard and competed in the Oklahoma City Memorial Marathon, my very first marathon.
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 conditions (for example, allergies) as a child?
- Do you have any brothers or sisters? Did any of them pass away during childhood?

**Questions about adulthood**

- How far in school have you gone?
- 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?
- What habits (sun exposure, physical activity, smoking, etc.) have you had that could have affected your health?
- Did you develop any health conditions or illnesses as an adult? At what age? Did any of these conditions 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 occupations and pastimes)?
- What do you remember about your grandparents? Where and when were they born?
- Do you recall any health conditions or physical ailments that affected your parents and/or your grandparents?
- Do you recall if they took any over-the-counter or prescription medications 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 near any sites that may have been hazardous or lived through any major disasters that may have affected their health?
- What foods does your family usually eat? Describe a typical family breakfast or dinner. Do you eat special foods for special occasions?
- Do you know of family members who experienced difficulties in pregnancy or childbirth? What kinds of difficulties?
- Are there any conditions or illnesses that you think might run in our family?
- Has anyone in the family been born with any birth defects or had problems learning in school?
- 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.

*Sookyung’s story*

Trying to obtain family health history was not as easy as I thought. I originally thought that I could just call up my parents, call up my in-laws and ask them about our family health history. I assumed they would be more than willing to help my husband and I find an answer to the mystery of our son...was I ever wrong.

Although my parents were very willing, it took over two years of pleading and convincing before my in-laws would finally agree to give any type of information and samples of blood for genetic testing. They did not want the results to come back and show that they were the reason for my son’s disability. They were scared of being blamed.
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 determine your risk for getting a disease.

In the Asian culture, having a genetic disorder is like having a scarlet letter: disabilities are considered taboo. Now, I realize how important it is to know about your family health history and how vital it is to share family health history information with others in your immediate and extended family. Knowing about the genetic issues that run in the family now, we can help prepare and plan ahead for when my daughter starts thinking about having her own family.
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 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.

Family Health Portrait Legend

□ male ○ female ☑ deceased

18 DOES IT RUN IN THE FAMILY?
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. Any men in the portrait are drawn as squares.

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 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

Heartland Collaborative
www.heartlandcollaborative.org

University of Oklahoma Medical School
www.medicine.ouhsc.edu

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 Genetics Section discovers new knowledge about the genetic determinants of human disease; educates and mentors students, trainees, other interested health professionals, and the public, in genetics; applies genetics clinically to improve the health of patients, families, communities, and the population; and, offers selected state-of-the-art genetic laboratory services.