A Guide to
Family Health History

DOES IT RUN IN THE FAMILY?

BROOKDALE UNIVERSITY HOSPITAL
AND MEDICAL CENTER
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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.

“Using this guide to family health history can be interesting! Whether you make it a hobby, a passion, or just something to do, it is important to learn about your family health history. It comes in handy and useful when you are ready to make decisions about your life.”

– Verna
Program Coordinator
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.

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**Denaya’s story**

I was diagnosed with sickle cell disease as soon as I was born. I am the only one with it in my family. My mother did not even know she had the trait until I was conceived. Her awareness of her status along with my father’s could have prevented a lot of hard times for all of us. When I am ready to have children...
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.

of my own, I plan to make sure my partner does not have the trait or disease. I also plan to make sure my children are well aware too. This way sickle cell disease can stop with me.
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.

Julia’s story

After a wonderful pregnancy we were excited to have a beautiful baby girl. The call from the sickle cell program asking us to come for a repeat test for newborn screening came as a shock. Our baby was diagnosed with sickle cell disease and we were
tested and told we had the trait. Our daughter is an adorable seven year old and we love her. But we wish that we had been educated about our status before the pregnancy. This way we would not have been shocked and unprepared. I wish my parents had told me that sickle cell trait ran in the family.
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

It's important to record all the above information.

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

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

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.

The Nwoke’s story

Twelve years ago our oldest child was born with sickle cell disease. Five years later we had quadruplets. The sickle cell program arranged for cord blood collection as the babies were born. They were tested and we found that one of the babies had sickle cell disease. But the good news was that one of his brothers was a perfect match, and he later received a cord blood transplant. He was cured. Our older child was given a medication called Hydroxyurea to reduce the symptoms of the disease. As parents, we knew we carried sickle cell trait, so
• 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.

we made an educated choice to have our children. Knowing about our family history allows us to be more informed about the decisions we make.
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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**Donnette’s story**

I came to the United States in my late teens. I had always had episodes of pain but did not know why. It was thought that I had arthritis because of the swelling of the joints. During one of these episodes in the U.S., I was told I had sickle cell trait. I had no idea what that was. However, it was only after many more
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!

pain episodes that I was properly diagnosed with SC disease, a form of sickle cell disease. My family and I knew nothing about sickle cell. Knowing my condition could have saved me much unnecessary pain.
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)?
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?

• 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 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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**Anndis’ story**

I knew I had sickle cell trait. This did not cause me any problems. But my baby was born with a form of sickle cell disease (SC disease), and I was shocked. I knew that my partner did not have the sickle trait, and we got tested again. My partner had the “C” trait. This is not sickle trait, but it is a similar defect in the hemoglobin of the red blood cells. We found out that SC disease is similar to Sickle cell (SS) disease.

There is also a condition called beta-thalassemia trait. If a person with sickle trait has a partner who has beta-thalassemia trait, they 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 determine your risk for getting a disease.

A one in four chance of having a baby with sickle-thalassemia, which is also like sickle cell disease. To make sure that you do not have a hemoglobin problem that is inherited, it is important to do a special test called the hemoglobin electrophoresis. If this was done, we would at least have been prepared.
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.
Onasias’ 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 sisters 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. I wrote her age at death under her circle.
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

Sickle Cell Disease Association of America
at 800-421-8453

Other Sickle Cell Resources
www.yourgenesyourhealth.org
www.scinfo.org
www.sicklecellbrooklyn.org
www.sicklecelldisease.org
www.sctpn.org
The Comprehensive Pediatric Sickle Cell Program is dedicated to improving care, increasing education, knowledge, outreach and advocacy for sickle cell disease and trait.

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