

DOES IT RUN IN THE FAMILY?

1

A Guide to Family Health History



A PROJECT OF WWW.ABORTIONCARENETWORK.ORG

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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 Genetics and Health” to learn more:

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



What is family health history?



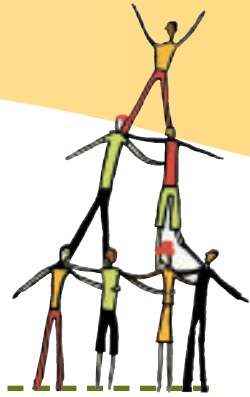
Family health history is information about diseases that run in your family, as well as the eating habits, activities, and environments that your family shares. Knowing about the diseases that run in your family can help you make healthy choices.

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 Terry
President and 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.

Wendy's story

WENDY discovered well into the second trimester of her pregnancy that her baby has hydrocephalus and that the rapidly increasing fluid in the brain would lead to many serious complications for the baby. Wendy and her partner met with a genetic counselor and learned that she was carrying an X-linked gene mutation. Wendy and her husband opted to terminate the pregnancy.

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.

Her mother later confided that Wendy's aunt also had a son who died at birth due to hydrocephalus.

NOTE: All pregnancies carry a 3-5% chance that a baby will have a minor or major birth defect. A small percentage of these conditions can be linked to an inherited risk factor.



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.



Shaquira's story



SHAQUIRA talks with a counselor at the clinic about birth control. She says, “My family has lots of cancer, so I don’t think I should take hormones.” She states that her grandfather had lung cancer. She thinks that her grandmother was diagnosed with breast cancer in her 70’s. Also, Shaquira’s sister had cervical cancer. The counselor tells Shaquira that most cervical cancer is linked to the HPV virus for which there is a vaccine. Regular use of condoms can also help protect against HPV. The counselor tells her

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



that almost all cancers are age related--as we get older the risk increases. Only 10% of cancers are inherited. For instance, lung cancer is almost always linked to a personal history of smoking or workplace exposure. The counselor encourages Shaquira to write down her family health history.

NOTE: The concern about hormonal birth control has been studied and not shown to have a significant factor in increasing a woman's lifetime chance of developing breast cancer. However, hormonal birth control DOES LOWER a woman's lifetime risk for ovarian cancer.

What information should I collect?

Who to collect information on:

- Yourself
- Your parents
- Your brothers and sisters
- Your children
- aunts, uncles, cousins



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
- miscarriages or abortions
- adoptions

- 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 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. 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.

Naima's story

NAIMA has irregular periods and has an appointment today for a pregnancy test and ultrasound. She was diagnosed with a seizure disorder as an adolescent and takes a medication to control her seizures. She tells the technician that epilepsy runs in her family--two of her cousins on her father's side of family also take seizure medication. "If I am pregnant I have to either stop taking my medicine or have an abortion."

Naima learns that she is about 7 weeks pregnant and the medical staff encourage her to call Mother to Baby, at 1-866-626-6847. This service at www.mothertobaby.org is dedicated to providing accurate information about medications and other exposures during pregnancy

- 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.

to mothers, health care professionals, and the general public.

NOTE: It is important to continue treating a seizure disorder during pregnancy. Some medication can increase the chance for problems for the developing baby. There are seizure medications that are preferred during pregnancy.

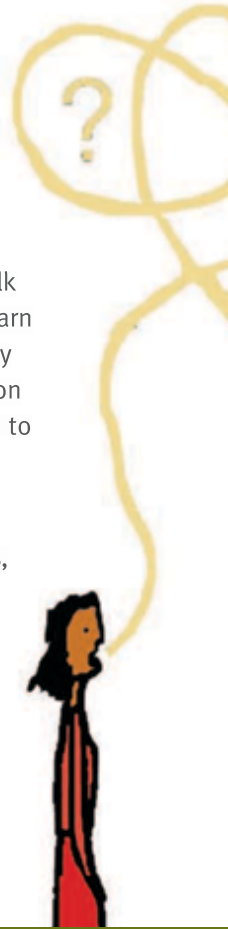


How do I ask my family members about family history?

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.



Kim's story

KIM has 3 children and feels she cannot have another and still be able to care for her family. She decides to have a medication abortion. When the nurse at the clinic explains that she should call the office if she saturates two pads an hour for two consecutive hours. She says, “Oh, I have that much bleeding with my period! And so did my mother and grandmother.” The nurse suggested that she get tested for a bleeding disorder.

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!

She does, and finds out that she has Factor IX deficiency, an inherited genetic condition. She now understands why she and others in the family bleed more than others. Now she can use a medication when there is a concern about bleeding, like during surgery.



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?
- 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 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.](#)



Tiffany's story

TIFFANY tells the counselor that she is not ready to bring a child into the world, stating “I sometimes worry that I will have a child like my aunt's. My aunt told us that her baby's condition is inherited. I don't remember the name. I'm not sure what that means since no one else in our family has a baby like this.” Soon after her aunt brought her niece home from the hospital, she got a call from her doctor who told her that the baby tested positive on a newborn screening test. The baby had more testing and was diagnosed with a rare condition. Her niece is now on a special diet and a very expensive formula.

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.



The counselor encourages Tiffany to ask her aunt to write down the name of disease and talk to her doctor or a genetic counselor to learn if she has a risk.

NOTE: Newborn screening identifies conditions that, when detected early, can be treated to prevent death or limit disability. Each year, millions of babies in the U.S. are routinely screened.



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

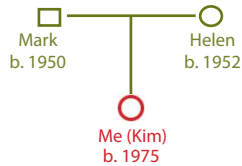


Kim's story

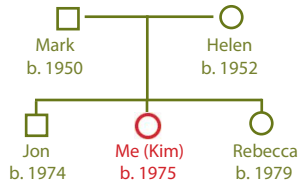
- 1 To start my family health portrait, I added myself. Any women on the portrait are drawn with a circle. Under my name, I wrote my birth

Me (Kim)
b. 1975

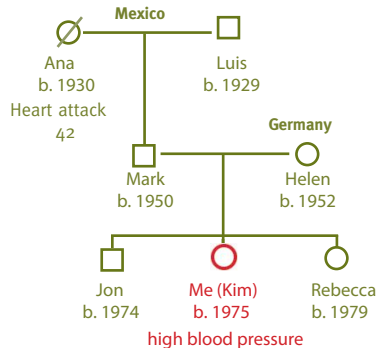
- 2 Next, I drew in my mother and father. Any men in the portrait are drawn as squares. I connected my parents to each other using one line and drew another line that connected to me.



- 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 “Book 2: A Guide to Genetics and Health.”



Resources

Genetic Alliance Family Health History Resources

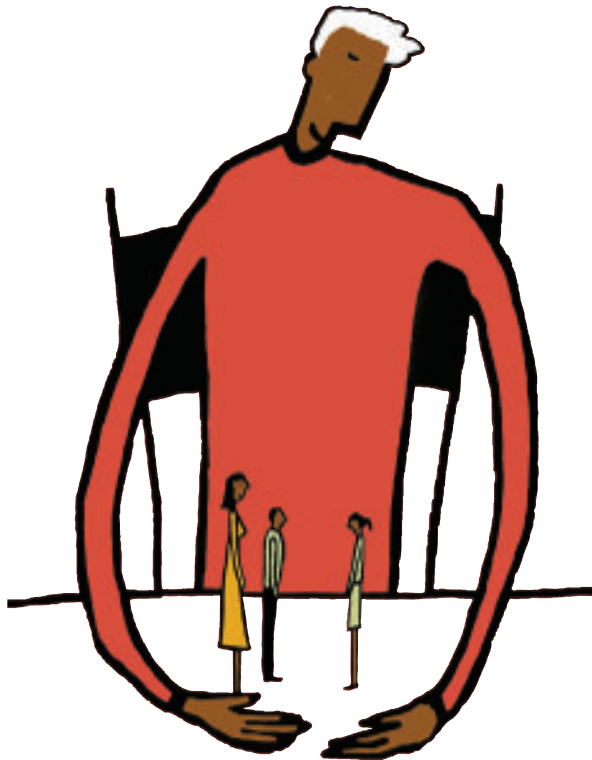
www.geneticalliance.org/familyhealthhistory

My Family Health Portrait Tool (in English and Spanish) from the Surgeon General

<http://www.hhs.gov/familyhistory/portrait/index.html>

Family Health History (Centers for Disease Control and Prevention)

<http://www.cdc.gov/genomics/famhistory/>



The Abortion Care Network

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The Abortion Care Network is committed to creating a community, with independent providers at its core, that supports the right of all people to experience respectful, dignified abortion care.



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