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.

“Knowing your family health history can be very useful in helping you make the right choices in a variety of areas of your life.”

– Laura
Minnesota
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.

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.

Henry’s story

I was finally diagnosed with Alpha-1 after years of being treated for what was thought to be asthma. I learned that Alpha-1 was in my family. Since both of my fathers’ sisters passed away from Alpha-1, I asked my doctor to test for it. I want to be taking medications that are the best for helping my condition. The right diagnosis helped my doctor and me get it right.
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.

My brother was diagnosed as a ZZ Alpha last year. Even though I haven’t been tested myself, I’ve decided to quit smoking just in case I have it too.

– Gary
Indiana

Lisa’s story

Our daughter, Sam, has Alpha-1 and had a liver transplant when she was 10 months old. It was a very scary time for us. We have a 5 year old son, Justin, who has lived a normal healthy life so far. My husband and I questioned whether we needed to test Justin for Alpha-1 too, even though he seemed to have no symptoms. My husband and I decided to test ourselves first to see if our children would later need testing. We wanted to know our own status to better understand the risk for our children.
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.

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)
• Chronic lung disease
• Chronic liver disease
• Current and past medications
• Deafness/hearing loss at a young age
• Developmental delay/learning disorders
• Diabetes/sugar disease
• Genetic conditions like Alpha-1 Antitrypsin Deficiency
• Heart disease
• High blood pressure
• 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

You don’t have to collect everything! 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.

- 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. However, it is important to know that if you discuss health concerns with your physician this information may be placed in your medical record, affect your insurance coverage or have other implications. You may consider requesting that your physician not place this information in your medical record if you have questions or concerns surrounding your diagnosis.

- 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.

Paul’s story

My wife and I decided to talk to both of our families to find out what conditions our families are prone to. After learning that my wife’s grandmother had Alpha-1 and her mom is a carrier, we decided it would be best to speak with a genetic counselor for a professional opinion about any risks and having children.

Knowing what we can possibly be up against ahead of time made us feel more comfortable about our decision to start a family of our own.
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.

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!

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?

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?
- 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
- 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?
- 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. You may consider requesting that your physician not place this information in your medical record if you have questions or concerns surrounding insurance issues that arise from your family history. 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.

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 determine your risk for getting a disease.

Isabel’s story
My grandmother died of a massive heart attack when she was 39 years old. Even though my mother was so careful about healthcare for our family, she did not know that she had a very serious heart condition. She felt just fine, but during a routine checkup two years ago, a doctor discovered my mother’s uncontrollable heart arrhythmia. Mom was taken to the hospital immediately, and a cardiac pacemaker was implanted the following day. Since the doctors knew my grandmother had died of a heart attack at a young age, they took my mother’s symptoms very seriously.

This knowledge about my mother’s and grandmother’s health scares me, but I feel it is good to know. I know you can feel healthy but have a serious health condition. Whenever I go for my checkups, I always talk to my doctor about my grandmother’s and mother’s heart conditions. She checks my heart thoroughly and always runs a special test on it because of my family health history.

Though I can’t change what happened to my mom and grandmother, I can use the information to manage my health better and lower my risk of heart 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. Visit [www.familyhistory.hhs.gov](http://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.

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**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.

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**Family Health Portrait Legend**

- ![male] (square)
- ![female] (circle)
- ![deceased] (diagonal line through 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

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

Alpha-1 Foundation
www.alphaone.org

Alpha-1 Association
www.alpha1.org

AlphaNet, Inc.
www.alphanet.org
The Alpha-1 Foundation is dedicated to providing the leadership and resources that will result in increased research, improved health, worldwide detection, and a cure for Alpha-1 Antitrypsin Deficiency.