

DOES IT RUN IN THE FAMILY?

1

A Guide to Family Health History



INTERMOUNTAIN HEALTHCARE

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.

Introduction 1

Collect

Information to collect 6
How to collect 8
How to ask questions 12
Sample questions 14

Organize

How to organize 16
Family health portrait 18

Understand

What now? 20
Resources 21

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?



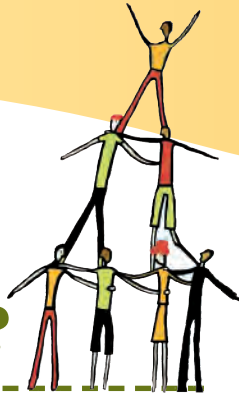
Family health history is a collection of information about diseases that run in your family, as well as the eating habits, activities, and environments that your family shares. Knowing about diseases in your family can help you make healthy choices.

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.

“Talking about your family history with your healthcare provider can help keep you healthy. Make sure you know your family’s stories and share them with your doctor or nurse.”

– Marc S. Williams, MD
Director
Intermountain Healthcare
Clinical Genetics Institute

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.

* Carlos' story

Every man in my family has dropped dead before the age of 50—my father, my grandfather, and my uncles. I always assumed that I wouldn't make it to 50.

A few years ago my cousin told me that he told his doctor about our family health history. His doctor did some tests and found out that my cousin was at risk for heart disease—maybe even a heart attack.

He put my cousin on medication to lower his cholesterol and told him to stop eating so many fried foods.

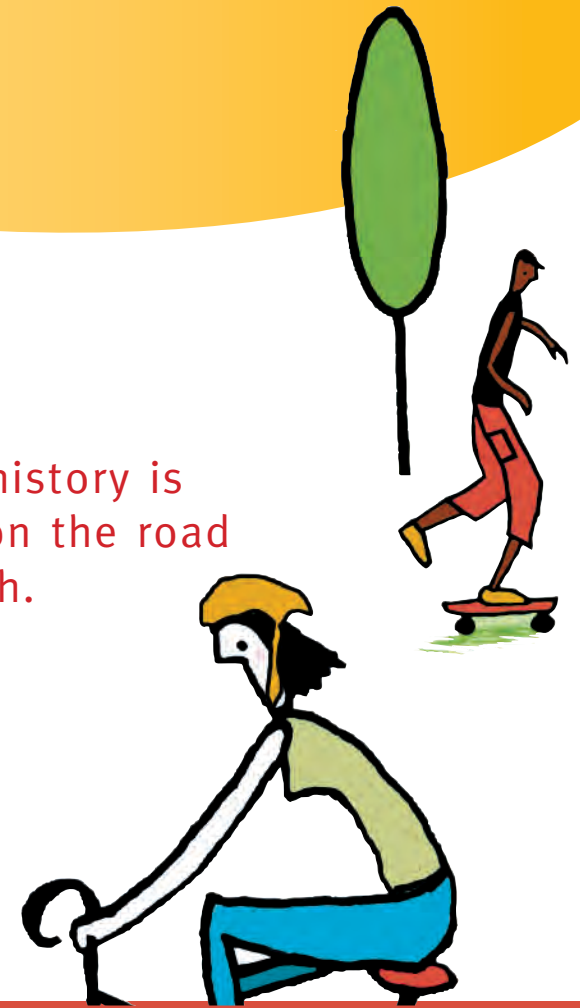
I talked to my doctor and got the same tests and advice. Last year, I threw the biggest 50th birthday party ever!



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.

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



Kathleen's story



PHOTO BY RICK GUIDOTTI

I've always known that some of the relatives on my father's side of the family died in early adulthood. At 23, I started to experience heart problems. I worried that I would die young like my aunt Kathleen, after whom I was named. Like many of my relatives who died, I was unusually tall, and everyone said I was Aunt Kathleen's "spitting image."

I was in medical school at the time and drew a family tree. When I shared my family health history with a few

specialists, they did some tests and diagnosed me with Marfan syndrome. I contacted all of the members of the family who I feared were affected, and they were able to get lifesaving treatment.

Now I don't live in fear that I might die suddenly like my aunt. I don't worry for my daughter Marissa, who also has Marfan syndrome. We take the proper medication, get checkups regularly, and can get on with our lives. Our ancestors did not die in vain. Their story was heard and saved many.

To find out more about Marfan syndrome, visit www.marfan.org.

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)
- 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

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.
- 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.



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

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.



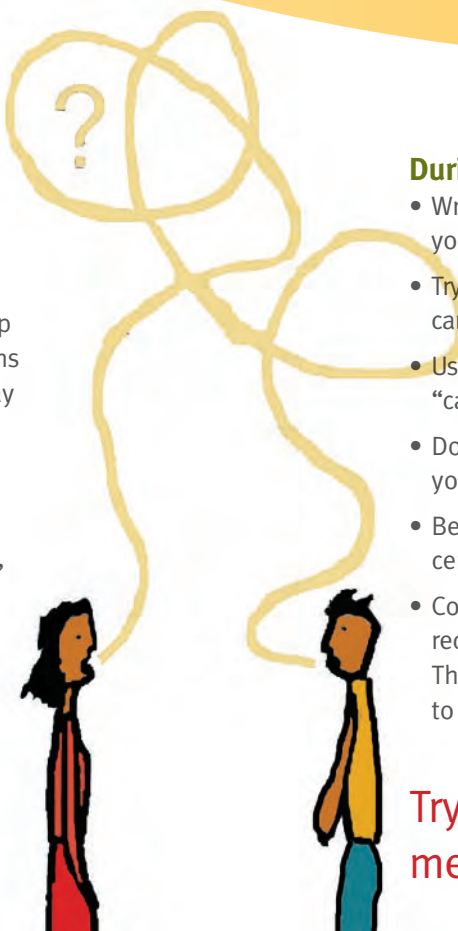
To find out more about MCADD, visit www.fodsupport.org or www.intermountainhealthcare.org/xp/public/primary or call Utah Metabolic Services at 801-585-2457.

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!

* Starr’s story

As a professional genealogist, I understand the importance of knowing not only my genealogy but my family health history, too—I survived breast cancer twice. Having recurrent breast cancer felt like a death sentence. But because I knew my family health history and that four generations of my father’s family had died of cancer, I was able to get screened sooner. Now my family talks about our family’s health history and uses this

knowledge to make better decision about screening. Nobody wants to see their children suffer from a disease that could have been prevented if they had known there was history of it in their family.

Most of us probably have some of our family health history in our genealogy records and we don’t even know it. Using what you already have can help you start a conversation with your family.

Tell us Your Story contest Utah Department of Health 2006

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

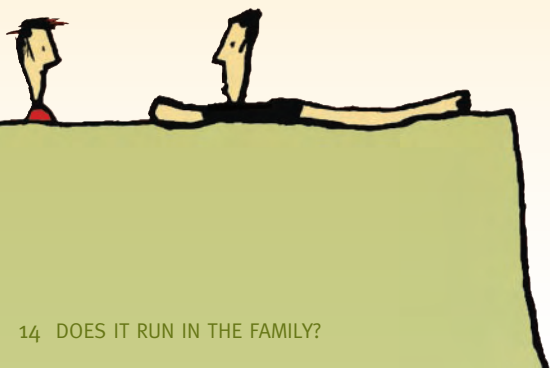
- What jobs have you had? Can you tell me about a typical day?
- What was your work environment like?
- Do you have children? What are their names and when were they born?
- What habits (sun exposure, physical activity, smoking, etc.) have you had that could have affected your health?
- Did you develop 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?



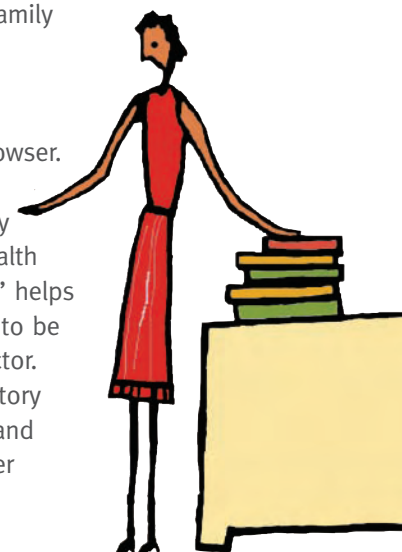
The family health history information you collect can be written down or typed into the computer. It is important to summarize all of the information so it makes sense to you, your family, and your healthcare provider. We have included some useful and creative ideas below for organizing your information.

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.](#)

Create a family health portrait online

“My Family Health Portrait” is an online family health history tool from the U.S. Surgeon General. It can be used on any computer connected to the web that is running an up-to-date version of a major Internet browser. A link to the tool (familyhistory.hhs.gov) can be found on the Family Health History page of Intermountain Healthcare’s MyHealth patient portal. “My Family Health Portrait” helps users organize family history information to be printed for presentation to the family doctor. The tool helps users save their family history information to their personal computers and share family history information with other family members if desired.



* 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.

A link to the tool (familyhistory.hhs.gov) can be found on the Family Health History page of Intermountain Healthcare's MyHealth patient portal.

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

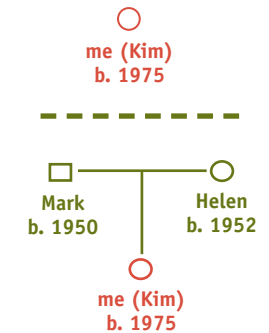
- Write your name and the date at the top of a large piece of paper.
- Draw yourself at the center using a square if you are a man or a circle if you are a woman.
- Draw your parents above you and label each symbol with his or her name and birth date (or approximate age).
- Draw a line between them and 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

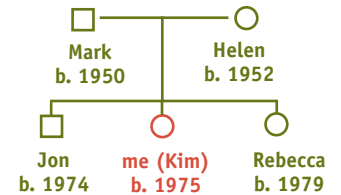


Kim's story

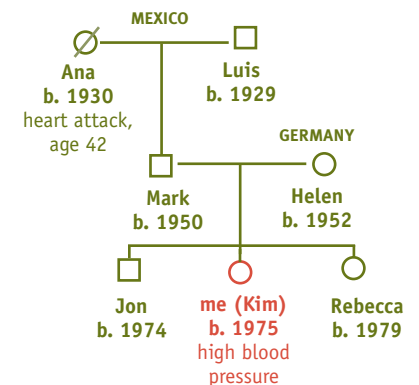
- 1** To start my family health portrait, I added myself. Any women on the portrait are drawn with a circle. Under my name, I wrote my birth date.



- 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 your health summary sheet printed from the *My Family Health Portrait* website and talk with your healthcare provider about your family health history. If you do your own family history pedigree chart, make a clear summary of your family's health history and take it to your health care 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](#)

[The Smithsonian Folklife and Oral History Interviewing Guide](#)

and visit the [American Folklife Center website](#)

Condition specific information

[Genetics Home Reference](#)

Using Family History to improve your health

[Genetic Science Learning Center](#)

[My Family Health Portrait](#)

Access My Family Health Portrait web version

Intermountain Healthcare patient education links

[Asthma](#)

[High Blood Pressure](#)

[Cancer](#)

[Mental Health](#)

[Cholesterol](#)

[Preventative Health](#)

[Diabetes](#)

[Stroke](#)

[Heart & Vascular Services](#)

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