

DOES IT RUN IN THE FAMILY?

1

A Guide to Family Health History



ANGIOMA ALLIANCE

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?



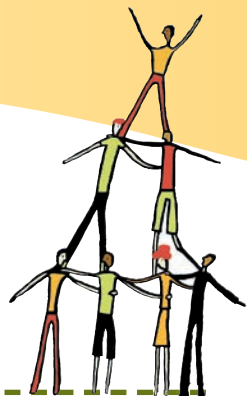
Family health history is a collection of information about diseases that run in your family, as well as the eating habits, activities, and environments that your family shares. Knowing about diseases in your family can help you make healthy choices.

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.

“Our ancestors dwell in the attics of our brains as they do in the spiraling chains of knowledge hidden in every cell of our bodies.”

– Shirley Abbott

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.

Joyce's Story

It took 15 years of persistence and finally insisting that my doctor do a brain and spinal cord MRI before I was diagnosed. My diagnosis alone wasn't enough to help my family. After I found out that cavernous malformations run in my family, we lost a nine-year-old cousin of mine to the illness. After she died, many of my family members got tested. It is too bad it took a tragedy to make this happen.

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.

My children were tested when they were at an age where they could make that decision on their own. They both tested negative. In the future if they want to have children, they will know the chances of passing on the cavernous malformation gene to their own children.



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.



Tamara's story



My family found out I had cavernous malformations when I was 2 years old and had my first seizure. It's genetic in my family — my mom, aunt, and cousin have them, too. When I first left home, I did a lot of research on this disease, and also got genetic testing.

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



All the knowledge I received helped me so much with the decisions I have made about my health.

If I had children, I would have them tested. It's important to find out all that you can about the health of you and your children. Being well-informed is the first step in being proactive about your health.

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
- Genetic conditions like cerebral cavernous malformations or oculopharyngeal muscular dystrophy
- 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

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.

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.



Anjoleen’s story

During my dad’s second surgery, my sister and I were displaying symptoms and the doctors offered to do a MRI on each of us. We found out that we both have cavernous malformations. Knowing the diagnosis explained my symptoms. It explained why the standard migraine drugs didn’t help me. It made us better prepared to handle what may come in the future.

When I was diagnosed, I already had my son. My sister will not have children. She doesn’t want to take the chance of passing this on. I chose to have my

- 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.

child tested and, unfortunately, he has the gene. It is a constant watch with routine check-ups for my son. My hope is that my son remains asymptomatic, but if not, I hope knowledge of our family history of cavernous malformations helps keep him alive.



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.



Sara's story

When my mother and I found out that we had the inherited (or familial) form of cavernous malformations we wanted to know the rest of our family history. Because my mother is adopted, this information was not easily available. The adoption agency tried to help, but they didn't have the answers we needed. Although I don't know my mother's health history, there is something that I can do for my children.

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!

I am starting my family health history with my health issues, including all I know about cavernous malformations. Then, my children will be able to add it 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, headaches or seizures) 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.



Joe's story



Initially, my neurologist said I shouldn't worry myself or my son with genetic testing. But as he's going to be 18 this fall, I'm going to ask to be tested - first myself, then, if I test positive, my son. Since he's going to be an adult, it's only fair that he have information about a potential medical condition so he can make an informed choice when the time comes.

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.



For more information about genetic testing for the hereditary form of cavernous malformations, talk to your family doctor or call the University of New Mexico Neurology Department at 505-272-3342. Genetic testing is performed by taking a sample of your blood and sending it to a laboratory. Your results will be sent to your doctor who will explain them to you. In many cases, your health insurance will cover the cost of testing.

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

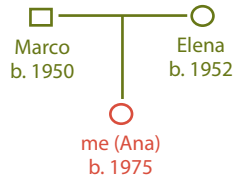


Ana's story

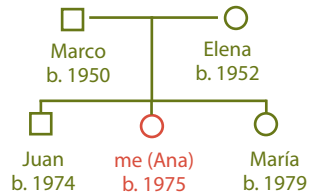
- 1** To start my family health portrait, I added myself. Any women on the portrait are drawn with a circle. Under my name, I wrote my birth date.

○
me (Ana)
b. 1975

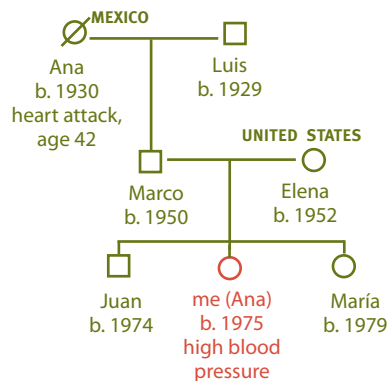
- 2** Next, I drew in my mother and father. I connected them to each other using one line and drew another line that connected to me.



- 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 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

For Cerebral Cavernous Malformations:

Angioma Alliance

www.AngiomaAlliance.org

866-432-5226

For OPMD:

University of New Mexico

Oculopharyngeal Muscular

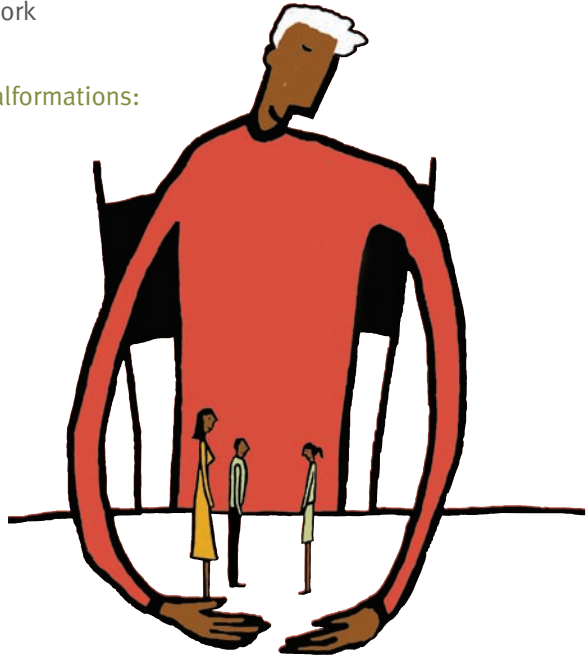
Dystrophy Hotline

hsc.unm.edu/som/

programs/opmd

505-272-OPMD

or 505-272-6763





www.AngiomaAlliance.org

142 West York Street, Suite 708
Norfolk, VA 23510-2015

Phone: 1-866-432-5226 Fax: 1-757-623-0616
info@AngiomaAlliance.org

Angioma Alliance informs and supports individuals affected by cerebral cavernous malformations while facilitating improved diagnosis and management of the illness through education and research.



WWW.GENETICALLIANCE.ORG

4301 Connecticut Ave. NW, Suite 404, Washington, DC 20008-2369
Phone: (202) 966-5557 Fax: (202) 966-8553 info@geneticalliance.org

*Funded in part by a grant (U33 MCo6836) from the Maternal and Child Health Bureau,
Health Resources and Services Administration.*