A Guide to Family Health History
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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.

“Families are the heart of our community. Our heritage is rich with family stories. Knowing our family’s health stories can help us live healthier lives.”

– Dr. Kang Xiaaj
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.

Shao’s story

I am still a young man, but I have devastating gout, with pain in my joints and nodules full of thick white fluid. Fortunately, my kidneys are healthy, because some people with gout have kidney stones or kidney failure. My parents didn't have gout, but my cousins do. We are told that gout runs in families.
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.

I worry that my children will get gout also. I tell them that they need to stay healthy, see their doctor, and not worry about the future. But if they get gout, then they should take the doctor’s medicine, and check their kidneys. Because they know their family health history, they can stay healthy and prevent problems of gout.
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.

May Yia’s story

I am 66 years old. I have had diabetes since I arrived in this country over 30 years ago. I have been able to live well with diabetes because I have taken good care of myself. I eat a lot of vegetables, eat only a little rice every meal, and don’t eat a lot of fatty meat. I exercise on my exercise machine or I walk outside every single day of my life. And I take the medicine my doctor gives me.

When we lived in the mountains, we did not have diabetes. We walked up and down the mountains, breathing hard,
and sweating. We ate healthy and didn’t gain a lot of weight. The weather also fit us. In coming to this country, we have gotten sick. We need to keep our cultural traditions alive, by exercising every day and not getting fat, so we can stay healthy in this country also.

My children are concerned that they and their children could develop diabetes in the future. Because they know I have diabetes and they know that diabetes runs in families, they take care of themselves. They eat well, exercise every day, and don’t gain weight. They know that Hmong cultural ways are healthy ways.
What information should I collect?

Who to collect information on:

• Yourself
• Your parents and grandparents
• Your brothers and sisters
• Your children

Include both sides of your family (kwvtij and neejtsa)

Basic information to collect:

• Name and relationship to you (myself, parent, child, etc.)
• Ethnicity (Hmong, Lao, French, etc.)
• Dialect (White Hmong, Green Mong)
• 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:**
- Alpha Thalassemia
- 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, liver)
- Current and past medications
- Deafness/hearing loss at a young age
- Developmental delay/learning disorders
- Diabetes/sugar disease
- Gout
- Heart disease
- Hepatitis B
- High blood pressure
- High cholesterol
- History of surgeries
- Mental health conditions (such as depression, PTSD)
- Obesity
- Pregnancy (such as number of children, miscarriages, complications)
- Stroke
- Substance abuse (such as alcohol, drugs, opium)

**Lifestyle:**
- Exercise
- Habits (such as smoking, drinking, gambling)
- 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.

Send a questionnaire

You may wish to send out questions by email or mail asking for health information from relatives. Consider doing a school project. 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.

• Consider going to the doctor with your older family members so you can learn about their health, illness, and medicines. Otherwise review their medicines, doctors’ records, and hospital papers.

• It is important to respect others. Some relatives may not want to share their medical histories. Some may not know their family history.

Mai Neng’s story

When I was a senior in college, I discovered that my kidneys were failing from IgA nephropathy. It was a frightening experience for my family and I. “You are so young and active, how could this happen to you?” asked my family. At first, they didn’t believe I was sick, but as my condition worsened, it was clear I was very sick. I was afraid I wouldn’t get well without treatment. My family was afraid of the biopsies, dialyses, and kidney transplantation that the doctors described.

Since I discovered I had IgA nephropathy 14 years ago, I’ve learned that three other first cousins also have IgA nephropathy. We now know that IgA nephropathy is an inherited disease. Perhaps my ancestors also had it, but we
• 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.

didn’t know about kidney failure when we lived in the mountains of Laos, so my generation is the first to live with this realization.

Having had a transplant 11 years ago, I am healthy today. I am happily married with an 11-month-old daughter. It is scary to think that other family members could develop kidney failure also. But now that we know about this disease, we can actively protect our kidneys, be alert to early signs of failure, and help each other when failure does occur.
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.

MaiKia’s story
It’s God’s grace that my grandparents lived healthy lives well into their late 90s and early 100s. They were great gardeners, carpenters and builders, being physically and mentally active every day. Looking at my parents now, they too are healthy and vibrant in their old age. I know I have some great genes, but I also know I need to be just as active to reap the benefits. Being
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, letters, and other family keepsakes, as well as medicine bottles, doctors’ reports, hospital papers, videos, and albums. 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!

active and eating healthy traditional meals, learning age old remedies and retaining the wisdom of my elders, will help me pass on our family’s healthy strengths to generations to come.
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 as a child?
- Do you have any brothers or sisters? Did any of them pass away during childhood? Do you know why?

**Questions about adulthood**
- What daily work and chores did you do? 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 any of them die? What happened?
- 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)?
- What medicines do you take (over the counter, prescribed medicines, Hmong herbal medicines, or Asian medicines)? What are you taking them for? What other treatments do you use?
Questions about parents and grandparents
• When and where were your parents born? What do you know about them?
• When and where were your grandparents born? What do you remember about them?
• Did your parents or grandparents have any health problems?
• Did they take any American medicine? What traditional Hmong healing treatments did they use? Why?

Questions about family life
• In what ways did the refugee flight affect your health?
• Do you eat more American fast food or Hmong food? How much rice and fried food do you eat every day? How often do you eat at an Asian buffet?
• 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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Tchuyi’s story

I was weak and tired. My skin was becoming yellow. My doctor tested me. She told me I had liver failure from Hepatitis B. She said I would need a liver transplant. I was scared, but I knew I would die without it, so I received a new liver. I am glad I did. I am alive and healthy.

Hepatitis B is not a genetic disease. It is an infectious disease that affects families. My doctor said we had to test everyone in the family, to see if anyone was sick.

I am glad that all of my family members listened to me and got tested. Some have the virus; they are tested every year to make sure they
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.

don’t develop liver failure or liver cancer. Some people were already protected, but others needed the vaccine to protect themselves.

Every Hmong person needs to know if they have Hepatitis B or not, so they can stay healthy and prevent liver failure.
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.
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.

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.

Next, I added my brothers and sisters and their birthdates. I connected each of them to the line that connects my parents. I have more siblings than this, but I did not have room to show them. In the paper I have at home, I included all of my siblings, aunts, uncles, and cousins.

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 did the same for my mother's family, because njej tsa and kwv tij are both important for family history. I added where each side of the family was from. Finally, I drew a line diagonally through my grandparents to show that they died.
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

Hmong Health
www.hmonghealth.org

SPIRAL = Selected Patient Information Resources in Asian Languages
spiraltufts.edu/hmong

Healthy Roads Media
www.healthyroadsmedia.org/hmong

Hmong Cultural Center
www.hmongcc.org
Genetic Alliance increases the capacity of genetic advocacy organizations to achieve their missions and leverages the voices of millions of individuals and families living with genetic conditions.

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