A Guide to Family Health History
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.

**Contents**

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Introduction</td>
<td>1</td>
</tr>
<tr>
<td>Collect</td>
<td></td>
</tr>
<tr>
<td>Information to collect</td>
<td>6</td>
</tr>
<tr>
<td>How to collect</td>
<td>8</td>
</tr>
<tr>
<td>How to ask questions</td>
<td>12</td>
</tr>
<tr>
<td>Sample questions</td>
<td>14</td>
</tr>
<tr>
<td>Organize</td>
<td></td>
</tr>
<tr>
<td>How to organize</td>
<td>16</td>
</tr>
<tr>
<td>Family health portrait</td>
<td>18</td>
</tr>
<tr>
<td>Understand</td>
<td></td>
</tr>
<tr>
<td>What now?</td>
<td>20</td>
</tr>
<tr>
<td>Resources</td>
<td>21</td>
</tr>
</tbody>
</table>

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.

Brigitte, Health Educator

At Comprehensive Community Health Centers we recognize that family health history is vital and important to your health.

If you know the illnesses and diseases that run in your family you can help your medical provider be more aware of what you may be at risk for and how you can take action to stay healthy. In this way, your medical provider can guide your current and future care.
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.

Be proactive! At your next visit ask to get screened for a disease that you already know runs in your family.

Also, don't forget to share your up-to-date family health history with your medical provider, or help us update your family health history if we already have your information.
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.

Aida's story

I have Diabetes and high Cholesterol. At my last doctor visit, I was recommended to eat healthy and engage in exercise to control my Diabetes and Cholesterol. Although it is not easy, I try to consume healthy foods that benefit me.

For example, I cook steamed fish, instead of fried fish, and I decided to stop eating organ meats, such as liver, because of its high cholesterol content.
Knowledge is power. Finding out the illnesses that run in our families can be just the motivation we need to start making healthier choices and save lives. It is never too late to care.

Barbara E. Jackson, RN
President/Founder
CATALYST

In regards to exercising, I try to walk regularly every day and my goal is to lose weight. My son also has Diabetes, and as a mother, I’m setting a good example for him.
What information should I collect?

Who to collect information on:
- Yourself
- Your parents
- Your brothers and sisters
- Your children
- Your grandparents

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!
Who to collect info from
Collect the medical and health information on:
Yourself
Your brothers and sisters
Your children
Your parents
Then go back a generation at a time and include:
Grandparents
Aunts and Uncles
Cousins
Nieces and nephews

Basic info to collect
• Name and relationship to you (myself, parent, child, etc.)
• Race, ethnicity and/or origins of family
• Date of birth (or if the information is unavailable, write your best guess—for example “1940’s”)
• Place of birth
• If deceased, age and cause of death

What information should I collect?
Who to collect information on:
• Yourself
• Your parents
• Your brothers and sisters
• Your children

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

• 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

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
• Osteoporosis
• Rheumatoid Arthritis (RA)

Be sure to record age at onset of symptoms (when the disease started)

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.

Maria's story

I have had a history of Diabetes for a while now. My sister was diagnosed with Diabetes 10 years after I was diagnosed with it. My parents never had Diabetes or were ever medically diagnosed with it. But I do recall my mother having an ankle injury in her earlier years.

While walking, a stick perforated her skin at her ankle and the wound was slow healing. In fact, it never completely healed, the wound was always open. Even though she was never diagnosed with Diabetes, to this day I suspect that perhaps she may have had high blood sugar or was Pre-Diabetic.
• 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 stay healthy I feel I’m doing well with managing my Diabetes and following my doctor’s orders. I eat low fat balanced meals and I walk every day or up to two times a day as an exercise routine. I take my medications regularly, as prescribed by my doctor, in order to keep my blood glucose controlled.
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.

Gizelle’s story

I just found out that in my family there is a genetic cause for Diabetes, Cancer, High Blood Pressure, Autism and Mental Health Issues.

I know that I cannot change my family history. I can adapt to the fact with Diabetes, it can be controlled with diet and exercise. With Cancer, I eat a lot of garlic and onions. Knowing that I get
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!

overwhelmed, it’s nice to know that I can and will get mental health services (for myself) on how to deal with my son’s, Kirkland, Autism. Also getting involved with my community makes me feel a whole lot better.
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?
• Do any of my siblings or cousins have any health problems?

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)?
• Do you have any brothers or sisters that have had health problems?
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?
- Do you know what the doctor has told your parents or grandparents about their health recently?

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?
- What role do your religious beliefs play in your eating habits?
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.

---

**Ryan's story**

Growing up as a kid we used to go to the beach as a family a lot. I remember getting so sun burned that on the way home I couldn't lean back on the seat. As I got older I noticed strange black spots on my back and neck. I could have written them off as big freckles or moles. But after talking to my grandparents, I found out that my family has a history of different cancers, including skin cancer.

So, I decided to take their advice to go to a Dermatologist and got a simple checkup. Judging by the color, size and shape of these spots, the doctor decided to do a biopsy. At 23 years old, I was diagnosed with benign melanoma and the moles that could have become malignant were
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.

removed.

Thankfully we caught it early. Any longer and it could have developed into skin cancer. A simple surgery and the moles putting me at risk were gone.

Now eight years later, I am happy but still careful and protect my skin daily. I plan on getting regular checkups for this and other cancers. Prevention is very important for a longer life.
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.
Valerie'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.

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

Centers for Disease Control and Prevention Family Health History Resources
www.cdc.gov/genomics/famhistory

U.S. Surgeon General Family Health History Initiative
www.hhs.gov/familyhistory/
To ensure the health and wellness of each individual so every person may reach their fullest human potential within a caring environment.