DOES IT RUN IN THE FAMILY?

A Guide to Family Health History

BEAUMONT CANCER GENETICS PROGRAM
COVENANT COMMUNITY HEALTH CENTER
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.

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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.

Knowing your family health history could save your life.

Francis Collins, MD, PhD
Director, National Institutes of Health (NIH)
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.

Breast cancer gene

Several of my aunts died of breast cancer, so I was very worried when I was diagnosed with breast cancer at age 42. When I talked about my family health history with my doctor, he was also concerned and referred me to a geneticist. At the appointment, I learned that some people inherit a gene that increases their risk for developing breast cancer younger. I decided to undergo testing for the gene.
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.

I was surprised when I tested positive. Knowing that I have this gene was powerful information. I was able to make important health decisions, like prophylactic mastectomy (removal of breast) and oophorectomy (removal of ovaries) to reduce my risk of developing cancer.
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.

It's good to keep a history

My friend said that when she goes to the doctor they give her a clipboard with a list of illnesses to find out what runs in her family: she just puts "no no no". I told her it's very important to know your family history because doctors can't help you prevent problems unless they know what you are at risk for. She replied, "That is personal information. Besides, I don't have any of those diseases now."
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

She questioned sharing such information with an unfamiliar doctor. I explained that her appointment is confidential and that doctors aren’t being nosy; they want to be helpful. Tracking family health history now can help prevent the onset of diseases, such as cancer, through better screening and prevention.
What information should I collect?

Who to collect information on:
- Yourself
- Your parents
- Your brothers and sisters
- Your children
- Grandparents, etc

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!

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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
- Age of diagnosis of disease
- Any prior genetic testing

- 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 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
A questionnaire or survey asking for health information from relatives may be an easy way to collect information. Example questionnaires can be found on the internet [see page 21]. Remember that not everyone will feel comfortable sharing their information in this way, and be sure to explain why you are asking and share the results with the family.
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.

Opening up about cancer

My mom passed away from cancer in 2007. At a reunion, we all talked of Mom and her illness. It turns out that the entire family has had some type of cancer. The 'female' types were what interested me the most. I have had a cousin die of breast cancer and another of melanoma. This was most enlightening. I remember my mom talking about her uncle's prostate cancer and another family member's cancer. Now more of the family members are open to discussing this - we are aware of our genes and history and do take precautions. I have discussed my cancer family history with my doctor. We do focused screening exams, such as mammograms, and my doctor has referred me to a
• 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.

[Image: A genetic counselor to discuss my family history and options to assess my risk. I found out more about the importance of good nutrition, exercise, and not smoking. There is information out there and people who have been through this who can help. If they don’t know the answers, they can guide you as to where to find them.]
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.

Passing on the knowledge

I was only three years old when my mother passed away. I really have no memory of her, but it was explained to me that she was diagnosed with a "female" cancer. She was only 35, and she left behind a husband and three young boys. At the age of 38, I was diagnosed with Stage III colon cancer. At the recommendations of my doctors, I also pursued an angle that was also less obvious to me — genetics. There was a pattern here.
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!

and I was diagnosed with an inherited colon cancer syndrome. I had an answer. Today, I am happy to be cancer free. I have a chance of seeing my children grow up. My children now have information to prevent a cancer themselves
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?

**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)?
- What type of cancer screening, such as mammograms or colonoscopies, do you do? How often?
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?
- Did anyone ever have a cancer diagnosed? How old were they? What type?

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?
- Do you discuss health history with your family members?
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.

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**Colon cancer**

My mother was 37 when she died of colon cancer, and I was 18. We never discussed her disease. Why? I’m not sure. At that time cancer was the dreaded "C" word, even though my mom, dad, grandmother, and aunt all died of colon cancer. I’ve made sure my family receives regular physical exams, but one day I realized I was following the same path of silence by not discussing our family’s health history. I want to leave the best legacy possible for my children, so I decided to break the code of silence that runs in my family.
Healthcare Provider Card
Online (www.geneticalliance.org/ccfh), 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.

I gathered information about colon cancer from the American Cancer Society and set up a formal meeting with my children to have our first conversation about the family's health history. Many conversations have followed. Our knowledge about colon cancer and other health issues in our family has grown. Now I really feel I am leaving a good legacy for the people I love.
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.
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

Surgeon Generals Family Health History Initiative
http://www.hhs.gov/familyhistory/

Michigan Association of Genetic Counselors
http://www.magcinc.org/
Beaumont Cancer Genetics Program
http://cancer.beaumont.edu/genetics

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Royal Oak, MI 48073-6769
248-551-3388

Covenant Community Health Center
http://www.covenantcommunitycare.org/

The goal of the Beaumont Cancer Genetics Program is to identify high risk individuals, and implement state of the art technology to prevent cancer.