

DOES IT RUN IN THE FAMILY?

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# A Guide to Family Health History



LIVE FOR LIFE  
DUKE INSTITUTE FOR GENOME SCIENCES & POLICY

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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.

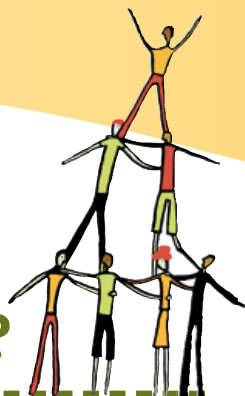
Your family's health is one part of the entire history of your family. While collecting your family health history, pay attention to events, stories, and experiences as well. Gathering your family history helps you share your heritage and culture with your relatives and future generations.

**“One of the most important things we can do for our health is to learn about our family health history and share it with our relatives and health providers. Help your family become health aware.”**

– Victor J. Dzau, MD, PhD  
Chancellor for Health Affairs  
President and Chief Executive Officer  
Duke University Health System

# How can family health history affect my health?

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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.



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## Opening up about cancer story

My mom passed away from cancer on 8/10/07. At a reunion, we all talked of Mom & 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 lung 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

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.

the ‘regular’ screening exams and I get the tests done. Through Live for Life I have found out more about nutrition and exercise and stopped smoking through QuitSmart. There is information out there and people who have been through this that can help. If they don’t know the answers, they can guide you as to where to find them.

~Toni, Division of Pulmonary Medicine



# How can my choices affect my health?

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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.



## History of addiction story



My teenager was born to a 19 year old woman and became my daughter through the wonderful process of adoption. Medical histories were collected through Social Services, but were limited in their usefulness due to their lack of detailed information. The birth mother shared with me that both of her parents had been heavy drinkers and how this affected her childhood. I also learned that the birth father had been born to a woman who abused substances and was raised by another family.



“Our family’s past  
health history is key to  
our future wellbeing.”

– Geoffrey S. Ginsburg, MD, PhD  
Director, Center for Genomic Medicine  
Institute for Genome Sciences & Policy

As my daughter grew up and her curiosity grew, I told her about the extensive history of addictions in her biological relatives and explained what was known about inheriting addictive traits. She resolved to stay away from alcohol, drugs and tobacco. Even through the teen years, despite extensive peer pressure to try these things, her resolve has never wavered. I am very proud of her and how she has responded to the knowledge about her biological health history.

~ anonymous Duke employee

# What information should I collect?

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## 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
- Heart disease
- High blood pressure
- High cholesterol
- History of surgeries

- Immunizations
- Inherited conditions (such as Sickle cell, Cystic Fibrosis)
- 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?

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## 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

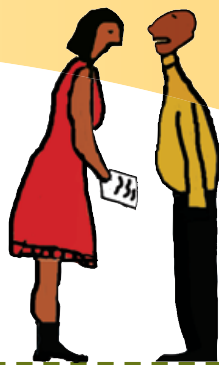
After you've introduced the idea of family health history, you may want to talk with certain family members to get a more complete record of what they know. If possible, it is a good idea to record these interviews so you can go back later and review them. This guide includes sample questions to ask.

## 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

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- 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.



## Your family health story

### Suggestions to get started:

1. Take advantage of fun family gatherings such as birthdays, holidays or reunions.
2. Use old family photos to help spark memories.
3. Explain what you are doing and why.
4. Print out extra copies of these booklets to share, available at [www.genomestohealth.org](http://www.genomestohealth.org).

- 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.

We all have diseases in our families – melanoma and prostate cancer, heart disease, diabetes and Alzheimer’s. Some of us have more health problems in our families than others, but that’s okay. Knowing about our family health histories has had direct impact on each of our lives and health choices.

~Mark, Terry and Ronnie,  
Parking and Transportation

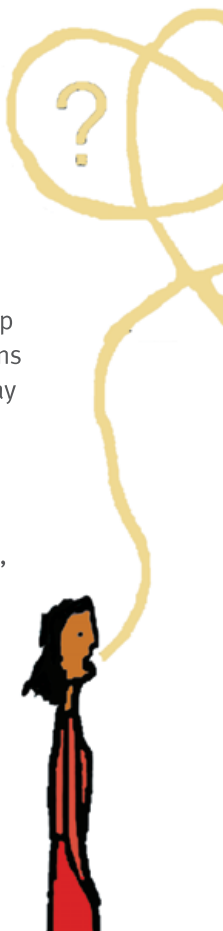


# How do I ask my family members questions about family history?

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.



## Facing diabetes story

My entire Cuban family, it seems, has diabetes...and I am bound and determined to not be diagnosed...it frightens me! So, I watch my eating, joined a weight management program, exercise regularly and get routine physicals. Being 45 is not like being 25! I cannot eat the way I used to and expect to be slim! A hard truth, but a reality check that I have faced the last few years!

## 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!**

Healthy foods taste good and I am so glad there are weight management groups here at Duke. Now, I actually look forward to the aging process because I know that I am doing all that I can to age wisely.

~Cari, Patient and Visitor Relations



# Sample questions

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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 (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)?
- Do you believe you are at risk for any health conditions? Why is that?





## Questions about parents and grandparents

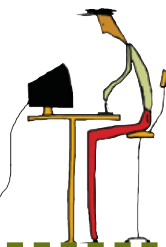
- When and where were your parents born? What do you know about them (for example, their jobs and hobbies)?
- When and where were your grandparents born? What do you remember about them?
- Did your parents or grandparents have any health problems?
- Do you know if your parents or grandparents took medicine on a regular basis? If so, for what? Did they use home remedies? What kinds and for what?

## 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 kinds of physical activity do you enjoy with your family?

# How can I organize my family health history?

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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.](#)



## Inheritance of health story

My mother died when I was young, so I was raised by my grandparents. My grandmother was ahead of her time in many ways, and she was determined that I know our family's health history. I was told about our family's diseases – my mother's, grandparents on both sides, as well as uncles, aunts and cousins. I didn't really "get it" when I was young. Now, I'm so thankful she understood the importance of this history. She knew that some diseases are inherited.

Because of the wealth of information I have about our family health, I have been proactive about glaucoma checks, bone scans, having my blood sugar tested and monitoring my blood pressure. Some of these

## Healthcare Provider Card

Online ([www.geneticalliance.org/ccfhh](http://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.



diseases have no symptoms; but if caught early enough, they can be treated successfully.

I go to the Health Fair here at Duke yearly and get a lot of answers there – and I go to my doctor. Find out the health history of your family – it could help you live longer!

~Diane,  
Institute for Genome Sciences & Policy



# How can I draw a family health portrait?

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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](http://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



# Blue Devil'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 (Blue Devil)  
b. 1922

- 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. Any men in the portrait are drawn as squares.

□ Washington b. 1820      ○ Artelia b. 1829  
|  
□ me (Blue Devil)  
b. 1922

- 3** Next, I added my two brothers and their birthdates. I connected each of them to the line that connects my parents.

□ Washington b. 1820      ○ Artelia b. 1829  
|  
□ Benjamin b. 1855      □ James Buchanan b. 1856      □ me (Blue Devil) b. 1922

- 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. I wrote her age at death under her circle.

ENGLAND  
○ Dickey b. 1780  
unknown cause, age 50  
|  
□ Washington b. 1820      ○ Artelia b. 1829  
|  
□ Benjamin b. 1855      ○ James Buchanan b. 1856      □ me (Blue Devil) b. 1922  
'March Madness'

# What now?

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- 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](http://www.geneticalliance.org/familyhealthhistory)

## Duke Medicine Resources

If you are concerned about health risks due to your family health history, talk to your doctor or nurse. Find out if there are steps you can take to address your health risks such as diet and fitness programs or more specific prevention plans including medical screens or tests. To make a medical appointment, call (888) ASK-DUKE or visit [DukeHealth.org](http://DukeHealth.org).

## Genetic Resources

### Medical Genetics Clinic

(919) 684-2036, [medgenetics.pediatrics.duke.edu](http://medgenetics.pediatrics.duke.edu)

### Fetal Diagnostic Clinic

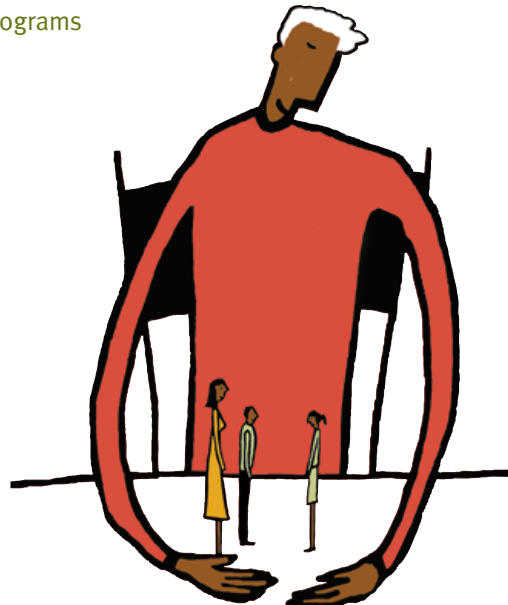
(919) 684-3604, [www.dukehealth.org/Services/Perinatal/About](http://www.dukehealth.org/Services/Perinatal/About)

### Hereditary Cancer Clinic

(919) 684-3181, [www.dukehealth.org/Services/HereditaryCancer](http://www.dukehealth.org/Services/HereditaryCancer)

### Genomic Medicine and Research Programs

[GenomesToHealth.org](http://GenomesToHealth.org)





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