

DOES IT RUN IN THE FAMILY?

1

A Guide to Family Health History



LESBIAN & GAY
FAMILY BUILDING PROJECT

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

How to get started 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?



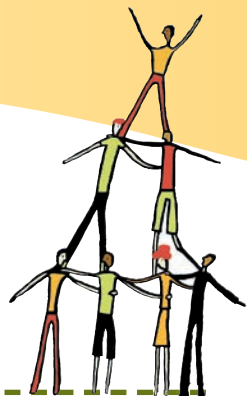
Family health history is a collection of information about diseases that run in your family, as well as the eating habits, activities, and environments that your family shares. Knowing about diseases in your family can help you make healthy choices.

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.

“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 F. Terry
President & CEO
Genetic Alliance

How can family health history affect my health?



You inherit many things from your family. 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 from your biological relatives. **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 biological parents.

Michael's story

My son was diagnosed, after a period of time, with Factor 5 Leiden deficiency. He complained of pain in his leg (calf). We thought he was trying to evade gym class. It turns out that he had a deep vein thrombosis (DVT) and spent months in a local hospital. Most physicians don't expect to see this until later

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.

in life. His mother was tested, as this disorder is always genetically transmitted. She was negative. However I tested positive (heterozygous), but fortunately I am asymptomatic.



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.



Tina's story



My partner had a brain tumor last summer that resulted in surgery and some long term side effects. Because of this situation we had to move across the country to be closer to family. Unfortunately, this move and some unforeseen circumstances caused my partner to lose her insurance coverage. We have a 2.5 year-old daughter and although we are each recognized as her legal parents, we have had a difficult

“Families comprise persons who have a shared history and a shared future.”

– McGoldrick M and Carter B, 2003



time getting health insurance together as a family of three since we are “not married.” My partner now has to wait 90 days to get individual insurance coverage, and we are hoping that she has no urgent medical needs until her plan is in effect. In the meantime, we also learned that my partner’s family has a history of brain tumors. She was never aware of this, as it was not a topic of conversation among family members until her diagnosis came about. Fortunately, we learned that her type of brain tumor, although caused by genetic factors, is not hereditary.

What information should I collect?

Who to collect information on:

- Yourself
- Your parents (biological & non-biological)
- Your brothers and sisters (biological & non-biological)
- Your children (biological & non-biological)

Then move on to your extended family.



Basic information to collect:

- Name and relationship to you (myself and my biological and non-biological parents, children, 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
- Mental health disorders (such as depression, schizophrenia)
- Obesity
- Pregnancy (such as number of children, miscarriages, complications)
- Sexual health
- 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.

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. 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.

Susan's story

Before beginning to inseminate, I saw a genetic counselor (fortunately, covered by insurance), because I had an older sister who had died from severe birth defects at 3 days old. The counselor couldn't say for sure without hospital records, which were not available. But based on the limited information I had, the counselor was able to make a good guess that my sister's death was related to that particular pregnancy, and my chances of a similar problem were no bigger or

- 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.

smaller than anyone else’s. This was quite helpful, since when I actually became pregnant this aspect of my family history was not hanging over my head.



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.



Chad’s story

When we adopted our son we had limited information on the health of his birth mother. There was some dispute as to his father’s identity. When a court terminates a parental relationship both parents’ rights must be terminated. Our son’s mother indicated a certain man was our son’s father. He disputed this claim and after a court ordered paternity test, he was ruled not

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!

the father of our son. Therefore, we were left with limited health information from the birth mom and no health information from the father. However, we know that he was robust at birth and time has proven him to be very healthy and energetic.



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 (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)?



Questions about parents and grandparents (biological and non-biological apply)

- 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?

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.](#)



Ellen's story

My partner and I adopted our little girl from Guatemala. We do not have very much information on her biological family's health history. We were given a large stack of papers with some health history information that her biological mother provided, along with a snapshot of her biological mother holding her before they took a DNA test. This test was to prove that the baby and her biological mother were in fact related and that she gave her consent to the adoption. Our daughter's

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 determine your risk for getting a disease.



biological father was listed as “unknown” so we have no information on him. With regard to our daughter’s ethnicity, it is likely that she is of mixed Mayan and Spanish descent, as are a majority of the Guatemalan people.



How should you begin collecting your family health history?

Here are a few ideas to get your personal health history project off the ground:

Schedule some time to think about what health means to you. Also, consider if your lifestyle choices are ones you have consciously made or if many of them were passed down to you from past generations.

Do a little at a time. A family health history project can seem a little overwhelming, but focusing on a smaller period of your life can make it feel more manageable. Also, this project is ongoing—it will last your entire lifetime.

Ask yourself the questions you would ask an ancestor if you had the opportunity.

Jog your memory with old photos, letters, cards, yearbooks and other memorabilia. These things can all serve to bring back those memories that have been pushed to the back of your brain.

Invite your biological and non-biological family members to share and collect health information and you will have a record of family health history that will be a resource for generations to come.

Why do LGBT people need to be given special consideration when collecting family health history information?

LGBT people often face financial, personal, and cultural barriers when attempting to access health care and health information. Many LGBT people fear or experience discrimination when attempting to find a healthcare provider that will understand their unique family situation. Since their families do not always fit the traditional structures for which family health history collection forms are formatted, many LGBT people do not keep track of this important information.

The LGBT Healthy Families Initiative is aware that even though LGBT families are not always completely biologically related, the way that we live and the health choices we make, as well as our genetic makeup, affect our future health and the future of our families.

Chosen families are an important part of LGBT families. These are people, related or not, that you have brought into your family circle. Such families spend time cooking, vacationing, and sharing stories and traditions with their non-biological family members. These people affect the past and futures of LGBT families. Be sure to include your non-biological relatives when collecting your family health history.

For more tips and information about the importance of collecting the family health history in your LGBT family, visit www.lgbthealthinitiative.org.



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

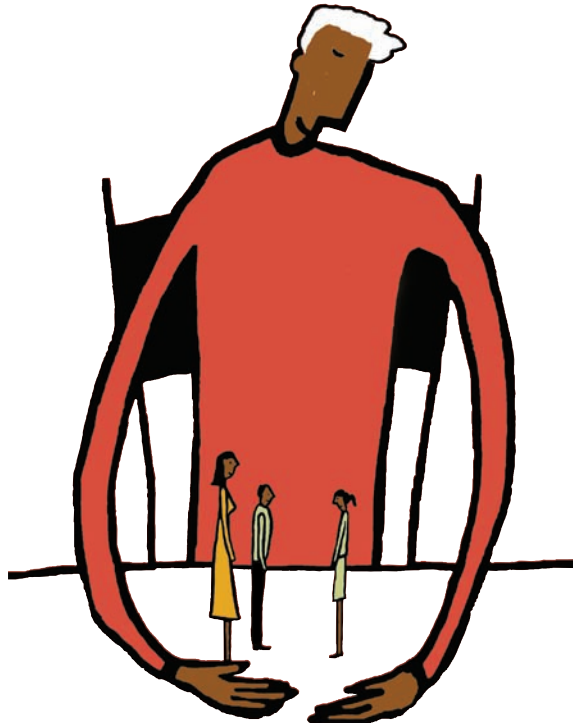
Genetic Alliance Family Health History Resources

www.geneticalliance.org/familyhealthhistory

LGBT Healthy Families Initiative

www.lgbthealthinitiative.org

This website will provide useful tools for you to use to create your unique family tree, including how to talk to your family, keeping a scrapbook or journal, and creating your own personal health profile. The standard family tree utilized by many healthcare professionals, depicting male-female and biological relationships, does not adapt well to families created through surrogacy, sperm/egg donation, and adoption, or for individuals whose gender identity may differ from their biological gender. It also does not provide a means to clearly depict non-biological relatives in chosen families. The LGBT Healthy Families Initiative seeks to provide tools for health history collection for all individuals and families.



Lesbian & Gay Family Building Project

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