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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.

“Knowing your family health history can assist you in enhancing your present health conditions and overall well being.”

– Esperanza Gomez
Wellness Center Coordinator
Progreso Latino
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.

Hugo’s story

In 2001 I was diagnosed with stomach cancer and I had surgery and treatment for five years. My doctor considers me a “cancer survivor” at this time. Today I am 71 years old and I suffer from diabetes. In the workshop on genetic diseases I learned that cancer can be a genetic disease that runs in families. I remember that my mother died from cervical cancer. I also know that there are other risk factors, such as your lifestyle that can influence the manifestation of cancer. Since this realization I have met with my children and asked
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.

them to get cancer screenings yearly so that in case they get cancer it could be detected early, since due to the family history they are at risk and so is their children. I have also begun to change my eating habits and have included fruits and vegetables in my diet. I no longer drink alcohol.
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.

Emilia’s story

My name is Emilia, I am 74 years old and I am a participant of the diabetes support group at Progreso Latino. I suffer from diabetes although nobody in my family has ever had this disease. But when I learned about the family tree I realized that my father died of a stroke and my mother of a heart attack. After learning about genetic disease I have learned that these are also complications of diabetes and that I’m also at risk for these diseases. When I was 50 years old, I realized I had
Family health history is the first step on the road to better health.

diabetes because they took me to the emergency room and the doctors found very high sugar levels after I ate a large quantity of candy with almonds. Since that day I take insulin and other medicines for high blood pressure and cholesterol. I am also aware that I have to take care of myself and I attend workshops where I can learn more about diabetes and how to keep a balanced diet. I also attend to a daily exercise program at Progreso Latino.
What information should I collect?

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
- 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 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.

Pedro’s story

Today I have decided to write about my family health history. I have learned that my health history can affect my health and I can pass diseases on to my children through my genes.

As I think about my family’s health history for the first time, I realize the pattern of health similarities within my family. My father’s older brother experienced a kidney extraction when he was 30 years old; his sister died of maxilla cancer, and my father died from a stroke. My brother was diagnosed with kidney disease and had to have a kidney transplant. My father’s youngest brother died from a heart attack.

My mother had seven siblings; the oldest one died of a heart attack; one of her sisters died from stomach cancer, and another sisters died from a stroke. My
• 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.

mother suffers arthritis. I suffer from high blood pressure and high cholesterol.

I thought that my blood pressure and high cholesterol were due to the way my body managed itself and had never really connected this to my family’s history. I see the importance of educating my children and hopefully minimizing their risk of these diseases, and I hope that after reading this you do too!
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.

Amanda’s story

Dementia is a disease that affected my mother at the age of 50 and my sister when she was young. I have four children and I have spoken to them about this disease because it is a very serious disease that they could develop. As I continue to get older I have to worry about developing dementia, so it is important for me to take care of my physical and mental
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!

health. This is a disease that many Latinos don't speak about and yet many people suffer from it, so it is important to learn your family history so that you can receive the early testing and medical care you deserve.
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 conditions (for example, allergies) as a child?
- Do you have any brothers or sisters? Did any of them pass away during childhood?

**Questions about adulthood**
- What jobs have you had? Can you tell me about a typical day?
- What was your work environment like?
- Do you have children? What are their names and when were they born?
- What habits (sun exposure, physical activity, smoking, etc.) have you had that could have affected your health?
- Did you develop any health conditions or illnesses as an adult? At what age? Did any of these conditions require medical treatment or surgery?
Questions about parents and grandparents

- When and where were your parents born? What do you know about them (for example, their occupations and pastimes)?
- What do you remember about your grandparents? Where and when were they born?
- Do you recall any health conditions or physical ailments that affected your parents and/or your grandparents?
- Do you recall if they took any over-the-counter or prescription medications 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 near any sites that may have been hazardous or lived through any major disasters that may have affected their health?
- What foods does your family usually eat? Describe a typical family breakfast or dinner. Do you eat special foods for special occasions?
- Do you know of family members who experienced difficulties in pregnancy or childbirth? What kinds of difficulties?
- Are there any conditions or illnesses 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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**Sebastiana’s story**

My name is Sebastiana and I want to share my story of glaucoma. It is very common and it is a genetic disease, but people don’t think of it as one. I was diagnosed with glaucoma ten years ago, and my brother was diagnosed twenty-years ago.

In discussing this with my brother he informed me that my mother also had glaucoma. This health information is valuable to my family as my daughter, who is 36 years old, was diagnosed...
Healthcare Provider Card
Online (www.geneticaalliance.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.

this year. If I would have discussed this information earlier with my family I could have assisted with my daughter’s eye care. As a mother and grandmother I understand that speaking about this health issue will assist my family’s future generations.
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.


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.
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.

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.

3. Next, I added my brother and sister and their birthdates. I connected each of them to the line that connects my parents. Any men in the portrait are drawn as squares.

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 grandfather’s circle to show that he 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

Progreso Latino and Progreso Latino Wellness Center
www.progresolatino.org, www.progresolatino.org/#wc

Rhode Island Department of Health
www.health.ri.gov

The Smithsonian Folklife and Oral History Interviewing Guide
www.familyoralhistory.us/news/view/the_smithsonian_folklife_and_oral_history_interviewing_guide/
and visit the American Folklife Center website:
www.loc.gov/folklife/fieldwork
As the largest bilingual multicultural empowerment community-based agency in the state of Rhode Island, Progreso Latino helps the Latino and immigrant communities achieve greater self-sufficiency and self-determination.