A publication of the Texas Cancer Genetics Consortium

¡Buena Vida!

A Guide to Family Cancer Research

Does cancer run in your family?

- *What you should know*
- *How you can learn more*

Family cancer studies

How you can help

To learn more about cancer studies, call:

Purpose of this Booklet

It has been found that some types of cancer tend to run in particular families. This means people in these families may have a higher risk of having the disease at some time in their lives.

Researchers are gaining new information about how and why these cancers occur in families. As a result of this research, new tests can help determine if a person in one of these families has a risk that is higher than normal.

This booklet provides information about cancer and the importance of medical studies in the fight against this disease. It is hoped that this information will help you consider taking part in these studies.

The more you know about cancer and about your personal and family risk, the better you can make decisions that are right for you and your family.

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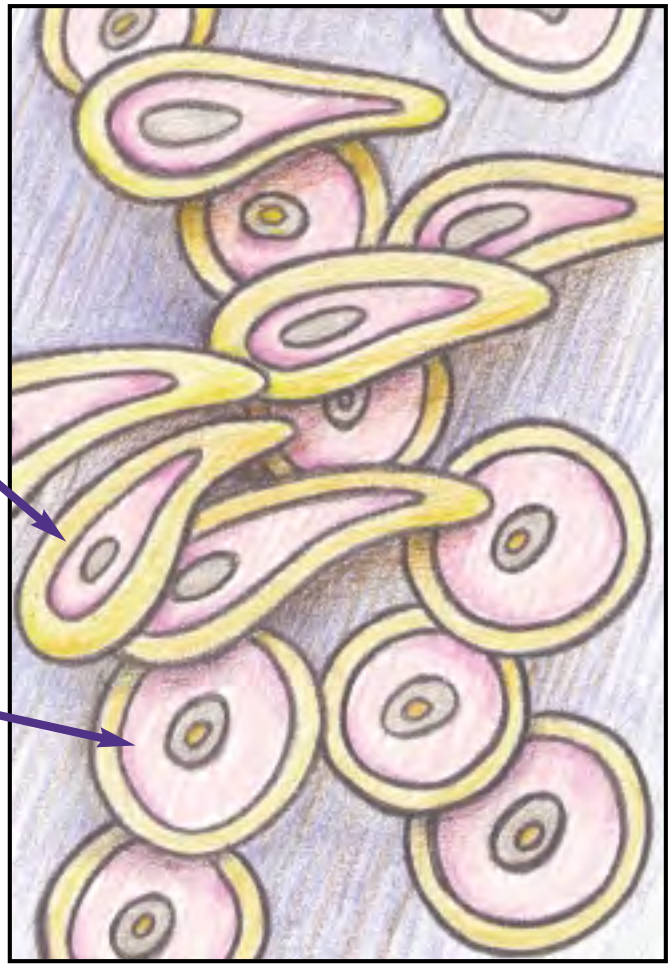
What is cancer?

Cancer is a disease that causes abnormal growth of cells in the body. These abnormal cells can cluster to form tumors, which may grow in almost any part of the body. People become sick when these tumors grow and affect the way their body works.

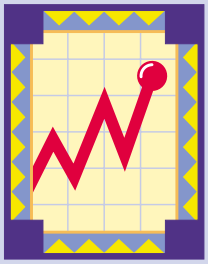
Researchers are learning more about cancer everyday. This booklet will show how you may be able to help.

No one is safe from cancer. The disease can affect men, women and children of all ages. It is found in people of all races and ethnic groups.



Graphic courtesy of National Cancer Institute

Are Hispanics at high risk for cancer?



In all ethnic groups, cancer is a leading cause of death. In Hispanics, the risk is high for certain types of cancer. These include cancers of the cervix, breast, stomach, liver and gallbladder. However, Hispanics can get any type of cancer.

Some common types of cancers are:

- Breast cancer
- Lung cancer
- Skin cancer
- Colon cancer
- Prostate cancer
- Liver cancer

"I had a higher risk of cancer because I have an extensive family history of the disease. I didn't know about cancer research when I was diagnosed, but I've learned so much since then – and I would definitely participate in a study."

Mary Gonzalez, 47, a breast cancer survivor who was diagnosed 14 years ago, is shown with husband Mauro and their 10-year old son Matthew.

What is my risk of getting cancer?

Some people are more likely to get cancer than others. In other words, they are at higher risk. Many factors influence a person's risk for cancer. These factors include age, diet, smoking habits and work conditions.

For some types of cancer, another factor is heredity. We know that many traits, such as hair color, can be passed down from generation to generation. This is because these traits are found in our family's genes.

The same is true of specific kinds of cancer, such as breast cancer. This means certain families may be at higher risk for this disease than other families. Individuals in these families may have specific genes that increase their breast cancer risk.

For example, if breast cancer has appeared in other members of your family, the chances of you having breast cancer in the future may be higher.

Alex Peña, 40, had a grandfather who died of cancer and a grandmother who was diagnosed with breast cancer. His father has prostate cancer.

The types of cancer that can run in families include:

- **Breast cancer**
- **Ovarian cancer**
- **Colon cancer**
- **Prostate cancer**

"I know that just because people in my family have had cancer, that doesn't mean I will definitely get it. But it means my chances may be higher, and I've been considering getting genetic testing."

How do researchers learn more about cancer?

We learn more about diseases through medical studies. Often, this research involves patients or members of their families. These studies are known as "clinical studies" or "clinical trials."

In cancer research, the goal of these clinical studies is to learn everything we can about this disease and how to treat it. With this new information, doctors are able to help patients today, as well as those who may have cancer in the future.

Medical studies play a very important role in the fight against cancer. What researchers are learning today offers hope for your children and grandchildren!

I used to think that people in medical studies were just 'guinea pigs.' But I found out it wasn't like that. I felt like what I was doing was safe – and it could make a difference in someone's life someday."

Although Aurora T. Guajardo, 58, left (shown with her friend Marta Cortez and "puppy" Spike), has never had cancer but took part in a cancer study because she felt it might benefit her daughter and granddaughters.

Can I take part in cancer studies?

Yes, you may be able to help.

We can only learn about the effects of cancer on a specific ethnic group through studies that include members of that group. To gain information about cancer in Hispanics, researchers need to enroll Hispanics in their studies.

The same is true of research in the types of cancer that run in certain families. To learn why this happens, researchers need to conduct studies that include people from those families.

If cancer has appeared in your family, you may be a very good candidate for a study.

Studies that investigate the genes that may cause cancer to run in families are called "genetic studies."

Marta G. Cortez, 68, a longtime cervical cancer survivor, would be willing to participate in cancer research.

"I think it's important that Hispanics help each other whenever possible. I know that researchers are looking for more Hispanics for their cancer studies, and I think that's a good way to help."

Why should I take part in a cancer study?

You may be able to learn more about your cancer risk by participating in a study. There are tests available to see if you have one or more genes that may place you at higher risk.

If tests show that your risk is high, you can then make decisions based on this new information. Or you may learn that your risk is low.

It's true that taking part in a cancer study can help you personally. But remember, many other people also may benefit from your participation:

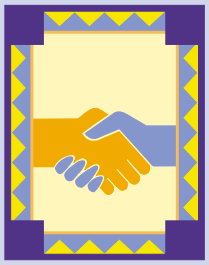
- Members of your family
- Your children and future generations
- Other Hispanic families

You should carefully weigh the pros and cons of participating in a study.

"When I got cancer, it affected everyone. My daughters know that they may be at higher risk. But until you're tested, you can't know for sure."

Sylvia Lavin Beilstein, 62, a breast cancer survivor, is shown with her large family, including her husband, children and their spouses, and grandchild Kyler, 2.

Why should I consider my decision carefully?



If cancer seems to run in your family, you may consider taking part in a study. Many people are very happy with their decision to participate.

However, before you decide, you should call for more information about the study. And you may wish to talk with your doctor.

You should carefully consider how the information you learn in the study may affect you. Ask yourself: How will I feel if I find out that the cancer risk is higher for me? And what can I do with this information?

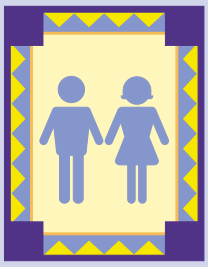
Ruben Ruiz Jr., 39, shown with his Dad (Ruben Sr.) and nephew (Matthew Mason, 13), has a family history of cancer.

Remember...

- If tests reveal that your cancer risk is high, it may not be possible to reduce that risk.
- If tests reveal that your cancer risk is low, that does not mean you can't get cancer. The disease can strike anyone.

"When I called about joining a cancer study, they answered all my questions. They told me I should think about it carefully and make my own decision."

What else should I know about studies?



You should be aware that everyone who participates in a study has certain rights. For example:

- Before enrolling in a study, the researchers must give you all the facts about that study.
- You have the right to stop taking part in the study at any time. This means that after the study begins, you can still change your mind.
- Researchers can not reveal your identity to others. This information is confidential.

Make a list of questions you want to ask the researcher. For example:

- **What is the purpose of the study?**
- **What will I be asked to do?**
- **How much of my time will it take?**
- **Can I talk with other people who are in the study?**

"I was nervous about being in a cancer study, but I listened to my doctor. Being involved in a study has helped my doctor with the treatment of my cancer."

Ernestina Rico, 58, shown with her granddaughter Ashley Rico, 9, is a colon cancer patient who participated in a cancer study that her doctor recommended.

How can I participate in a study?

If cancer seems to run in your family, you may be wondering how you can learn more. To get more information and help you decide if you wish to participate in a cancer study, follow these 3 steps:

Step 1 Call for information
There is a telephone number on the cover of this booklet.

Step 2 Ask questions
When you call, the research staff will be glad to give you any information you need. You may also want to ask your doctor some questions before making a decision.

Step 3 Follow the instructions
When you call the number in this booklet, the research staff will tell you everything you need to do to take part in a study.

Common Concerns

Distant travel

"I've found out that I can be in a study right here in town."

—Ruben Ruiz Sr., 65, with grandson Matthew

Time commitment

"The study really didn't take much of my time, and I was able to work it into my schedule."

—Cambri Carmona, 28, who participated in a cancer study

How can I learn more?

To find out more about being in a cancer study, you can call the telephone number on the cover of this booklet. Other sources of information include:

Telephone

National Cancer Institute's Cancer Information Service (CIS)
1-800-4-CANCER (1-800-422-6237)
(This is a free call. Se habla Español.)

Internet

National Cancer Institute:

http://cancerTrials.nci.nih.gov

http://cancernet.nci.nih.gov

For information about genetics studies in Texas:

Baylor College of Medicine, Houston – (832) 824-3334

University of Texas Health Science Center, San Antonio – (210) 567-6549

University of Texas M. D. Anderson Cancer Center, Houston – (877) 900-8894

University of Texas Southwestern Medical Center, Dallas – (214) 648-1919

Web site

http://texas.cgnweb.org