



Cancer Cluster Investigations

When exposure to environmental contaminants is suspected.

What is cancer?

Cancer is a term used for diseases in which abnormal cells divide without control. These cells are then able to invade other tissues. Some may spread to other parts of the body. Cancer is not a single disease. There are over 200 types of cancer. Although they attack the body in a similar way, not all cancers are the same, nor are their causes. Certain risk factors add to the chance of getting cancer. Many relate to health habits, such as:

- Whether or not someone smokes or otherwise uses tobacco
- Whether or not someone drinks alcohol
- Whether or not someone eats a healthy diet
- Whether or not someone gets enough exercise

The federal Agency for Toxic Substances and Disease Registry (ATSDR) suggests that if we could stop tobacco use, we could prevent one-third of all cancer deaths in the nation.

Distinct risk factors play a role in cancers that occur in different parts of the body. Asbestos is a known risk factor for lung cancer. Contact with radiation or benzene is a risk factor for certain types of blood cancer (leukemia). Your diet and exercise habits affect your risk for colon cancer. Too much sun exposure may raise your risk for skin cancer.

More than one risk factor can cause most cancers. For instance, as we age our body's ability to repair damage goes down. Therefore, most types of cancer are far more common in older people.

With many types of cancer, the chances of a cure are higher when you catch it early. These include cancers of the breast, cervix and colon. Making sure you get the right kind of screening at the right time could result in getting early treatment. The earlier a cancer patient gets treatment, the better the treatment outcomes. Once cancer spreads, it is much harder to stop.

Some cancers start in one place in the body (the primary site) but then spread to another site. We call this metastasis. The most common sites for cancer to spread include: bone, lung, liver and brain. Cancer registries record cancers based on where in the body they started, not where they spread. This is also how medical experts analyze cancer cases.

Certain vaccines also help decrease risk for some cancers. The human papillomavirus (HPV) vaccine helps women avoid most cancers of the cervix, vagina and vulva. The hepatitis B vaccine can decrease the risk of liver cancer. Educating people about their cancer risks, explaining the value of screening, and helping them find the services they need can reduce cancer rates. It can also decrease cancer deaths.

Cancer is a very common disease.

It is not as rare as most people tend to think. According to the American Cancer Society, 1 in 2 men and 1 in 3 women are at risk of developing some form of invasive cancer during their lifetimes. Also, one in four men and one in five women will die from it. Cancer is the second leading cause of death in this country.

Adults are more prone to get cancers such as:

- Lung
- Breast
- Colon or rectal (colorectal)
- Prostate
- Skin (melanoma)

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How do children get cancer?

Each year, close to 1 in 450 children learn they have cancer before they turn 15. The most common childhood cancers are leukemia, brain tumors, and lymphomas.

Many childhood cancers occur very early in life. Some types run in families, but for most kinds, the cause is unknown. Radiation exposure also promotes certain types of childhood cancers. Other factors in childhood cancers may include:

- **Infections**
- **Prenatal conditions**
- **Certain medicines**

Unlike most cancers in adults, we cannot link childhood cancers to lifestyle risk factors. Many organ systems in children grow at a rapid rate in the first years of life. During this time, they can be at special risk of harm. The types of cancer that children get vary greatly from those seen in adults.

In children, the most common types of cancer are cancers of the:

- **Blood (leukemia)**
- **Brain and other nervous system tumors**
- **Lymph-nodes**
- **Bone**
- **Soft-tissue (sarcomas)**
- **Kidneys**
- **Eyes**
- **Adrenal gland**

Note: The information on children and cancer comes from "Childhood Cancer-General Statement," published by the American Cancer Society and found in ATSDR's fact sheet on cancer found at: www.atsdr.cdc.gov/COM/cancer-fs.html

The Five Most Common Types of Cancer in Florida
(Age-adjusted Incidence Rates per 100,000 Population for Select Cancer Sites by Sex in 2012)

Females	
All Cancers	396.5
Breast	116.7
Lung & Bronchus	54.5
Colorectal	32.2
Uterine	22.3
Non-Hodgkin's Lymphoma	14.1

Males	
All Cancers	462.3
Prostate	92.98
Lung & Bronchus	72.4
Colorectal	41.4
Bladder	33.5
Head & Neck	26.8

*Excludes non-melanoma skin cancers
Data Source: Florida Cancer Data System (FCDS)

What cancers are most common in Florida?

In 2012, there were 106,166 new cases of cancer diagnosed among Floridians. The table this page shows the rates of the five most common types of cancer in Florida by sex. Adjusting the rates for age allows for comparisons between communities that have different age groups. In 2012, Florida males had a higher rate of occurrence of all cancers combined, excluding non-melanoma skin cancers, compared to Florida females. For every 100,000 males, there were approximately 462 new cancers diagnosed compared to 397 new cancers diagnosed for every 100,000 females.

Florida has the second highest cancer burden in the nation. The state cancer registry, the Florida Cancer Data System (FCDS), receives over 100,000 new cancers each year. As of 2011, cancer is now the leading cause of death for Floridians, with over 42,000 cancer deaths per year. The FCDS has been collecting cancer incidence data from hospitals since 1981 and from non-hospital sources (i.e., ambulatory surgical centers, radiation therapy centers, pathology laboratories, and private physician offices) since 1997. The main goal of the FCDS is to gather complete, accurate, and timely data to assist policy makers and researchers. The data helps them develop policies and programs to reduce death and illness due to cancer by better understanding cancer trends and possible causes. To learn more about this database, please visit: www.floridahealth.gov/diseases-and-conditions/cancer/cancer-registry/index.html.

What are the signs of cancer?

Everyone should learn to watch for the early signs of cancer. There is usually no pain in the early stages of cancer. This may lead to a delay in finding and treating it. Early symptoms can include:

- Unexplained weight loss
- Strange bleeding or discharge
- A persistent upset stomach with no known cause
- The presence of white patches inside the mouth or white spots on the tongue.

If you notice these symptoms, you should report them to your doctor right away. One of the most important things you can do if you think you might have cancer is to go to your doctor as soon as you can to share your concerns with them. Keep in mind that some of these signs could be due to a cause other than cancer.

How can people increase their chances of surviving cancer?

Cancer is easier to treat when found early. Tools to find cancer include:

- Self-exams
- Biopsy (taking out tissue to view under a microscope)
- Ultrasound (which uses reflected high-frequency sound waves to help decide if tissue is healthy or not)
- Computed tomography (also known as CT or CAT scan, which uses x-rays to show what the inside of parts of the body look like)
- Magnetic resonance imaging (MRI, which uses magnetic fields and radio waves to show changes in soft tissues without x-rays.)

What are some ways to promote health and avoid cancer?

Ways to help you stay healthy include:

- Cut down on or avoid exposure to known or suspected carcinogens (things known or suspected to cause cancer like cigarettes)
- Eat a balanced diet of vegetables, fresh fruit, whole grains and enough fiber
- Cut down on eating harmful types of fat, like trans fats
- Cut down on eating food preserved with some chemicals (like nitrites in processed meat)
- Get exercise on a routine basis
- Get enough sleep (at least eight hours per night)
- Cut down on stress or learn how to better cope with it
- Get a physical check-up each year
- Learn to do testicular self-exams

What role do chemicals play in causing cancer?

Many people believe chemicals cause most cancers. However, research shows that the role they play is small and unclear. We do not know very much about how contact with most chemicals may or may not cause cancer.

However, some of the few common chemicals with known links to cancer include:

- Arsenic
- Asbestos
- Benzene
- Trichloroethylene (TCE)
- Vinyl chloride

There are some chemicals that might cause cancer. They include:

- Chloroform
- DDT

Adults are more prone to get cancers such as:

- Lung
- Breast
- Colon or rectal (colorectal)
- Prostate
- Skin (melanoma)

- Formaldehyde
- Polychlorinated biphenyls (PCBs)

Getting cancer from a chemical depends on the following:

- The kind of chemical you come into contact with
- How much of the chemical you were in contact with (dose)
- How long the contact (exposure) lasted
- How often you were exposed
- How it entered your body (eating, drinking, breathing, touching)
- Your health at the time of contact
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- How it entered your body (eating, drinking, breathing, touching)
- Your health at the time of contact

Just because a chemical is near where you live or work does not mean that it has entered your body or will cause cancer. There must be a way for it to come into contact with your body. It also depends on if it is the kind of chemical known to cause cancer or not. You must also have contacted enough of it for a long enough period of time for it to affect your health. Remember that not all chemicals are harmful.

What role do animal studies play in cancer research?

For many chemicals, no human health data exists to assess if it is toxic. This is especially true when a new chemical first begins use.

Therefore, to gauge such risks, researchers often rely on animal studies. These studies give them control over testing to see if human health effects are likely from contact with a certain chemical. They also allow them to precisely measure the amount of chemical given to a test animal.

We call this the “dose,” like a medicine you take when ill. A dose that affects a test animal helps predict if chemicals may cause cancer or otherwise make people sick. The short lifetimes of small mammals also can result in getting an answer far more quickly than human studies would. While animal studies avoid the ethical questions that arise in chemical tests on humans, some people still have concerns about animal testing.

What role does chemical exposure have in cancer clusters?

For many chemicals, scientists can predict the average cancer risk to large groups of people from exposures. However, scientists cannot predict the precise risk of cancer for a single person from exposure to a chemical.

Studies that measure such risks include testing for chemicals in the air, soil and water. These studies also test for chemicals in human blood or urine. We call such tests bio-monitoring since they measure the levels of toxic chemicals in the body. This type of study may take many years until scientists can make any conclusions or findings, so they remain rare.

What do we mean by the word “environmental” when it comes to cancer?

For most people, the term “environmental” means chemicals found in an area’s air, soil, or water. However, when scientists talk about cancer having an “environmental cause” they often mean the cause is “something other than heredity.” That means they cannot link the cancer to genetics. “Environmental causes” include diet, exercise, smoking, alcohol use, health care, etc. Some 5 to 10% of all cancers run in families. We call these types of cancers “inherited,” which means passed down from a parent.

What about diseases with names that get confused with cancer?

People sometimes think someone has cancer when they do not. It is not uncommon for people to report that they see too many cases of cancer in an area when some of the observed diseases are non-cancer illness with unusual names. Some of these include: Lou Gehrig’s disease, cystic fibrosis, ulcerative colitis and pernicious anemia.

How have changes in diagnosis and treatment affected cancer rates as a whole?

First, cancers are mainly diseases of old age. America now has more elderly persons than ever before. The aging of America has increased the rates of cancer in the nation. In the past, most people died from heart disease, from getting sick with something other than cancer or from simply getting hurt. However, as our nation has made gains against these other types of health problems, more people are living longer so they have an increased chance of getting cancer.

What is the Department doing to combat cancer?

The Department has a plan to help control cancer. This includes programs designed to address:

- Prevention
- Diagnosis
- Treatment
- Access to cancer care
- Cancer survivorship

You can learn more about the plan at: www.floridahealth.gov/diseases-and-conditions/cancer/cancer-control-florida.html.

The Centers for Disease Control and Prevention (CDC) provides funding to programs in Florida to address breast, cervical, and colorectal cancer. To learn more about breast cancer, please visit: www.floridahealth.gov/diseases-and-conditions/cancer/breast-cancer/index.html.

On this website, you can learn more about:

- Screening guidelines and resources
- Risk factors
- Benefit programs
- Educational materials
- Support agencies

To learn more about cervical cancer, please visit: www.floridahealth.gov/diseases-and-conditions/cancer/cervical-cancer/index.html. The website provides information on prevention, early detection, screening, and cancer burden.

In addition, the Department's Breast and Cervical Cancer Early Detection Program (BCCEDP) makes it easy to get the screenings doctors suggest. They are free or at a low cost if you qualify. To find out more, call your county health department or call the American Cancer Society (ACS) National Hotline at 1-800-227-2345 to get details on the program. There are many BCCEDP sites throughout the state.

To learn more about the Department's efforts related to colorectal cancer, please visit: www.floridahealth.gov/diseases-and-conditions/cancer/colon-cancer/index.html. On the website, you can get details on screening guidelines, symptoms of these types of cancers, and known risk factors.

The Department also has a program called Florida Environmental Public Health Tracking (EPHT). This program partners with the CDC to track diseases that might relate to environmental exposures. The EPHT website (www.floridatracking.com) provides datasets on hazards in the environment. It looks for associations between those hazards and health outcomes. These efforts serve to inform people about disease trends. They also provide guidance on methods to improve community health.

One feature of the EPHT website is access to county-level cancer data and information about things like air and drinking water quality in the state. Users can view the cancer incidence rate for 18 different types of cancer at the county or state level. A national EPHT workgroup chose the cancer types because they may have a link to the environment. These include cancers of the:

- Breast
- Lung and bronchus (including mesothelioma, a type of lung cancer with known links to breathing in asbestos fibers)
- Bladder
- Brain and other parts of the nervous system
- Thyroid (a gland at the base of the neck just below the Adam's apple that helps control how the body uses food)
- Blood (including Non-Hodgkin's Lymphoma, a type of cancer that affects the white blood cells and four kinds of Leukemia)
- Pharynx (throat)
- Larynx (voice box)
- Esophagus (the long, hollow tube that runs from your throat to your stomach that takes

How does the way society views cancer now differ from in the past?

Much of the stigma that cancer once had has now gone away. These days, cancer patients are more likely to talk about it than they were years ago. In addition, the media plays a role in putting a spotlight on cancer; we hear about cancer more often now than in the past.

food you swallow to your stomach for digestion).

- Pancreas (an organ that secretes enzymes that aid digestion as well as hormones that help control the breakdown of sugars)
- Skin (specifically melanoma, the most serious kind of skin cancer that forms in the cells that contain pigment)
- Liver and Intrahepatic Bile Duct (the latter of which begins in the smaller duct branches of the liver and is linked to some types of chemical exposure)
- Kidney and Renal Pelvis (the latter of which is the top part of the ureter, a long tube that connects the kidney to the bladder)

Users can adjust their search to find the rate of a specific type of cancer at the state or county level, for the years 1999 through the most recent year available from the FCDS. The user can select the cancer rate for a certain age group or get an overall age-adjusted rate. They can also pick a certain gender, race, or ethnicity. Users can also query the data to produce multiple outputs: graph, report, or dynamic map.

What is a cancer cluster?

The CDC defines a cancer cluster as a greater than expected number of cancer cases that occurs within a group of people in a geographic area over a defined period of time (www.cdc.gov/nceh/clusters/). This definition can be broken down as follows:

A GREATER THAN EXPECTED NUMBER When the observed number of cases is higher than one would typically observe in a similar setting (a group of people with similar age, gender, race, etc.).

OF CANCER CASES All of the cases involve the same type of cancer or different types of cancer that science has proven to have the same cause.

THAT OCCURS WITHIN A GROUP OF PEOPLE The cancers are occurring in a carefully defined population. This may include factors such as race, ethnicity, age or gender.

IN A GEOGRAPHIC AREA The boundaries for the area of study are carefully defined.

OVER A PERIOD OF TIME The time period over which the number of cases occurred.

Why do community concerns often focus on cancer clusters?

People may suspect an excess of cancer if it occurs in a group where it is not likely to occur. For instance, we would not expect to find many cancer cases among children in a small town or neighborhood. We also would not expect to find large numbers of rare cancers in a neighborhood.

We define a cancer cluster as a higher number of the same type of cancer than is expected within a certain amount of time in a given area. For instance, when people learn that quite a few friends, family members, co-workers or neighbors have the same type of cancer, they may suspect a cancer cluster. Many people today believe that there is something in the air, soil or water that causes cancer, even when there is not a proven link.

What are some of the notable cancer clusters?

A few studies have linked cancer cases to high amounts of chemicals in the workplace. No studies in the U.S. have ever proven that a chemical in the air, water, or soil in a community was responsible for a cancer cluster. Therefore, most studies of the causes of cancer now focus on personal choices and lifestyle factors, not exposure to chemicals.

Some of the very few documented clusters with links to chemical exposures involve high doses of an unusual chemical over a long period of time. The dates of work-related cancer clusters related to high doses of exposure that are not common in daily life include:

The Department

has a program called Florida Environmental Public Health Tracking (EPHT). This program partners with the CDC to track diseases that might relate to environmental exposures.

1775 Cancer of the scrotum in chimney sweeps exposed to soot from coal

1929 Cancer of the jawbone in watch dial painters exposed to radium

1965 Mesothelioma and lung cancer in asbestos workers

1974 Liver cancer in chemical workers exposed to vinyl chloride

The dates of two cancer clusters unrelated to workplaces include:

1971 Vaginal clear cell carcinoma in daughters exposed before birth to DES (a drug given to pregnant women in the mistaken belief it would cut down on the risk of problems or miscarriages)

1981 Kaposi sarcoma in homosexual men with AIDS exposed to the human herpes virus B

All of these examples involved high doses of a chemical among workers or a common exposure to a drug or to a virus.

Workplaces are now required to take steps for safety. In industry, many workers must wear special gear to reduce contact with substances known to cause cancer. These include special clothing, gloves and sometimes a breathing device. These items serve to protect workers from exposures to hazardous chemicals at much higher levels than most people contact (such as in drinking water).

What is a cancer cluster?

The CDC defines a cancer cluster as a greater than expected number of cancer cases that occurs within a group of people in a geographic area over a defined period of time.

What is a cancer cluster investigation?

There are many steps needed to look into a possible cancer cluster. Each one takes time and money. To learn more about the detailed plan (called a protocol) the Florida Department of Health uses, see the 2013 Cancer Cluster Guidelines from the CDC found at: www.cdc.gov/mmwr/preview/mmwrhtml/rr6208a1.htm?s_cid=rr6208a1_w.

The steps include:

1. INITIAL CONTACT AND RESPONSE The purpose of this step is to collect facts to decide if they suggest a need for more study. Data to collect includes:

■ **The types of cancer.** Note: Different types of cancer have different causes. If the types of reported cancers vary, it likely means that it is not a cluster. Also, some cancers are common. Having a lot of cases of a common type of cancer in one community may not mean a cluster exists.

■ **Number of reports of cancer**

■ **Age of people with cancer**

■ **Geographic area of concern**

■ **Time period of concern**

■ **Chemical of concern.** Note: Does a known link to cancer exist for that chemical? Is it present at levels of health concern in the community? Is there a way for people who live there to come into contact with it?

2. ASSESSMENT The purpose of this step is to decide if the statistics of the suspected cancer cluster are higher than expected for a community of its size and make-up. This step uses data that already exists. It calls for deciding what group of people to study (the study population), choosing which type(s) of cancer to study, finding a similar group of people to compare the study group to, as well as deciding what kind of statistical methods to use in the study.

3. DETERMINING THE FEASIBILITY OF CONDUCTING A STUDY The purpose of this step is to gather more data to see if it is likely that it will show whether or not the cases relate to a common cause (also known as an etiological or causative risk factor). If possible, the outcome of this step should include what type of study design might do the best job if further work occurs.

4. CONDUCT A STUDY The purpose of this step is to find out if it is likely that contact with a certain risk factor or chemical in the environment might relate to the suspected cancer cluster.

At the end of each step, the Department must review the gathered information. The Department must then decide whether or not to move to the next step. Each step has standards (called criteria) to help decide if the Department should take the next step in the process.

Note: A key fact to keep in mind about suspected cancer clusters is that most studies do not result in finding a cause in the environment.

What can a cancer cluster investigation tell you?

No community is disease-free. We can expect a certain number of cancer cases in any place where people live. The main question in a cancer cluster investigation is, “Does a community have a higher number of cancer cases than what is expected?” But to find this out, a study must include a large number of people. This is because health studies that do not include enough people cannot find a relationship, even if one exists. In these cases, it may lack “study power.” It is harder to find out if any contrasts seen are due simply to chance. “Statistical significance” is a measure of confidence in whether the differences are real.

For these reasons, research of very large groups of people followed over a long time leads to learning more about the causes of cancer. Study of a large group of people allows scientists to best see patterns in cancer rates. We call the people who study these patterns, causes and effects of diseases in a group, epidemiologists.

What we can learn from community cancer cluster investigations is limited. Sometimes we simply cannot do one if a community is too small. Another challenge is that we may find chemicals in the air, soil, or water, but there is no known link to cancer. Or we may have very few tests of the area’s air, soil or water to review. In some cases, contamination occurred long ago. This may mean that there was no testing back when it first got into the air, soil or water. Other times, the amounts of a chemical found in the air, soil or water are too low to cause cancer.

What role does chance have in cancer clusters?

A cancer cluster may be due to chance alone, like the clustering of balls on a pool table. Sometimes, a cluster may be due to certain types of behaviors. These include drug, alcohol, or tobacco use. Finding an exact cause is very hard to do. Follow-up studies may take years to complete. They often take a great deal of research and money with no cause ever pinpointed.

What other information does the Department need to confirm cancer cases in a cancer cluster investigation?

As part of an investigation, we must know the details of each case such as:

- **What is the age of onset (or how old were they when a doctor found out they had cancer)?**
- **What is the person’s race?**
- **What is their gender?**
- **What type of cancer is it?**
- **Where did they live?**
- **How long did they live in the area of concern?**

The team who investigates a suspected cancer cluster may include:

- **People who are trained to study diseases (epidemiologists)**
- **People who can compute the rate of cancer cases (data analysts)**
- **People who can assess known risk factors found in air, soil, or water (health assessors)**
- **People who study the toxic effects of chemicals on human health (toxicologists)**
- **Medical Doctors**

What is the purpose of a cancer cluster investigation?

The reason to do a cancer cluster investigation is to see if the number of cases that have occurred is truly larger than expected and if it relates to a given chemical.

Other agencies in the state or county might also help, including:

- The county environmental agency
- The Florida Department of Environmental Protection (DEP)
- The U.S. Environmental Protection Agency (EPA)
- The U.S. Agency for Toxic Substances and Disease Registry (ATSDR)

How is the rate of cancer analyzed in a cancer cluster investigation?

In an investigation, the rate of disease is the number of new cases in a group of people in a given area that occur in a certain period of time. We express the amount of cancer as a rate by dividing the number of new cancer cases by the number of people at risk. As a rule, the FCDS and the National Cancer Institute both report rates per 100,000 persons.

What is an “average rate” or a “higher than average rate” of cancer?

Science has made a great deal of progress in recent years to learn more about as well as treat, cancer as a whole. However, it remains a very scary illness because it is still not conquered. Also, cancer remains linked to a great deal of pain and loss for its victims and their friends and family.

Every year, groups of people report more than a thousand potential cancer clusters to public health agencies across the nation. Of these, most do not meet the guidelines for investigation as a cancer cluster. Of those that do, 5% to 15% of studies may confirm that the number of cases of a certain cancer exceeds what is expected. Even then, in most cases, science cannot pinpoint a cause.

Here are some things to keep in mind about “average” or “higher than average” rates of cancer

AS A RULE, WE BASE AN “AVERAGE” CANCER RATE on some large group of people, such as a state.

“HIGHER THAN AVERAGE” really just means higher than the average for that large group. For instance, a town with many retired people may have a prostate cancer rate that is higher than the state’s average rate. This is because it is a type of cancer that occurs more often in older men. A town with mostly college students has fewer older adults. That may result in a prostate cancer rate that is lower than the state’s average rate. Each group of people in any given area is unique. Therefore, their cancer risk factors may vary widely. This can affect cancer rates.

CHANGES IN THE NUMBER OF PEOPLE IN A CORE STUDY GROUP can change the “average rate” because as people move in and out of an area, it can change a group’s traits or size.

IN MOST GROUPS, FEW, IF ANY, WILL MATCH A STATEWIDE RATE OF CANCER since the rates turn out either higher or lower than that found at the state level.

AGAIN, EVEN IF AN INVESTIGATION SHOWS A HIGHER THAN EXPECTED CANCER RATE it does not mean we can prove that something specific like a chemical is causing the cancer.

BY THE SAME TOKEN, EVEN IF A CANCER CLUSTER INVESTIGATION shows a lower than expected rate, it does not mean that something is protecting a study group’s members from cancer.

For general information about cancer, please visit:

■Agency for Toxic Substances and Disease Registry (ATSDR) at: www.atsdr.cdc.gov/com/cancer-fs.html

■American Cancer Society at: www.cancer.org

■Centers for Disease Control and Prevention at: www.cdc.gov/cancer

■National Cancer Institute at: www.cancer.gov/

For information on cancer rates, please visit:

■National Cancer Institute at: www.cancer.gov/statistics

■Florida Cancer Data System at: <http://fcds.med.miami.edu/inc/welcome.shtml>

■Centers for Disease Control and Prevention at: www.cdc.gov/nceh/clusters/default.htm

For more information about cancer cluster investigations in Florida, call the Department of Health, Division of Community Health Promotion, Public Health Research Unit at 850-245-4585.

Ask to speak to someone about a cancer cluster investigation.

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