

From: Dauster, Nicholas [mailto:Nicholas.Dauster@dshs.state.tx.us]

Sent: Thursday, January 21, 2010 11:47 AM

To: Mayor - Jody Smith; Place4 - Jean Levenick

Cc: Villanacci, John; Williams, Melanie; Valadez, Adolfo; Shewmaker, Evelyn; Govt Affairs; Zoretic, James

Subject: Information on the DSHS investigation in Flower Mound

Mayor Smith and Mayor Pro-Tem Levenick,

Please find attached a document that we hope addresses some of the major concerns and misunderstandings concerning the investigation. I hope it is useful to you and to the constituents you represent.

We know that there will be additional questions as this investigation proceeds. Please feel free to contact us if we can be of additional assistance.

Regards,

Nick Dauster, Director
Government Affairs Unit
Center for Consumer and External Affairs
Department of State Health Services
(512) 458-7263
nicholas.dauster@dshs.state.tx.us



The Texas Cancer Registry in Flower Mound

Background:

The Texas Cancer Registry (TCR) collects statewide data in order to serve as the primary source of measuring cancer in the state. In response to concerns raised by members of the Flower Mound community about a potential cancer cluster, TCR has agreed to investigate the number, types, location, and timeline of cancer cases in the area in collaboration with the Environmental Epidemiology and Toxicology Unit at the Texas Department of State Health Services (DSHS). Because of the natural concern that such investigations raise and the media coverage of this issue, it is very important that accurate information about these investigations be provided to the community.

TCR is the fourth largest cancer registry in the United States, and currently meets the high quality data standards of the Centers for Disease Control and Prevention (CDC). It has achieved Gold Certification from the North American Association of Central Cancer Registries. This is the highest level of certification that a cancer registry can achieve.

What is a cancer cluster?

Cancer clusters are defined as a greater-than-expected number of cancer cases that occur within a group of people in a geographic area over a period of time. Epidemiologists have identified certain conditions that are most likely to indicate a true cluster:

- A large number of cases of one type of cancer, rather than several different types
- A rare type of cancer, rather than common types
- A number of a specific type of cancer in age groups not usually affected by that type of cancer

Reports of even an unverified cancer cluster in a community can cause great anxiety among its residents. A true cancer cluster can only be determined after research using verified, valid, and complete data collected over time.

Additional detail on cancer clusters can be found on the DSHS website at <http://www.dshs.state.tx.us/tcr/clusters.shtm#whatis> and on the website for the CDC at <http://www.cdc.gov/nceh/clusters/>.

What can a TCR investigation tell us?

A TCR analysis can only determine whether there appears to be an excess of cancer in the area over a given time period. The investigation cannot determine whether any particular exposure caused cancer. There is often a lag between the exposure, the onset of the disease, and the resulting symptomatic illness or illnesses. This lag between exposure and the occurrence of symptoms complicates efforts to link cancer to a specific cause.

How are the concerns in Flower Mound being addressed?

TCR is conducting two investigations. In the first, the TCR is working with the community to confirm the number and type of childhood cancer cases in zip codes 75022 and 75028 by using available data from 2008 to the present. If needed, a follow up is conducted with hospitals and physicians. The review of cases will start the evaluation of whether the number of cancers found for these years appears higher than what would be expected.

In the second investigation, TCR will conduct a statistical comparison of cases in those zip codes with statewide data to determine whether the incidence of cancers is higher than expected for the most recent years in which information is complete (1998-2007). The cluster investigation will examine childhood leukemia subtypes, leukemia subtypes for all ages, and non-Hodgkin's lymphoma for all ages. Other cancers may also be evaluated as additional community concerns are raised and reported to DSHS. This investigation will also be updated as complete data for the state becomes available.

Has TCR conducted any previous cancer studies in the Flower Mound area?

In 2008, TCR responded to a request from an individual in Flower Mound for research into thyroid cancer in the area. In that investigation, TCR determined that the number of thyroid cancer cases in the area fell within an expected range; therefore, TCR was not able to identify an actual cluster.

Why aren't TCR data for 2008 and 2009 available for the cancer cluster investigation?

The determination that a cancer cluster may exist and warrants further study has serious repercussions for the people living in the affected community. It is of the utmost importance to follow a rigorous and standard scientific protocol when investigating these concerns, as well as when collecting the cancer cases.

For an investigation to be valid, whether it determines there is a cluster or not, it must use complete statewide data that has been subject to many rigorous quality assurance measures. TCR requires time to gather all of the information on cancers in a community, and then consolidate that information into the most complete record possible. Each year, TCR collects over 250,000 reports of cancer that result in over 100,000 newly diagnosed cases of cancer from over 500 hospitals, cancer treatment centers, ambulatory surgery centers, and pathology laboratories located throughout the state.

TCR follows investigation protocol and data collection procedures based on recommendations made by the CDC, but unfortunately, it is painstaking work that requires time. TCR meets the highest national cancer registry standards for timeliness and quality of its data. Not using standard protocols and collection procedures, or not taking the time to validate the data, could lead to incorrect conclusions.

The following examples illustrate how incomplete data can lead to erroneous conclusions:

- If a patient in the community being studied travels to another state to see a specialist, that information is not available until the other state reports its data to Texas. That could lead to the underreporting of cancer in the community.
- A cancer study in a community will likely produce complete data. Comparing that information to incomplete statewide data runs the risk of leading a community to the mistaken conclusion that a cancer cluster exists.
- Cancer patients often travel to receive their diagnoses and treatment, and are frequently seen for the same cancer at more than one hospital or cancer treatment center. If multiple records for cancer patients are not consolidated into single record, statewide rates will be erroneously high

When will the results be released?

Because of the serious nature of these investigations, TCR must make every effort to ensure that the data and the calculations are performed correctly using standard protocols. For that reason, it may be March before the results are finished and released.

If you have further concerns or questions, please feel free to contact Nick Dauster, Director of Government Affairs at the Center for Consumer and External Affairs for the Department of State Health Services. He can be reached at (512) 458-7263, or nicholas.dauster@dshs.state.tx.us.