



FACT

FAMILIES AGAINST CANCER & TOXICS
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TUCSON AZ 85717-1285

May 17, 2005

Dear Dr. Rubin and the rest of the Sierra Vista Childhood Leukemia Cluster Investigative Team:

I am writing to register a protest, and request a decision reconsideration. There are three children with leukemia who are associated with the Sierra Vista cluster, but do not meet the official case definition. These children are being excluded from the biomonitoring analysis. Please reverse this decision, and invite the three associated children and their families to participate in the biomonitoring analysis.

When the CDC team came to Southern Arizona in February 2004, FACT presented you with a memo of concerns and expectations for the investigation. We wrote:

We hope for an end to the hair-splitting over which kids are officially parts of the cluster and which aren't. It sends the impression that some kids don't "count," and makes the health officials seem heartless and uncaring. Find a way to run the registries and cluster investigation so that everyone counts.

After CDC announced that they will offer biomonitoring to the *Sierra Vista Herald* on February 25, 2005, health officials promised that the affiliated children would be included.

Question: What is the official number of childhood leukemia cases that we're working with?

England: We're looking at 10 cases who were diagnosed while living in Sierra Vista, plus two more that we know of who were diagnosed after moving out of the area.

Question: Are the two who were diagnosed in other areas included in the numbers?

England: *They're included in the investigation.* We're past the point, as far as I'm concerned, of whether you name a particular cut off or not. We're going to be looking at it. [emphasis mine]

Here is an overview of the three children, with particulars about each:

1. **Cody Hergut** lived in Sierra Vista for three years; his family then moved to Tucson where he was diagnosed with leukemia just one month later. Because the official case definition requires living in the Sierra Vista area at the time of diagnosis, his case is excluded. His mother registered her frustrations with this policy to the *Arizona Daily Star* on February 7, 2005:

"They're never going to admit that anything in Sierra Vista has damaged our children, or could be causing this," said Veronica Herget, whose 9-year-old son, Cody, came down with leukemia in August 2002 after living in Sierra Vista for three years.

Herget is especially frustrated because Cody will not be included in the testing and is not even in the cluster case count because he was diagnosed a month after moving to Tucson.

"The real total in this cluster is 18 children, but they try not to include as many as possible," she said. "I would really like to know what pattern of exposures shows up in these children. But in Cody's case, I'll never know."

2. **Annastacia Warneke** was diagnosed with leukemia just a month after her family moved from Sierra Vista to Fallon NV. Her family moved back to Sierra Vista, where they live now. After the Nevada Health Department said they wouldn't include Anna in the Fallon cluster because their case definition required having lived in the area prior to diagnosis, her father Matt protested, and they were finally included in the Fallon investigation. Matt and Anna have their biomonitoring results from Fallon, but a follow-up test could reflect new exposures, and reveal how well their bodies are removing the toxic substances found previously.

Matt Warneke is newly married and he and his wife are expecting a baby. Since research has shown that the first genetic "insult" happens before birth, including the Warnekes in this study would capture data on any exposures of concern Yvonne Warneke might presently be experiencing.

3. Dale Durkit has two daughters with AML leukemia. This is deeply tragic, and astounding. His daughter Jessica is in the "official" count, but his other daughter, **Kellie Miner-Durkit**, does not meet the case definition. Kellie lives in the Phoenix area with her mother, Dale's first wife, and comes to Sierra Vista for visits. Many advances in scientific understanding of disease have come from twin studies. Including Kellie in the biomonitoring may yield clues about what caused two of Dale's daughters to develop this disease.

Having non-standard case definitions that result in excluding cases raises concern whether the investigation is legitimately seeking truth. It is causing anxiety amongst the affected families, who wonder if they should participate in the investigation since they don't believe it is seeking truth. Two families have flatly refused to participate in the biomonitoring.

There are only ten children in the official count, and several of these families won't be able to participate because they have been stationed elsewhere. Even bereaved families are being excluded! This makes no sense given that there are still parents and siblings that could be invited to participate in the bio-sampling.

The number of families participating has whittled down to only *four*! Epidemiology benefits from studying large numbers, in order to build "statistical power." Sampling the three affiliated families would gather additional data to study, and still allow you to stratify the results according to your strict case definition.

Please let me know your decision in this matter. If you have any questions, call me at 520-795-7228.

Sincerely,

Terry Nordbrock

Mom of Henry and Linus, a 6-year-old Tucson kid with leukemia
President and Co-founder of FACT, Families Against Cancer & Toxics