

CHILDHOOD CANCER AWARENESS

August 21, 2008

Senator Kuehl
10951 West Pico Blvd. Suite 202
Los Angeles, CA 90064

Dear Senator Kuehl:

I am writing you on behalf of Childhood Cancer Awareness. We wanted to thank you for all the help you have given us regarding the Retinoblastoma cases in the west valley. Your efforts for resolving our community's health concerns are greatly appreciated.

As you are aware, the cancer registry issued a report of their investigation into the incidence of Retinoblastoma in an area around SSFL. This report has several flaws which are criticized by Dr. Hal Morgenstern as well as our group. Additionally, the report did not include 4 of our known cases for the following reasons. Two cases were missed because the area they investigated was a ~10 mile radius from some central point within SSFL (the radius still varied between 8.5 and 10 miles, and the central point was not even true center). Two other cases were missed because the families had moved prior to diagnosis, therefore the location at diagnosis fell outside the study area, but location of birth fell within the area.

We were contacted by Dee Lewis of National Disease Cluster Alliance. During our discussions we learned that there are several flaws in assessing cancer incidence, and that the epidemiological assessments always conclude as statistically insignificant. Her organization has developed a process for identifying and investigating potential disease clusters. This process is based on recommendations of the Johns Hopkins University Study 2007 ,(please see attached study) and we believe this is a great opportunity to improve the cancer registry/community relationship. Additionally, the adoption of early environmental monitoring will greatly improve the science so that future environmental risks can be mitigated prior to community exposure.

Childhood Cancer Awareness would request the following:

Hold a meeting between us, Senator Kuehl and National Disease Cluster Alliance. This meeting will discuss their procedure for improving the identification and investigation of potential cancer clusters.

Discuss environmental testing (radiological, carcinogenic, viral and microbial) of the water, soil and air for the Retinoblastoma community.

Sincerely,
Cindy K. Mays
Jeff Mays
Lori Tucker

Dean Tucker
Cindy Braggs
Glenn Braggs

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CC:
Dee Lewis, Disease Cluster Alliance
Hal Morgenstern PHD, University of Michigan
Dan Hirsch, Committee to bridge the gap
Barbara Boxer, U.S. Senator
Diane Feinstein, U.S. Senator
Kurt Snipes PHD, California Cancer Registry
Robert Greger, Department of Health Services
Christina Walsh, cleanupRocketdyne.org
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