WTC Health Registry Cancer Research Description for NIOSH

The World Trade Center (WTC) Health Registry is in the early stages of analyzing any potential relationship between cancer and WTC exposure among its 71,000 enrollees. Because the induction period--the time it takes for cancers to develop, and the latency period-- the time to detection can range from five to 20 years after environmental or occupational exposures, this research will continue for as long as the Registry is funded.

Physicians are required by law to report information to state cancer registries about cancer diagnoses among their patients. As a first step in its cancer analysis, the WTC Health Registry is confirming cancer diagnoses by matching the names of its enrollees with cancer registries in New York and 10 other states where more than 90% of all enrollees currently reside. This is a critical step because it provides researchers with essential information, including the date of diagnosis and the type of cancer. This summer, the Registry expects to complete matches through 2008 in all 11 states (there is a lag between the time physicians report cancer data and when the state is able to compile it). Future matches will take place every 2 years.

Once the WTC Health Registry has completed the matches to all 11 state cancer registries through 2008, it will conduct a preliminary analysis of the data to determine if there is an excess incidence of post 9/11 cancer overall, and by specific types of cancer, among enrollees by comparing the number of cancer diagnoses among enrollees to those expected based on rates among the general population of New York State (the New York State Cancer Registry calculates the incidence of cancer based on gender, age and ethnicity). This is known as an external comparison.

The WTC Health Registry plans to submit the results of this first, or baseline, analysis among enrollees compared with New York State cancer rates for publication early in 2012. Thereafter, the WTC Health Registry plans to conduct similar analyses every five years, using matches from all 11 state cancer registries and comparing them to rates of cancer in New York State because the Registry population is believed to be most similar to that of New York State. External comparisons may also be made to the general US population. This will facilitate comparison of findings with WTC researchers who may be using this population for their analyses.

In addition, the WTC Health Registry will attempt to conduct internal comparisons based on the degree (high, intermediate, low) to which an enrollee was exposed to the WTC disaster. A group of national experts, including representatives from the American Cancer Society, Memorial Sloane Kettering Hospital and Harvard University, recommended that WTC cancer researchers use internal comparisons whenever possible because they are likely to have greater scientific validity than external comparisons. However, internal comparisons are challenging for two reasons: 1) even though the Registry has the largest cohort of persons exposed to 9/11, the cohort is relatively small, thus limiting the statistical power of cancer analyses; and 2) information about specific types of WTC exposure is limited.

227 Submission to Howard (NIOSH) via email from Farfel (WTC Health Registry at the New York City Department of Health and Mental Hygiene) - 6/20/11 The WTC Health Registry is committed to employing the best methodology possible in its ongoing investigation to determine any potential links between WTC exposure and increased cancer risk. As part of this commitment, it will continue to work with other WTC researchers, including those from the Fire Department of New York and the New York/New Jersey WTC Clinical Consortium, in the WTC Analytic Methods Workgroup, which was established to implement the recommendations from national experts in June 2010. These recommendations can be accessed in the 2010 WTC Medical Working Group annual report

(http://www.nyc.gov/html/doh/wtc/downloads/pdf/news/2010_mwg_annual_report.pdf). In addition, the WTC Health Registry will continue to consult with these and other experts, as needed.