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Huge Study of Health Impact

20-year survey to track thousands

By Laurie Garrett
STAFF WRITER

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New York City and federal health officials Friday launched what they hope will become the largest scientific registry of humans ever compiled. The goal: To find out how the collapse of the World Trade Center will, over time, affect the health of New Yorkers.

Officials said yesterday they hope tens of thousands who lived or worked below Canal Street on Sept. 11, 2001, or during the cleanup that followed, will sign up for the voluntary study, which they anticipate will continue 20 years. Officials would not specify the enrollment they're seeking, though privately indicated 200,000 is a goal.

"It is critically important that New Yorkers who were exposed enroll in the registry," City Health Commissioner Dr. Thomas Frieden said at a press conference in a waterfront park blocks from Ground Zero. "What we're saying here is this is the best way to find out. And the best way to succeed is to have large numbers of people sign up."

The launch is more than a year overdue, a result, Frieden said, of logistic and scientific complexities involved in setting up the framework intended to find, interview and keep track of such a multitude over 20 years. Federal Emergency Management Administration designated \$20 million to establish the registry.

Assistant Commissioner of Health Polly Harris said in an interview that several scientific advisers were involved in the registry's design, and delays were caused by the need to create a database that could hold such large amounts of information and maintain individual confidentiality.

Working with the city health department are the national Agency for Toxic Substances and Disease Registry and the CDC's National Center for Environmental Health. Both federal agencies are run by Dr. Henry Falk.

"The answer is, the better the participation, the better we will be able to see subtle health effects," Falk said. "We want it to be as large as possible, in order to answer as many questions as possible."

The Research Triangle Institute in North Carolina is also attempting to track down thousands of people who volunteered to work at Ground Zero who now live in other regions.

To date the largest health registry is the Three Mile Island survey of Pennsylvania residents and workers near the 1979 nuclear power plant

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accident. In 1980 the national disease registry enrolled 36,000 people, agency nurse Sharon Campolucci said yesterday, almost 90 percent of whom remain. Analysis of the health trends has shown that the leukemias and other cancers that were feared have not materialized. The registry has, Falk says, been a source of comfort and "empowering" for the people of Pennsylvania.

"This is an enabling mechanism for the city," Falk insisted.

"We know that there were particulates in the air. This registry will be the best way to say what, on a population basis, were the long-term health impacts," Frieden said in the press conference."

The city Department of Health estimates 300,000 people were exposed to the dust and fumes.

The launch alone is of a grand scale: Every person who registers will receive a phone call from a trained interviewer, which is expected to last a half-hour - amounting to 50,000 hours of interviews if 100,000 people enroll.

One who found the registry wanting was attorney Joel Kupferman of the New York Environmental Law and Justice Project. "This is too little, too late, being done by the wrong people," he charged.

Kupferman, whose organization represents downtown residents and union workers who worked at or near Ground Zero, claimed that the city health department "worked hand-in-hand with the EPA to mislead people. They even issued a statement right after 9/11 saying that pregnant women and children need not have any special concerns about going downtown."

But Frieden said at the press conference, "It's critically important in the public sector that we provide open, accurate information. That's what we do."

Though Frieden said Friday that anybody who spent even "moments" downtown during the first post-9/11 days ought to enroll in the registry, the category on the Web site is limited to rescue workers and volunteers.

Who They Want in 9/11 Registry

The WTC Health Registry is asking people who fit into any of these four categories to sign up so their health can be monitored over the next 20 years:

People who were in a building, on the street, or on the subway south of Chambers Street on Sept. 11, 2001.

Workers involved in rescue, recovery, or cleanup at the WTC site and / or WTC Recovery Operations on Staten Island or on the barges anytime between Sept. 11, 2001 and June 30, 2002.

Students and staff at schools (pre-K-12) or day care centers south of Canal Street on Sept. 11, 2001.

People who were living south of Canal Street on Sept. 11, 2001.

Those wishing to register should call 311 or 866-692-9827, or log on to www.wtcregistry.org.

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