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Panel Traces Missteps In Aiding Post-9/11 Victims

By FLORA FAIR

With a decade of sobering experience to their credit, a group of panelists at a conference presented by the New York Committee for Occupational Safety and Health spoke Sept. 16 about the problems encountered documenting the health damage from 9/11 and treating victims.

The event, entitled, “Are We Prepared for the Next 9/11?” featured five panels on different aspects of the response to 9/11. It began with a group of medical and health experts who were the first-responders to the first-responders of 9/11—they began seeing the effects of exposure at the World Trade Center site almost immediately, and have carefully monitored how those effects have progressed.

Unknowns Hampered Efforts

Among the panelists were Lee Clarke, safety and health director for District Council 37, Dr. Joan Reibman, Director of the WTC Environmental Health Center at Bellevue, and FDNY Chief Medical Officer Dr. David Prezant, whose recent study linking exposure at Ground Zero to increased cancer rates in firefighters has caused a stir in the 9/11 community, which is still struggling to get cancer treatment included in the James Zadroga 9/11 Health Care and Compensation Act.

Dr. Reibman highlighted several problems with documenting the damage following the 9/11 attacks, among them how to balance research and treatment simultaneously. “We didn’t ask right off the bat, ‘Is there a potential for harm?’” she said. “...In the past 10 years, what we’ve learned is you have to ask and we have to work together.”

Dr. Prezant said the first need, if we’re to learn anything from the disaster, is to look at how the screening and monitoring programs were set up. “One can understand that, from the concept of the Federal Government, why would we treat illnesses that we don’t yet know exist and we don’t yet know are World Trade Center-related?” he said, explaining that initial funding was meant only to answer these questions, and not to treat people. He said this prevented effective treatment, especially for those who had no health insurance. He noted that treatment wasn’t part of the Federal program until 2006, though private donors and organizations had been contributing up to that point. “Next time around, we need to realize that monitoring and screening needs to be coupled with treatment,” he said.

Could Have Averted Suspicion

Dr. Prezant said that supervision, and the willingness to accept supervision, must be present in such situations. But he thinks the delay in registering potential victims, was among the biggest failures. “That’s where we let a lot of people down, and I think it’s come to haunt us,” he said. “Every disaster site should register all of the affected and the exposed...And when we do monitoring and treatment, it would allow us to avoid what has been rampant in this medical response, and that is, when we ask for funding, there is a huge suspicion about what is the truly exposed population, a suspicion that none of you deserve, and that would be completely eliminated if there was enrollment right from the beginning.”

Big Financial Toll, Too

Standing in front of images of the collapsing towers and their rolling dust cloud, Ms. Clarke wanted to remind the audience that there are other things happening to the population aside from illness. “They are facing a tremendous amount of financial devastation, and that only compounds having to go through treatment,” she said, adding that the ongoing contamination of the area is a concern. “Probably one of the worst pieces of advice was given by the City of New York and Feds to the residents in Lower Manhattan, and that was to clean up your own place, and you could use a mop or a dust rag.” She also faulted the U.S. Occupational Safety and Health Administration for taking a narrow view of what worker safety meant at the site, and not considering environmental exposure.

“In the early days after the Trade Center fell, within two weeks, Mt. Sinai accompanied DC 37 to the Office of Labor Relations in New York City, and we said to them, ‘Look, we need you to document all of the city workers who are at that site, and we need to set up a monitoring program.’ They threw us out,” she said. She reminded the audience that as recently as 2006, Mayor Bloomberg was reluctant to make the connection between illnesses and 9/11. All of these elements made it much harder for workers to collect benefits when they became ill or could no longer work.

‘Like the Wizard of Oz’

“New York State passed legislation to create a Worker Protection Task Force to look at the issues of the first-responders and where they needed help,” she said, explaining that she asked them why some responders who were registered and receiving treatment at a center were being denied their disability pension. The task force looked at this issue, and found that Ms. Clarke and her colleagues were right. “It was like the Wizard of Oz, and [medical boards are] behind the curtain and we can’t move that curtain to see what’s going on behind there to this day,” she said. “The task force suspects that the medical boards just are not looking at why are these workers ill and applying the proper criteria to determine whether or not it was World Trade Center-related. We cannot get answers to this day from those medical boards.”

She said all of these things exacerbate illness and trauma to a worker and his or her family: “So when you talk about the extent of harm, you have to look at everything that’s going on, not just the illnesses.”

When asked directly how a disease (like cancer) can be definitively connected to a disaster, the panelists were careful to couch their responses in scientific terms, which has been a part of the tension between responders and researchers. “All of this requires an immense amount of proof,” Dr. Prezant said. “And that is where there’s a difference between science and social need. We will lag behind the social needs.”

‘Start Treating While Studying’

Dr. Reibman agreed with this assessment, but added, “We have to keep thinking about balance, and at what point do we say, maybe our bar where we’re saying we must have scientific evidence should be left a little bit flexible so that we continue to study, but we might have to treat at the same time.”

Closing out the panel was brief testimony from Patrick J. Bahnken, president of Emergency Medical Service Local 2507 of District Council 37, who just two weeks short of retirement pulled no punches: “I figured, you know what? What the hell—let’s talk a little about cancer. It seems to be the 800-pound gorilla in the room that not a lot of people want to talk about, but I tell you that the bureaucracy involved with the Zadroga Act is killing people.”

He mentioned FDNY Paramedic Deborah Reeve, a 9/11-responder who had her disability pension approved a week after her funeral. He said all the arguments about data are missing the point. “Joseph Stalin said that a single death is a tragedy and a thousand deaths is merely a statistic,” he said. “In the Fire Department, we didn’t look at 343 people dying in one day; we lost one guy 343 times

...And the problem is that nobody told us to stop dying on Sept. 12. And here we are, in 2011, and we continue to hear the bagpipes play, we continue to carry the caskets, we continue to deal with the children and widows, the sick.”

‘Shouldn’t Die of Bureaucracy’

Mr. Bahnken recently called Dr. Prezant about a 40-year-old EMS employee and 9/11-responder who was denied his pension after having to retire early. “He said to me, ‘Pat, I can get you diagnostics done, I can get all the tests done, I can get all the evaluations done, but if they say the word cancer, our hands are tied. We can’t do anything for him after that,’” he recounted, calling Dr. Prezant a compassionate caregiver and advocate who is stuck in a bureaucracy.

Mr. Bahnken warned that there will come a day when the government acknowledges the health effects of what happened, just as it did with Agent Orange. “They said it at Arlington Cemetery to a group of dead people,” he said. “We are not lab rats, we are not statistics...We want to grow old. At the very least, we don’t want to die because of bureaucracy.”